FA Community Petition

Food and Drug Administration & Reata Pharmaceuticals: ALLOW INDIVIDUALS WITH FRIEDREICH ATAXIA ACCESS TO OMAVELOXOLONE.
# TABLE OF CONTENTS

**Introduction** .................................................................................................................... 1

**FA Community Response Letter to FDA & Reata Pharmaceuticals** ......................... 4

**Comments from FA Community** ................................................................................ 10
  - Individuals Living with FA who identified as MOXIe Trial Participants ............... 10
  - Parents & Family Members of Individuals who identified as MOXIe Trial Participants ................................................................. 17
  - Individuals Living with FA in the US .................................................................... 30
  - Individuals Living with FA Outside of the US ...................................................... 56
  - Parents & Family Members in the US .................................................................. 79
  - Parents & Family Members Outside of the US .................................................... 170

**Signatures** ................................................................................................................... 244
  - Individuals Living with FA in the US ................................................................. 244
  - Individuals Living with FA Outside of the US .................................................... 245
  - Parents & Family Members in the US ................................................................ 248
  - Parents & Family Members Outside of the US ................................................... 256
  - Friends, Advocates & Volunteers ....................................................................... 269
  - Healthcare Providers .......................................................................................... 348
  - Caregivers ........................................................................................................... 350
  - Researchers & Scientists .................................................................................... 352
  - Other ................................................................................................................... 353
  - Advocacy Organizations ...................................................................................... 354

**Letter from Healthcare Providers** ........................................................................... 355

**Letters from Advocacy Organizations** .................................................................. 362
74,070 individuals have signed on to the FA Community Response letter requesting Reata Pharmaceuticals submit a New Drug Application (NDA) on an urgent basis and FDA consider approval of an NDA for omaveloxolone in FA based on the existing evidence from clinical trials.

On January 5th, 2021, FARA invited the FA community to a webinar to learn about drug development and regulatory decision-making, including how their voices and experiences can and should be included in these processes. Omaveloxolone (omav), a potential therapy being evaluated in FA, was specifically highlighted including a review of results from two completed clinical trials along with published data. FA community members shared their experiences living with FA, participating in clinical trials and preferences and expectations for future treatments. FARA publicly shared available information about the FDA’s advice and feedback to Reata Pharmaceuticals suggesting that they conduct another clinical trial to further demonstrate the persuasiveness of the previous achieved results (omav). The community discussed how additional trials will take several years to complete and delay access to treatment, leading to significant progression of the disease, losses in ability/function and death. Concerns were also raised about the implications of this situation and the FDA advice for other drugs in the treatment pipeline that are to follow. FARA issued a Call to Action in the form of the FA Community Response letter asking individuals to sign-on in support of a request to the FDA and Reata that they work together to approve omav for FA as quickly as possible. FARA shared the FA Community Response letter via our website, email lists and social media channels. Sign-on opportunity was open from January 5-20, 2021.

74,070 individuals signed on from 118 countries, 48% or 35,382 signatures are from US residents, representing all 50 states.

*377 signers did not indicate a country
INTRODUCTION

There are individuals from 117 countries in addition to the US demonstrating the global nature of FA, the shared unmet medical need and the cohesiveness of the FA community. FA is a genetic disease and the mutation is most prevalent among those of European decent. The incidence in the US is estimated at 1 in 50,000 among Caucasian individuals, and we estimate that there are about 3,000 - 4,000 diagnosed in the US and about 15,000 worldwide.

More than 20% of the signatures were from individuals living with FA, parents and family members.

We heard from 1924 individuals (636 US) living with FA and at least 688 individuals (393 US) who identified themselves as a parent in written comments among the 13,899 individuals who selected their affiliation as a parent of family member of an individual living or deceased with FA. These parents and family members often represent the voice of our youngest FAers and those who have passed away prematurely due to FA.

We estimate representation of at least 20% of the diagnosed US population.
We provided the community the opportunity to comment and share their experience and opinions on why they support approval of omav. **We received 7,503 comments from those living with FA and parents and family members.** From these comments we have statements from >71 individuals with FA who were in one of the MOXIe studies and 148 parents and family members that have observed and lived experiences with their children and loved ones who participated in studies and had direct experience taking omav. Of note, based on published data, 69 individuals were enrolled in the first trial and 103 enrolled in the second trial, and we were not able to directly reach out to these individuals as their identities were not known to us.

Friends and supporters of individuals and families living with FA were the majority of our signers. We also heard from caregivers, researchers, healthcare providers, and advocacy organizations worldwide. Enclosed you will find 12 letters of support from FA and Ataxia organizations, writing on behalf of the FA patients they represent and joining FARA in making the request of FDA and Reata to urgently submit a marketing application, approve and provide access to omaveloxolone. While many of these organizations are outside the US, they know that an FDA decision will impact how quickly access can reach our global FA community.

FA clinical experts and the investigators who participated in the MOXIe studies have provided a separate letter that discusses the clinical significance of the MOXIe trial and omav results, and this has been signed by 11 experts along with 40 additional highly knowledgeable clinicians.

**What is FA?**
FA is a multi-system disease that typically has onset in early childhood and diagnosis is most often between the ages of 10-15 years. All individuals with FA experience the neurological symptoms, loss of coordination of movement in the upper and lower limbs. Most individuals lose the ability to walk about 10 years after onset of symptoms. FA also causes slurred speech (dysarthria), loss of vision and hearing, and pain. Cardiac disease including hypertrophic cardiomyopathy and arrhythmia cause early mortality in FA, the average life expectancy is 35 years. Fatigue is also highly prevalent, >85%, and has a profound impact on quality of life. About 20% of individuals have a later onset of symptoms, >25 years of age, and they experience a slower progression.

Footnote:
Community signatures and comments were submitted via Google Form and the data was handled in the following manner. A total of 75,378 responses were received. A search and removal of duplicate signers was conducted by matching criteria for email address, name, location, and affiliation. To maintain the privacy of signers, they are represented by their first names and the first initial of their last names. Locations outside the United States were submitted as free text responses and were reviewed and standardized for spelling. In response to Affiliation to the FA community, the selection of Other/ free text entries were coded to be best fit to an existing category. For example, if the typed response was “Cousin” then the affiliation was coded as Parent or Family Member of an individual with FA. The comments in response to Question 5 were translated if they were submitted in a language other than English. The comments from Individuals Living with FA and their Parents and Family Members have been de-identified to only include the first initial if a first name was included. Other than de-identification, these responses are presented as they were submitted by the signer without edits. These comments were also reviewed for an indication of whether the signer or their family member participated in one of the MOXIe trials and also if they identified themselves as a parent and coded for reporting purposes.
FA COMMUNITY RESPONSE LETTER TO FDA & REATA PHARMACEUTICALS

FDA & Reata Pharmaceuticals: Allow Individuals with Friedreich Ataxia Access to Omaveloxolone

We, the Friedreich Ataxia (FA) community, are at a point where our investments in building this community, tools for drug development (such as our patient registry, natural history study, cell and animal models, and clinical network), and investments in research are translating into a pipeline of treatments. One important result is that as these drug development programs are maturing, we have reached the point where the companies developing the drugs, the regulators at the Food and Drug Administration (FDA), and we stakeholders in the process need to achieve clarity on sound guidance regarding pivotal issues such as what the bar for approving new drugs for FA should entail. How many clinical trials are needed? How robust of a finding in those trials must there be? As we know from having seen other trials fail, not all drugs make it this far. However, we have arrived at this decision point for omaveloxolone (omav), an experimental drug being developed by Reata Pharmaceuticals, which has been shown to improve neurological function in people with FA in well-controlled clinical trials. Omav has the potential to prevent long-term consequences, slow progression of the disease and improve FA symptoms by addressing the underlying pathologic processes associated with inflammation, mitochondrial dysfunction, and oxidative stress. Two placebo-controlled clinical trials, along with pre-clinical studies in FA cellular and animal models provide the evidence for these claims.

Why are we sharing this, and why now? It is because we come to you with a call to action. The voice of the patient is critical to the drug development process and FDA has been a strong advocate for identifying opportunities for the “patient voice” to inform and guide drug development. The 21st Century Cures Act requires sponsors to include and FDA to consider the patient perspective in making approval decisions for new drugs. The FA community contributed its patient voice in June 2017, when we hosted the externally-led Patient Focused Drug Development meeting on FA for FDA which revealed that nearly 100% of people with FA experience neurological symptoms including loss of balance and difficulty walking, loss of coordination of movement in the upper and lower limbs and fatigue. We described to FDA that these neurological symptoms have an enormous effect on quality of life as they lead to lost ability to perform activities of daily living and loss of independence. Many of these neurological symptoms (balance, gait, upper limb function, and speech) are measured in the clinic with a structured functional exam called the modified Friedreich Ataxia Rating Scale (mFARS). Data from an ongoing, large, prospective, longitudinal, FA natural history study has demonstrated that neurological symptoms as assessed by mFARS get progressively worse over time and that the mFARS score is highly correlated to activities of daily living in FA. We worked with FDA to improve this scale and ensure it is included in clinical trials in FA.
This brings us to where we are today. There are currently no approved treatments for FA. However, recently a well-controlled clinical trial of omav in 103 individuals with FA demonstrated a statistically significant, placebo-corrected 2.40-point improvement in mFARS after 48 weeks of treatment (p=0.014). In addition, individuals in the treatment arm reported improvements in activities of daily living, such as walking, quality of sitting position and swallowing compared to the placebo group. Given the positive clinical trial results, favorable safety profile of omav, and difficulty conducting clinical trials in FA especially during the current pandemic environment, we are asking FDA and Reata to work together to provide access to omav for people with FA as soon as possible. We hope you will read the information below, which will explain what omav is and the evidence that we have from it being tested in clinical trials. We ask you to review this information and, if you consider this information sufficient for individuals living with FA (and their doctors) to decide whether it is a good choice for them, to sign on to join us in this request.

**Background on Omaveloxolone (Omav)**

FA is caused by mutations in the FXN gene which results in decrease of the essential mitochondrial protein frataxin. Decreased frataxin in the cell leads to several maladaptive responses, including down regulation of Nrf2 which is an important transcription factor (signal for activating specific genes) and regulator of mitochondrial biogenesis. Omav is an activator of Nrf2 and suppressor of NF-κB. Based on data in cell and animal models, omav was identified as a potential treatment for FA.

**Omav Pre-Clinical Data**¹

Several research labs have demonstrated in both human FA cell models and mouse FA models that Nrf2 is downregulated. Treatment of FA cell and animal models with omav have demonstrated activation of Nrf2 and improvements in the mitochondrial function of these models. Treatment with omav reduced pathologic levels of oxidative stress, restored antioxidative response, restored complex 1 activity, decreased lipid peroxidation, decreased mitochondrial ROS, and omav prevented cell death following pro-oxidant challenge.
Studies to Evaluate the Efficacy, Safety, and Pharmacodynamics of Omav in the Treatment of People with FA

MOXIe Part 1

MOXIe Part 1 was a study designed to test the safety and potential efficacy of different doses of omav in FA. This study was needed to establish a safe dose of omav that was then used in Part 2, the larger, longer study designed to test if the drug improved symptoms of FA. The MOXIe Part 1 results provided evidence that omav positively affected the expression of specific genes, as well as neurological function in a dose dependent manner. Omav was also safe and well tolerated.

Details
Randomized, placebo-controlled, double-blind, dose escalation study to evaluate the safety of omav at various doses, designed to identify optimal dose for use in Part 2.
- 69 individuals enrolled and randomized 3 to 1 (drug to placebo) and studied for 12 weeks.
- Cohorts of 8 individuals studied at doses ranging from 2.5-300mg.

Results
- Omav dose-dependently increased Nrf2 target genes ferritin and GGT
- Omav improved neurological function, as assessed by mFARS
- Dose-dependent trends observed and optimal dose identified for Part 2
- Omav had a favorable safety profile in patients with FA in MOXIe Part 1

MOXIe Part 2

MOXIe Part 2 was designed to study the longer term effects on safety and function of FA symptoms in FA patients. This is the part of the trial that was designed to establish the effectiveness of the investigational drug. Again, omav was generally well tolerated. In addition, when compared to the placebo group, patients receiving omav showed improvement in both a clinical exam scale (mFARS) as well as in assessments of activities of daily living and other clinical endpoints.

Details
MOXIe Part 2: Randomized, placebo-controlled, double-blind, parallel-group study to evaluate the safety and efficacy of 150 mg omav in FA patients.
- The primary endpoint was change from baseline in mFARS at Week 48.
- 103 individuals with FA, ages 16-40 years, enrolled and randomized 1 to 1 (drug and placebo) and studied for 48 weeks

Results
- Individuals with FA treated with omav (150 mg/day) demonstrated a statistically significant, placebo-corrected 2.40 point improvement in mFARS after 48 weeks of treatment (p=0.014). The mFARS is a physician-assessed neurological rating scale used to measure FA disease progression. Improvements were observed in all prespecified subgroups and populations. All subsections of mFARS favored omav.
- Omav also significantly improved activities of daily living and other efficacy measures.
- Omav was generally well tolerated in patients with FA.
MOXIe Part 3

MOXIe Part 3, open-label extension (OLE) allowed previously enrolled patients who completed MOXIe Parts 1 and 2 to enter into a new study where they would be getting omav at 150 mg once daily (no placebo). Patients will not be unblinded to study treatment in Part 1 or Part 2 upon entering the extension study. This study is still ongoing however some of the data has been made available. The goal of Part 3/OLE is to demonstrate longer term safety and efficacy. Reata has shared results assessing the therapeutic benefit of the drug by comparing the function of patients while on drug to their function at the beginning of the study (baseline).

Details
MOXIe Part 3/Open Label Extension - Baseline-Controlled Study - The baseline-controlled study was designed to help assess the strength and certainty of the positive primary endpoint findings in MOXIe Part 2.

Results:
- Patients served as their own controls to assess changes in mFARS and included patients considered treatment-naïve prior to initiation of omav treatment in MOXIe Part 3 OLE (i.e., MOXIe Part 1 patients and MOXIe Part 2 placebo patients). All treated populations showed reversal of disease course and improvement P-value for primary analysis is 0.0022.

Rationale
FA is a devastating, progressive and life-shortening rare genetic condition that affects children and adults and for which there are no approved treatments. All individuals with FA suffer neurological symptoms which include loss of coordination of movement in the upper and lower limbs, loss of balance and gait ataxia leading to loss of ambulation and loss of independence in performing activities of daily living (eating, writing, dressing, bathing, etc.). Other common symptoms include dysarthria (speech difficulty), fatigue, cardiomyopathy, arrhythmia, and diabetes. The average life expectancy for individuals with FA is about 35 years.

Omaveloxolone targets a specific cellular dysfunction in FA and has been demonstrated in clinical trials to improve disease specific biomarkers and meaningful neurological clinical outcomes and activities of daily living. Omav has also been demonstrated to be safe and well-tolerated.

Given the clinical trial results, FA patient families and clinicians strongly encourage Reata and the FDA to work together promptly to give people with FA, who currently have no other choice for treatment, access to omav as soon as possible. FDA has emphasized the importance of the patient...
voice, especially for rare conditions without FDA-approved treatment options. As summarized in the report on The Voice of the Patient: Friedreich Ataxia, people with FA experience severely compromised quality of life, loss of independence and early mortality due to symptoms of FA. The majority of patients reported that balance/walking, upper limb function and fatigue have the highest impact on quality of life and treating even one of these individual symptoms would be meaningful. Ninety-five percent (95%) of individuals indicated that slowing or stopping disease progression would be extremely meaningful to them when considering a drug therapy.

The patients and clinicians of the FA community are fully aware of the clinical trial results evaluating the use of omav in FA and are convinced that the results demonstrate meaningful benefit and low risk. More than 95 percent of eligible individuals who participated in the clinical trials elected to enter the open-label extension study to continue their access to omav while awaiting formal analysis of the trial data and regulatory review. We ask Reata to submit a New Drug Application (NDA) on an urgent basis and FDA to exercise the flexibility granted by law and contained in FDA guidance in considering approval of an NDA for omav in FA based on the existing evidence from clinical trials.

References

1. Novel Nrf2 - Inducer Prevents Mitochondrial Defects and Oxidative Stress in Friedreich’s Ataxia Models
2. MOXle Part 1 trial results - Safety, pharmacodynamics, and potential benefit of omaveloxolone in Friedreich ataxia
3. MOXle Part 2 trial results - Safety and Efficacy of Omaveloxolone in Friedreich Ataxia (MOXle Study)
FA COMMUNITY RESPONSE LETTER TO FDA & REATA PHARMACEUTICALS

Allow Individuals with Friedreich Ataxia Access to Omaveloxolone

Email address: ____________________________________________________________
First Name: ___________________________ Last Name: __________________________

1. Please indicate your country of residence.
   - United States
   - Other: ____________________________________________________________

1a. If you reside in the United States, please select your state or territory.

2. Please indicate your affiliation with the FA Community. I am:
   - Living with FA
   - A Parent or family member of an individual with FA
   - A Parent or family member of an individual who died with FA
   - A friend to the FA community, an advocate, and/or a volunteer
   - A Healthcare provider
   - Caregiver
   - A Researcher or scientist
   - An Advocacy Organization (I have authority to sign on behalf of my organization.)
   - Other:

3. If you or your child have FA, what is your / your child’s age?

4. Which of the following best describes your /your child’s stage of disease with FA?
   - Newly diagnosed: 0-2 yrs from symptom onset and diagnosis
   - Been living with symptoms of FA for 2-8 years and/or able to perform most activities of daily living independently
   - Been living with symptoms of FA for 8-14 years and/or require assistance with activities of daily living
   - Been living with symptoms of for >15 years and/or require assistance with all activities of daily living

5. If you or your immediate family member has or had FA, please respond to this question. Based on the data currently available on safety and efficacy of omaveloxolone would you, your child and/or your family member want the option of taking the drug/medicine? Please explain your response. If you participated in the MOXIe part 1, part 2 or open label extension study, please feel free to share your experience or observations.
<table>
<thead>
<tr>
<th>NAME</th>
<th>COMMENTS</th>
</tr>
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<tbody>
<tr>
<td>Berivan A.</td>
<td>I take the drug myself. I am part of the study, I think it brings me a lot. That's why I wish that everyone can get the drug, it's not right that it is rejected and so many patients have to wait for it. There are sick people who are still partially okay, if they have to wait for it, it may be too late. I want it to be approved and that others have the chance to get it too.</td>
</tr>
<tr>
<td>Laurel A.</td>
<td>I participated in phase 2 of Reata’s trial of Omav and I am currently taking the open label. At first I did not notice any immediate affects but over time I became aware that I did not feel any new symptoms of an individual living with Friedreich’s Ataxia. My body does not feel as if it is progressing anymore. This positive experience is a direct response of being able to take Omav. These results are difficult to pinpoint in the beginning but the drug’s ability to slow down this awful disease is evident to me now. Please approve and help others, like me, experience the much needed therapy this drug will do for them!</td>
</tr>
<tr>
<td>Leah A.</td>
<td>Yes! I participated in part 1 and the open extension and I absolutely believe that my progression has slowed! My kids need their mum x</td>
</tr>
<tr>
<td>Penelope A.</td>
<td>Absolutely. I participated in part 1 and the open label but did not experience any positive results. However, I believe that the science and data provide excellent proof of the efficacy of omav in all other patients.</td>
</tr>
<tr>
<td>Scott A.</td>
<td>I was on part 2 of the trial. The difference it’s made particularly with my hands is incredible. My good days are so much better and frequent now and my bad days aren’t as bad. In my opinion it would be an absolute travesty if everyone wasn’t given the opportunity to try it for themselves.</td>
</tr>
<tr>
<td>Carrie B.</td>
<td>Have not got worse with FA since being on the Moxie drug</td>
</tr>
<tr>
<td>Cassydee B.</td>
<td>I’ve been in the open label study for about 2 years now and I believe it’s helped my symptoms stay somewhat fairly stagnant since I started the drug. My symptoms haven’t progressed rapidly while being on the drug.</td>
</tr>
<tr>
<td>Emily B.</td>
<td>I was in part 1 and the extension studies. I noticed an increase in my energy levels as well as my dexterity while being on the drug. I want this medicine to be available to the FA community.</td>
</tr>
<tr>
<td>James B.</td>
<td>I have taken part in the phase 2 trial. I have had no issues and although it isn’t a cure I think I have seen an improvement.</td>
</tr>
<tr>
<td>Justin B.</td>
<td>I haven’t lost a ability in two years and have gained some</td>
</tr>
<tr>
<td>Kelly B.</td>
<td>I’m in the open label. It has significantly improved my fatigue</td>
</tr>
<tr>
<td>Kyle B.</td>
<td>I am in the extension study and have been taking Omaveloxolone every day for about 2 years. I have had no side effects at all. Based on the positive data and the fact that it seems to be a safe drug I hope that the entire community will have the option to take it.</td>
</tr>
<tr>
<td>Lisa B.</td>
<td>I did the moxie trial and have been on the extension for two years. I have had no side affects and my progression has slowed down</td>
</tr>
<tr>
<td>Sam B.</td>
<td>Currently in the Open Label Extension Study. Yes. I would want to continue having Omaveloxolone as I have experienced important benefits, and I strongly agree that it should be available to the FA community. The main benefits for me have been: coping better with fatigue, being able to stand still (without swaying) for a prolonged period of time, and better quicker improvements at the gym, better endurance, and better gain in definition of muscle - especially my legs. From what I’ve seen and felt I truly believe that Omaveloxolone has been key for me to maintain a healthy body (in turn a healthy mind also) and further delaying the progression of my version of Friedreichs Ataxia (G130V Dot Point Mutation).</td>
</tr>
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COMMENTS FROM FA COMMUNITY
Individuals Living with FA who identified as MOXIe Trial Participants

Alex C.  
I am currently enrolled in the extension study, I participated in other trials before. I personally feel like omav has made a difference in my daily living, the positive outcome has relieved stress and anxiety in my life of feeling like, my body is failing and I’m going to be trapped in my own body. Not being able to care for myself and not being understood when communicating to others is a fear of mine. For the first time in a long time, I feel that might not happen. I’m asking for your assistance in making our lives easier and possibly longer.

Antonio C.  
Yes, agree with the option of keep taking the medication. I am a phase 2 patient/volunteer, I have no doubt about its benefits, for sure the best choice that the FA community has right now.

Carolyn C.  
Yes! I was in part 2. It’s helped my energy levels for sure.

Chelsea C.  
In 2019, I started receiving an experimental medicine known as Omav as part of an open label extension for a clinical trial. Almost immediately after starting Omav I noticed changes in my speech, more energy, and better fluidity of my movements. I’ve had no negative side effects.

Kayla C.  
It has slowed my progression down by years. Please push this through the FDA it could save so many people life.

Marinda C.  
Yes, I participated in phase 2 and now the open label extension. I feel that it has benefited my energy, endurance, and control of my motor skills throughout the day. We deserve medicine, we have nothing else.

Max C.  
I don’t see a different or feel a different. My mum says she notices a big difference and so do a lot of others.

Sean C.  
Yes, I am currently taking the study drug and have had no negative side affects. I feel I have also improved in certain areas.

Ashlee D.  
Yes, I participated in part 1 and the extension study. My symptoms have remained stable for 1 year now. I do not feel like I have progressed. I can still walk with the help of a walker and I have energy to work full time and participate in physical therapy.

Liam D.  
I am part of the open label extension, and believe in the benefits of the drug. I want to keep taking it as long as possible and want all friends with FA to have access to it. In my case I do not believe it has reversed certain problems. Indeed some things have gotten harder while on the drug. But I definitively feel less fatigued and that my overall progression has been slower. Importantly I have not noticed any side-effect. It is hard to measure progression. A few days ago I had my drug trial visit, and because of a mixture of insomnia and being the parent of a 2-year-old, I got two hours sleep the night before. Since neurologic symptoms worsen with little sleep, I scored poorly that day. But it solidified for me how subjective and inadequate testing can be. I did not show how I usually am, but instead how I am with 2 hours of sleep. Couple this with the fact that it is hard to measure progression and I do not think we can hold these testing results to the same rigor we can with many other drugs. I spoke to a friend the other night who I had not talked with in 2 years but had been close with for awhile before then. She said she had noticed I was harder to understand over the course of our close friendship, but had not changed over the past 2 years. Instances like that feel more trustworthy than trial visits- she knows me--not just on my bad days but my good days too. I do not think this drug is a cure. But I know it has helped in hard-to-capture ways and I want it to continue to help.

Eva E.  
I’m in the moxie study

Jackson E.  
Yes, I have participated in both parts of the study and have noticed little improvement, if any. However, reports from others that the drug has some degree of efficacy make me willing to keep taking it.

Alex F.  
I participated in MOXIe part 1 and am currently receiving medication during the open label extension. As a late onset FA'er, I am still ambulatory, living and working independently. I stay very active and regularly work 50-60 hour weeks for my family business. As my FA progresses, the effects of fatigue have become more noticeable over the years. I continue to worry that I will not be able to keep up with the high demands of my job while taking care of myself and independently maintaining my own household. Over the last year on the open label extension, my fatigue has significantly improved. After long days at work, I still have energy and motivation to cook a healthy dinner, exercise, and even pursue some hobbies when I come home every night. Not only is this a win in the battle against constant fatigue, but it reduces my stress and anxiety, putting me in a better mental state knowing I can live my life and maintain the things I value. Additionally, I feel more confident with my walking and others comment on my improved speech since starting the open label extension study. In my experience taking the medication over one year, it is safe and has led to improvements and stability in my condition - I would want the option to continue on this medication and strongly recommend other friends with FA consider using it to improve their condition.

Damián G.  
I participated in the Moxie trial. Despite I had some side effects it is related with traveling a lot from Argentina to the USA. But it improve my physical status

Katie G.  
I participated in part 2 and I walked at the end of 3 months, I stopped swaying, my voice didn't slur bad. This is not a treatment this is my answer.

Michael G.  
Yes, I am currently in the MOXIe open label extension, I have been for about two years, and I feel that MOXIe has significantly slowed my progression.
I was a part of the phase 2 and am currently in the open label extension. When I started with phase 2, I had the hardest time dealing with was exhaustion. When I am tired it is harder for me to do the easiest things and to deal with the pain in my legs. I would also fall multiple times a day. Since starting the drug I have ALOT more energy, I may only fall once or twice a week now, and have the energy to deal with my leg pain so much more.

Yes, i want the option of taking this medication. I participated and am currently participating in this trial and have experienced nothing but positive things. Before starting this drug the one symptom that I had the hardest time dealing with was exhaustion. I was incredibly saddened when time for the trial was over. I had told one of my later appointments with my neurologist that the open label extension would become available and I could hardly wait. Although I have had to transition to a wheelchair to remain safe, I can say that the energy that I have had remains at a level where I can still be a full-time teacher, a mother and more gain.

I was a part of the phase 2 and am currently in the open label extension. When I started with phase 2, I specifically remember two major improvements. At the time, I was using a walker full-time. I remember being able to whip that walker around in different directions very quickly and could walk at a fairly “normal” pace. It also took place during the month of December. I recall being amazed with everything I did that month, and not ever feeling I had to lay down at 6:00 pm because of exhaustion. I was incredibly saddened when time for the trial was over. I had told one of my later appointments with my neurologist that the open label extension would become available and I could hardly wait. Although I have had to transition to a wheelchair to remain safe, I can say that the energy that I have had remains at a level where I can still be a full-time teacher, a mother of an active 4th grader, and an active participant within my my family and my community. I wish that all people with FA should be given the same opportunity to experience less loss, and more gain.

I participated in the trial part 1 and the open label study. I saw my therapist six months after I started the open label study and had not seen her for those 6 months. I had only told her I started a trial drug. At the end of the session she noted that my speech had improved and I didn’t seem to need a nap at the end of the session as usual. The speech improvement has been great, but not needing a nap is life-changing. It’s a symptom that is so gradual, that you don’t notice how bad it is till it’s taken away. The fatigue you experience from FA is mentally and physically exhausting. You can’t think clearly or quickly and controlling emotions is very difficult. By Omav easing this symptom I can be a better mom, help with homework more, clean more, and just be out of bed! Also, I saw my sister who also has FA (She could not participate in the study because the travel was too difficult. She is anxiously awaiting the approval.) over the holidays and to see her progression compared to mine was devastating. Her speech when I started the open label trial was difficult for her, but she could be understood. Last year I was translating for her, and now I am struggling to understand her myself. My speech is nowhere near as difficult for me and I think I’m pretty easy to understand. I believe that Omav should be available to everyone with FA because the progress of the disease is devastating. Time is of the essence for our community. The affects I have experienced are extremely positive and with no side effects. I want continued access to this drug. To have this drug taken away would let me freefall into a progression that I would not tolerate emotionally well.

I have been trying to figure out what to write, but I think I figured it out. This approval would mean so much to a lot of people, including me. My whole life, I’ve known that I was different and in some ways, I’m okay with that but there are things I’d like to be able to like other family members and friends. I know this isn’t a cure all, but it is a step in the correct direction. I was very lucky to participate in Phase 2 and completed it and even got to be apart of the open label extension, however I was only allowed to be on Omav for about a month. I had to be taken off the extension due to safety reason, but after discussing it with Dr. L, the truth was that I came off Omav, because my liver was reactivating or turning back on to the full function. I was also told, had I been able to wait a couple days more, my liver enzymes would have come back down to a regulatory levels. Another positive effect that I felt was, I was only on Omav for a month and I was getting 30 second intervals of feeling that I could walk without any assistance. I use a walker for most of the days now. I have moments where I can move without it, but it is more difficult. So I ask both Reata and The FDA to give the members of The FA Community hope again! Though I have not been diagnosed with FA as long as some of my FAmily members, I strongly want us all to be given the life changing opportunities. With FA being such a rare disease and all of these signatures and testimonies, WE all strongly ask for this approval! Thanks for listening to all of us our voices and I personally hope you all stay safe and healthy!

It’s me. I have FA. I am currently in the reata open-label trial through USF and it’s definitely doing more than nothing. So???
**COMMENTS FROM FA COMMUNITY**

**Individuals Living with FA who identified as MOXIe Trial Participants**

**Kendall H.**
I participated in phase 2 and the open label extension. The drug has helped my debilitating fatigue and I have noticed improvements in hand dexterity as well as in my speech. While other symptoms have progressed, I am encouraged by the improvements in these areas and would love for the rest of the FA community to benefit from this drug. Our community needs hope in the form of treatments while we work towards a cure. This drug will provide that. Thank you.

**Michael H.**
I participated in the Moxie trial, and I feel and have felt it helps my fatigue and ability to perform everyday life immensely. It helps me to the extent that having to give it up is an important consideration of mine when looking at other trials.

**Sabine H.**
MoxiePart1

**Julia L.**
Yes, I am in the open label extension study, and this drug has given me the ability to work nearly full time. It helps my speech, my handwriting, and I don’t feel as though my walking has gotten worse since I started the drug. This drug has worked as an antidepressant and has given me hope for the future.

**Nathalie L.**
Part 1

**Naomi H.**
I participated in the phase 2 moxie trial and am currently in the extension study. I can objectively say that this drug has significantly improved my symptoms of FA as measured by the Friedreich’s ataxia rating scale! I have every hope that this drug will be approved and made available to everyone who lives with this condition!

**Emily M.**
Yes - I have been in part 1 and the extension and truly believe this drug is life altering and would like this to be true for others too. I have seen balance improvements and can stand with my eyes closed which I haven’t been able to do for 5 minutes. I am 27 years old and was diagnosed when I was 15 and can still walk on my own for the most part.

**Mary N.**
I have been living with FA for over 17 years. This was the very first clinical drug study that I was involved in about 6 years ago, and am currently involved in the extension phase. I would love the option of taking this medication. I would love this “pause” button medication to be available to all of my family. To experience loss of an ability is hard. To experience over 17 years of losses is hard. I’ve lost friends to their losses with FA. We don’t have time. The time is NOW!

**Austin P.**
Yes, I have been a part of the study and seen success.

**Courtney P.**
I participated in Part 2 and open label and this drug has halted my progression and dramatically improved my living with FA. Honestly, the thought of not having the drug and seeing my life stripped away from me, puts me in a dramatically dark headspace. Please don’t let that happen. Give everyone fighting FA the chance to see the improvements I’ve seen.

**Jennifer P.**
Dear Reata and FDA, I am a Moxie trial participant. The FA community urgently needs access to Omaveloxolone for 3 reasons: 1. Preservation - This is a progressive disease that steals life - the ability to live life on your terms and achieve your dreams; to live independently. I am 34 years old and this condition has taken so much - I was diagnosed at 22 - the prime of my life. I have been unable to move forward in my life due to physical limitations - I can’t live independently anymore, I have had to change my career choice, and I’m limited in my ability to meet my life partner, have children, and basically live a normal life. Access to Omaveloxolone means preservation - being on the Moxie trial means my physical abilities have stopped progressing for 2 years. This buys us time. Time to live - truly live. 2. FA deserves prioritization - We need a disease modifying drug now. Without this drug, we have nothing. This is a rare disease and the FA community does not have any more time to wait. Other conditions have more than 10 disease modifying drugs, while we have none - and our abilities waste away as we wait. Another trial and another few years as a result means that much more progression will happen to our community. This is a life-threatening disease - people will die waiting. 3. Family impact - Parents, siblings, and spouses have become caregivers, had to give up careers, and have suffered devastating financial losses due to this disease. No one asked for this, and it has forced suffering on so many though no fault of their own. This community deserves to be helped, and should be given some light at the end of the tunnel. Please know that I am available for an interview as to how the Moxie trial has impacted my life, and what access to Omaveloxolone means for the FA community. I implore you to act with urgency. Thank you.

**Luke P.**
I’ve participated in the MOXIe trial, and it has been the difference between being sitting at home on social security/Medicare and being able to be an active member of society - raising my kids, excelling in my career, and having a future. I know you may look at some numbers that may or may not meet some arbitrary threshold, but there are people and communities affected by the decision to allow this drug to make an impact on people like me where no other treatment exists.

**Titi P.**
Part 2

**Xhesika P.**
Yes. I was part of Moxie part 2, and it really changed my life. My balance and walking got better. I would be extremely happy if Moxie will be on market so can help our FA community.
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<th>Name</th>
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<tr>
<td>Clifton R.</td>
<td>I am on the part 2 trial and have seen great success and continue to push myself. This medication does work and it would be a mistake to stop its production by not granting FDA approval. As one of the folks hoping for something this is a light at the end of a tunnel. Omaveloxolone / Moxie is a medication that will benefit the Fa community more than just a physical it is alot mental on the hope aspect. As for me I have had great success on Omaveloxolone / Moxie. The physical and mental has been a great improvement. My fine motor skills have gotten better. My standing ability and walking has gotten much better. I no longer sway when standing and can stand with out having to hold on to anything for security. As far my mental state I can not begin to explain how great and how much hope it gives me that there is something that helps. Many of us will be more than happy to make a appearance for you and your staff to show you the improvements in person. Please do not stop the approval. Thank you.</td>
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<td>Don R.</td>
<td>It has stopped progression and improved my speech</td>
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<tr>
<td>Hayden R.</td>
<td>I am in the study and have noticed improvements over time.</td>
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<tr>
<td>Kaity R.</td>
<td>Yes, I did part 2 and open label and I see a big difference in my everyday life</td>
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<tr>
<td>Kiersten R.</td>
<td>My sister Lauren participated in the OMAV clinical trial and the open label extension. She has been doing well on the medication.</td>
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<td>Natalie R.</td>
<td>YES! I am almost 5 years into my diagnosis with FA, and it has been my observation (having participated in the study) that my symptoms (mainly fatigue, minor lack of coordination, falling) have greatly reduced or diminished since being on the open label extension. Ever since I was diagnosed with FA, I began to fear time -- most of my friends are excited about the prospect of the future, whereas I struggle to look forward to it out of fear of what I will lose. Making Omav available gives us more time, and makes the future seem less frightening -- we may be a small community, but we have so much to give, and helping us pause our progression can help us continue to contribute to the world around us. And truthfully, flying to appointments regularly for a new/extended trial is frustrating to think about, after all the time and energy we’ve already expended for this study.</td>
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<td>Tyler R.</td>
<td>Yes. I participated in phase 2 and it appeared to slow symptom advancement</td>
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<tr>
<td>Brittany S.</td>
<td>I’m Brittany S, and I am a FARA ambassador. I was diagnosed with Friedreich’s ataxia (FA) at age of 13, in early 2007, with my sister who was 16 at that time. We have both been living with FA for 13 and a half years. Myself and my sister were participants in the MOXIe trial Part 1 from August to December 2015. Now, since April 2019, we both are continuing to take omav now during the open label extension in Los Angeles. My observations while taking omav, in short, are a slower progression of symptoms with more steadiness in my movements. Higher energy levels have also been noticed in my personal experience. I am a full-time wheelchair user but I am able to stand up in my kitchen to do some dishes. One time, my mom came into the room and mistook me while standing- at the sink- as my oldest sister, who is a non-FAer (someone without Friedreich’s Ataxia). My posture had absolutely no wobbliness in that moment. Also with my hand-writing and my nail technician skills (on myself), I have noticed my dexterity has improved because of steadier fine motor movements. Overall, my experience has been very positive with no significant adverse reactions. I am hopeful that the FDA will review the MOXIe trial data and understand the importance of the benefits omav has for progressing FA patients. Especially the FAmily members who are ever so patiently waiting. Thank you.</td>
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<tr>
<td>Chelsey S.</td>
<td>Yes. moxie part 1 and open label extension</td>
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<tr>
<td>Jami S.</td>
<td>Yes the drug made me feel more energetic and better</td>
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<tr>
<td>Jarrett S.</td>
<td>I am currently taking part in the MOXIe open label extension study. In my experience, I find that does lessen the effects of FA. I do want those with FA to have the option of taking this drug.</td>
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<tr>
<td>Joe S.</td>
<td>Yes, I would gladly take Omaveloxolone. I participated in part one of the clinical trial, as well as the open label extension, and have had no adverse events as a result, only benefits relative to symptom management.</td>
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Kyra S.  
I have been taking the drug for three years now and can with absolute certainty say it does help. It slows down the progression and for me it has also eased already existing symptoms. I have also not experienced any side effects which makes omav extremely advantageous for the treatment of FA.

Emily T.  
Currently on the drug and haven’t experienced much change.

Joseph T.  
I participated in Moxie part 2 and am on the open label extension study. I have been on open label for 20 months and see TREMENDOUS benefits! My speech is significantly better and my balance and coordination has improved too. I have had no adverse side effects. For me, Moxie is a game changer. I can see myself in my current job for years to come vs. a couple years ago I was planning on life based on the progressiveness of FA. I want all FA patients to have the chance to take Moxie. please!!

Shandra T.  
My name is Shandra T. and I am 23 years old. I was diagnosed with Friedreich’s Ataxia 11 years ago. I remember my first symptom, losing the ability to stand up on a balance beam in gymnastics, at age 9. I remember having chest pain when I tried to run in PE class at age 10, wondering why I couldn’t walk in a straight line when I was 11, and getting the blood test that diagnosed my FA when I was 12. I remember the pain of my spinal fusion surgery I had at age 12 like it happened last week. I remember losing the ability to run (age 14), jump (age 15), and then safely walk independently (age 19). I also remember the hope and excitement I felt while signing the consent forms for the open label extension study of Omav in February 2019 (age 21). I remember when I saw my reflection in a store window and could tell my walking looked more natural (age 21). I remember my mom and my friends asking me why I could walk better and excitedly informing them that I was taking Omav (age 21). I remember buying a pair of low-top converse because I no longer needed the ankle stability from high-tops to walk (age 22). I remember realizing that a 9 hour day of work and school didn’t tire me out, a huge improvement because I used to need to lay down after an hour at the grocery store (age 22). I remember my physical therapist’s comment that I was improving abilities at each session instead of slowing down the process of getting worse (age 23). You see, the process of getting worse each year with FA used to be inevitable. Every lost milestone has become a core memory. I was excited to join the open-label extension of Omav nearly 2 years ago, but I wasn’t expecting the milestones of regained functions that I experienced. This is because up until Omav, there were no clinical candidates that have made it this far in the clinical trial pipeline. There was no glimmer of hope for my community. Having a death sentence with no medicine to fix it makes people with FA view clinical trials with an extra perspective. You see a statistically significant 2.4 point improvement in mFARS, we see the difference between nearly normal speech and mostly unintelligible speech (2 points), the ability to stand for over a minute or for just a couple seconds (3 points), and the ability to sit on the edge of a bed with little difficulty or need back/arm support when sitting (2 points). These small point differences are huge in the context of standing at a sink to brush teeth, having a conversation with friends, and getting out of bed in the morning. The benefits in walking, stability, and energy that I have noticed on Omav have made it easier for me to maintain the stamina I need to get my degree in school while also enjoying activities and seeing friends in my free time. I have experienced no negative side effects from Omav and I firmly believe that it has put a considerable pause on my disease progression while also allowing me to regain some abilities. I do not want to go back to life before I had Omav and I want the rest of the FA patient community to have access to this medication as soon as possible. In the years it would take to complete another clinical trial, my friends with FA are going to experience more milestones of loss. They deserve access to a medicine that can put a pause on this relentless disease. Please reconsider the need for another clinical trial. Thank you so much!

Heather W.  
I was part of both study’s and would take the drug if possible again.

Josh W.  
Yes, I am a participate in the study and I have noticed that I have significantly more energy when I take it.

Kyle W.  
Yes, I have noticed it has slowed progression significantly. My heart has remained stable since I’ve been on Omav, fatigue has also improved.
Mike W.

Absolutely, I can’t state strongly enough how important this is. I took part in the study at UCLA, and being on the drug has been an absolutely crucial part of my life. I was on what I believe 100% was the placebo for about six months at first (the exact timeline I don’t recall), then they put me on what we knew to be the real deal. When I was on the placebo, I was spiraling. I was starting to get worse at a rate that seemed to be faster than it ever had been to that point. I had very slowly developing FA and frankly I was due to start seeing signs of deeper regression. It scared the hell out of me even though I knew it was inevitable. Once they put me on the real drug, it’s come very close to stopping the regression entirely. The math with the study indicates there’s only about a 1% chance the positive results were coincidence, but I don’t need the math. I know it works. It’s been something like 2.5-3 years since I’ve been on it, and I’ve been steady the entire time. If it wasn’t for this drug, I’d be in a wheelchair today. And there have been no side effects that I’ve been able to notice. You have to understand that FA is so much worse than simply not being able to walk. That’s just the most noticeable symptom. There are far too many things that happen to you when you have it to list here, but they all get worse and worse. And the worst of it, and I wish people understood this, is the mental anguish that comes with all of it. And it’s all day, every day. There’s virtually nothing you might do where it isn’t an issue. It even comes up in dreams while I sleep. There are no words in the English language to describe how exhausting it is, and the absolute terror of knowing that it will get worse and worse. It’s like being in a slow motion plane crash. It is hell. And when I listened to some parents of 2 kids with FA talk about how they see their daughter look at her older brother and his walker and him having problems when she thinks no one is looking, that makes me break down a bit, because that feeling of fear and inability to escape is something so entirely cruel that no one should be forced to go through it if there’s anything at all that might help. That girl can’t afford to lose any more time, and neither can her brother. They’ve already lost more than enough and been through so much mentally that’s so far beyond what anyone their age should have to go through. And it’s downhill from there. They need immediate help, and so does everyone else with FA. Myself included. I can’t afford to lose access to this drug. I feel like I’m on the edge of an abyss, and this drug is playing a huge part in keeping me from falling in. Please give everyone access. PLEASE.

Emily Y.

In March 2018, I was lucky enough to be part of the Omav trial part 2, and continued taking Omav in open label. My observations in this time have been that my walking ability has stayed consistent as well as my hearing, speech, and core strength. My arm strength has improved in terms of endurance and ability. I have even been able to keep hiring the same personal care staff, and I have not had to train them to help me do any more activities of daily living, just laundry and cooking. My experience with Omav has been life changing. I’ve completed 2 higher ed degrees, had multiple jobs, live independently, and travel often. I know you’re thinking there’s no way to tell what my progression would have been like without taking Omav, but I don’t think that’s entirely true. When I was in high school and early college, from 2012-2017, I can tell you every ability I lost to date, how often it happened, and how soon it would happen again. Since I started Omav these happen much less frequently, in fact when I wrote this speech I actively thought about looking at my progression over years of my life, compared to high school when it felt like a daily occurrence. I believe Omav should be available to individuals with FA because I have lived with this disease almost 12 years now and I cannot find the words to describe how difficult it is to experience the progression, the day I lose an ability and the fear of how soon it will happen again. I want to be able to plan for my future with success, prosperity, and the brightest of goals in mind. I don’t want to account for the abilities I will lose and what I am limited to doing. I want this option for the entire community too. I am hopeful that the FDA will find the MOXIe trial data sufficient for consideration of approval and understand the benefits Omav has for FA patients.
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<th>NAME</th>
<th>COMMENTS</th>
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<tbody>
<tr>
<td>Gabriel A.</td>
<td>Moxie part 2</td>
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<tr>
<td>Lorelei A.</td>
<td>My cousin has benefited from the drug “Omaveloxolone”</td>
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<tr>
<td>Lori A.</td>
<td>Part 2</td>
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<tr>
<td>Nancy A.</td>
<td>We would absolutely want the option of taking this drug. My son has participated in the Moxie part 2 and is currently in the open label extension. We have not received any results from this trial yet we have lived it. We believe my son was on the placebo during the part 2 trial. His progression of FA continued pretty dramatically during that year. When the doctor asked him after the 48 week trial if he thought he was on the real drug he responded, “I sure hope not.” In Sept of 2019 he started the real drug in the extension phase. After 6 months we felt like things hadn’t gotten worse but didn’t see much improvement. At 10 months we started to see a calmness in his movements. He is sitting up easier and no longer asking to be moved to a chair that supports his neck. He is eating with more precision. That fork full of rice is getting to his mouth with ease and not spilling. He is sitting at the edge of the bed and changing his cloths by himself. He is way less fatigued because it seems like he is not fighting with his body to stay still. A very noticeable difference is his nystagmus. His eyes used to be in constant motion and reading and focusing were a challenge. Now they are not. This has lead to him completing schoolwork at a much quicker pace. He used to constantly ask for breaks because sitting at his desk and looking at a computer was not easy. Now he literally never asks for a break in any chair. This has been a dramatic change. He is more social around the house. He has a huge stack of books next to his bed and reads for hours at night. I would say 18 months ago, he could read or work on his computer for 20-30 minutes and then need a break and ask to recline in a lazy boy chair because his neck was sore or his eyes hurt. As parents of an FA child you are constantly adapting to make things easier for your child such as wear to sit, how to eat, how to get up a few stairs. We are not making those constant adjustments. A lot of the symptoms and challenges of FA are difficult to measure in a doctor’s office. This drug is helping my child! Instead of watching him in a continued state of decline we are seeing progress. My hope is that every FA patient and family can have access to this drug and experience this progress.</td>
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<td>Paul A.</td>
<td>Our daughter participated in the MOXie trial for almost 2 years now. It is apparent to our daughter and to my wife and I, that there has been a considerable / noticeable slowing of disease progression. As we strive for the cure, perhaps a gene therapy approach, the efficacy and safety profile of Omav should be considered as a therapeutic. We would like to have our daughter continue taking Omav and urge you to reconsider approval of this drug. In a progressive disease such as FA, the benefit proven by the trial results, albeit modest compared to others, is significant to daughter.</td>
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<td>Vicky A.</td>
<td>My child was in the part 1 and the extension study. She was one of the only known individual in the trial that did not experience any sort of improvement. That being said, we are very excited that the results of this trial proved to be so positive for the FA community! We wholeheartedly support the immediate approval of this drug so that our loved ones can have the opportunity for a fuller life TODAY!</td>
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<tr>
<td>Zülfükar A.</td>
<td>My daughter runs the company. She takes the drug in the study and it helps her. That’s why we want it to be approved as soon as possible.</td>
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<tr>
<td>Alinga B.</td>
<td>Yes, we want Omav to be available. My daughter has been in part 2 and currently in open label.</td>
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<tr>
<td>Brandi B.</td>
<td>Yes, brother participated in the study and can see improvements.</td>
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COMMENTS FROM FA COMMUNITY
Parents & Family Members of Individuals who identified as MOXIe Trial Participants

Brent B.  Our son is on the trial and our other son + daughter need to take advantage of the positive results.

Brigid B.  My 23 year old son was diagnosed with FA over six years ago and was able to join the Horizon Actimmune trial shortly thereafter. For more than a year and a half during high school and college, he traveled back and forth to Philadelphia for many clinical visits. He had to keep the drug refrigerated, learn to give himself an injection three times a week and deal with the flu like symptoms that were a side effect. As you know, that trial did not meet it’s endpoints, a fact that our son was not surprised about. He said he never felt any benefit from the Horizon drug. When Reata announced the MOXIe trial shortly thereafter, he said “Mom, maybe I will pass on this one.” Understandable, he had clinical trial fatigue compounded with the desire to just enjoy being in college. I encouraged him to go to the screening visit and learn about the trial, one that had less clinical visits and just required taking pills. He did and was enrolled. We agreed that if the travel or trial became too burdensome, he could withdraw. After being on Omav for just a few weeks, my son said he would do whatever he needed to do to stay in the Reata trial. This drug was different. He had just come back from spring break with his friends and said he would not have been able to do everything he did, like walking down stairs in a darken bar, before taking Omav. Our son has been on Omav for two years now. He has completed college, moved to another city, and started a computer software programming job. Fatigue, now reduced, has not derailed his goals or his contribution to society. Yes, his FA has progressed but not at the rate his neurologist expected based on the natural history data. He continues to have strong sensations in his feet and hands, which, in turn, makes walking, driving, dressing, eating, typing, basically all aspects of daily living easier. He has remained mobile and active because he can. And, the ability to continue living his life is directly correlated to his positive and healthy emotional well being. Most of all, he has had no side effects from Omav - none. I have spent the last six years learning about drug development and how to expedite treatments for FA. I have heard many, many FDA officials speak about the various legislative actions taken to encourage research in rare disease and build in flexibility in the review process, all to get treatments to patients quicker. So, based on what I have been told, here is the risk/benefit analysis I see. With FA, there is a limited patient pool for clinical trials (approximately 5000 FAers in the US but only a faction of those qualify for trials) with an incredibly unmet need (no approved treatments) and serious outcomes (progressive loss of all abilities and early death). Omav has shown to not only slow progression but actually improve abilities and reduces fatigue allowing the individual to feel, function and survive better. There is also good safety data and personal testimonials that the medication is tolerated well. High benefit, low risk. Furthermore, a delay in approval will also have serious implications. 1) My son, as well as all Reata participants will be ineligible for all trials while a second Reata trial is conducted because they will still be on an investigatory drug. That could take up to five years! Omav helps FA but there are exciting candidates coming that could address the underlying cause. A delay will force all Reata participants to choose between a successful treatment vs a potential cure. 2) The delay hurts the most vulnerable in our community. My son was fortunate but many FAers are children and were ineligible for the Reata trial. The earlier the onset of FA, the quicker the progression. They have already been losing their abilities for years while the first trial was conducted, the time needed for a second trial could strip them of their mobility, or worse. 3) Conducting a second trial would not only waste precious resources of patient pool, money and time but would send a chilling message to patients, researchers, sponsors and investors regarding the FDAs application of flexibility around progressive neuromuscular diseases. In conditions where loss and gain are challenging to capture, the rejection of data showing a two year improvement may discourage future projects. Rather, an approval with further monitoring could confirm the results while providing that all FAers have the chance to stop, or even improve, their condition. Requiring that the second trial occurs before approval guarantees their further decline. Each and every day matters when you are facing a progressive condition. Just stopping my son’s progression would be enough for our family but a two year gain has been an incredible gift, and would also be to any family facing this horrible disease.

Conni B.  Yes. It worked for our family member during earlier trial.

David B.  YES, MY DAUGHTER HAS PARTICAPTED IN PART 2 AND OPEN LABEL EXTENSION STUDY. SHE HAS EXPERNENCED MORE ENGERY AND SOME IMPROVEMENT IN HER WALKING ALTHOUGH SHE STILL WALKS WITH A WALKER

Debbie B.  My daughter participated and is currently on omav. She, and we, noticed significant reduction in fatigue, which lent itself to better control of her coordination and speech, which gets worse when she is fatigued. She no longer needs 2-3 naps a day and is still walking with her Rollz, still trying desperately to delay using a wheelchair in her life. We believe omav helped her. We believe it slowed, paused, symptoms. We want any FAer who chooses, to have the opportunity to experience some of these benefits. We hope for a better life for the newly diagnosed as researchers continue to strive for a cure, and we believe omav is a “pause” button for FA. Please give FAers a chance, please give them hope. Thank you so much.

Dianne B.  One of our children is part of the study and therefore takes the omaveloxolone. The other two would like the opportunity to take it also.

Fariba B.  FA seemed to us a raging river in which our son was dragged along helpless to resist, until MOXIe somehow slowed it to a meander. So yes, without question, our son will continue using MOXIe. Diagnosed age 15 now 22 the progression in terms of lost capacity became predictable. That was until using MOXIe during part 1 and again now in the extension study. Most notable was regaining the ability to steady himself while standing. This ability has persisted along with reliable dexterity.
**COMMENTS FROM FA COMMUNITY**

Parents & Family Members of Individuals who identified as MOXie Trial Participants

Jennifer B.  
YES!!!  J. was in the part 2 study and is currently in the open label extension. Omaveloxolone has given us hope. J. has not lost any abilities since starting the open label extension as well as we have seen improvement. People in our small community have noticed a great improvement in his speech and their ability to understand him. Personally, I have notice that he is walking better behind his walker and more willing to walk. He is standing more upright instead of bent over. Another thing I have notice that he is not choking as often at meal times. We will do what ever it takes to keep J. on Omaveloxolone to keep his FA paused for as long as we can.

Joseph B.  
Yes, my niece is in the trial and has definitely seen an improvement since she started the treatment. She would certainly continue to take omaveloxolone if it were available to her.

Lynn B.  
Yes, I would like for my daughter (H.) to continue taking omaveloxolone. H. has been on this drug a little more than one year and is still able to walk. In the world of FA, walking at age 25 is rare. I know that this drug is making a difference. The trembling in H’s hands has improved, energy is almost back to normal, and her speech continues to improve. Omaveloxolone is giving us hope.

Mark B.  
Yea I want my wife to start taking the drug. My sister-in-law was in the clinical trial and has improved and doesn’t need to use a walker like my wife does. I know this drug would greatly improve my wife’s health and everyday life.

Michael B.  
Participated in clinical trials with some success and no ill effects

Susan B.  
Yes, it has improved some of C’s abilities and slowed progression of the disease.

Susana B.  
Part1

Catherine C.  
My niece was in the Reata trial for this drug and saw some benefit from it. Since there is no cure for FA, this drug is a huge step in treatment and hopefully a cure someday.

David C.  
Yes. K. (my daughter) is taking the drug now through a clinical trial and has noticed improvements in her condition.

Evie C.  
My brother has FA and was part of the moxi trial, I would want him to take the drug if he wasn’t already

Hannah C.  
My brother has been involved in the MOXie trial study basically since the beginning of the study. We believe he had the placebo during the trial though, because after the phase ended and everyone in the trial was able to begin taking the medicine we finally saw some changes with him! Now that he has been taking the medicine for about a year or a little longer, I believe that everyone with FA should have the option to take the medicine. In the eyes of someone with FA and in the eyes of someone who watches their family member suffer from FA, this community desires any form of help possible. While we all yearn for the day where FA has an official cure, anything that can slow the progression (i.e., omav) in the meantime is very desirable. I hope that my brother can continue taking this drug and that others in the FA community can be given this opportunity as well.

Jami C.  
Yes, my sister was on the study and the drug helped her.

Jan C.  
My son participated in the part 2 and open label

Jason C.  
My son D. has been diagnosed with FA for 8 years. He was diagnosed when he was 11 years old. He has been wheelchair bound for 4 years. Like all FA patients, D. has experienced loss after loss: first, his balance, then his mobility, then his dexterity, and then some speech. Since participating in the MOXIE part 2 and the open label extension study, the progression of D’s FA has slowed. He has not experienced any negative side effects. The benefits of OMAV to the FA community are huge. This drug has offered hope to us all. Please, REATA, apply for a new drug application. Please, FDA, grant approval of OMAV. Time is of the essence. Please stop the losses. Please give us hope.

John C.  
Two of my children live with FA. One took part in the trials for this drug. She immediately noticed improvement that endured for weeks. She did not suffer any noticeable side effects. It is her only hope.

Matthew C.  
My son is participating in the study. It is a very safe and effective treatment. I hope that all FA patients are allowed to have access to this treatment.
COMMENTS FROM FA COMMUNITY
Parents & Family Members of Individuals who identified as MOXIe Trial Participants

Shawna C.
I respectfully and urgently request Reata to submit a New Drug Application (NDA) on an urgent basis and the FDA to exercise the flexibility granted by law and contained in FDA guidance in considering approval of an NDA for Omaveloxolone in FA based on the existing evidence from clinical trials. My son has participated in the Part 2 of the MOXIe drug trial and is currently in the open label extension study. Since he started taking Omav, the FA progression my son has experienced has slowed. He has less fatigue and more energy to maintain some of his independence with daily activities. As with other FA patients, my son has experienced loss after loss: loss of some mobility, loss of some dexterity, loss of balance, and loss of some speech ability. So far, Omav seems to be slowing his losses and increasing his level of activity and hope for the future. This is the first time that the FA community has received any hope for abatement of the symptoms of this terrible disease. PLEASE move forward with the application and approval process for this drug. Please grant the FA community hope. With a grateful heart, I thank you for the research that has been done in the past, the work being done in the present, and in advance of the submission of the NDA and its approval.

Shirley C.
Yes. My daughter is on the extension study. Please approve.

Abby D.
Sister participated in trial and would like to continue taking The medication.

Jamie D.
My sister is 24 years old and was diagnosed with FA over 12 years ago. She participated in the MOXIe part 2 study and is now in the extended study. I can state without a doubt that she wants continued and forever access to omaveloxolone. The data you are looking at from these studies is not just positive but is a significant benefit to her and to the FA community. Omav has not nor will it ever give my sister the ability to run across the room or quit using her wheelchair. But it has improved her FA symptoms and slowed progression for her to live independently in her apartment while seeking her masters in social work. It has given her improved strength and stability to hold her godson in her arms independently of anyone else. It has given her the stamina to hold an internship while studying for her social work licensing exam so that she can pursue a career to serve her community. It has given her several things that equal significance in her world living with FA. FDA and Reata please work together to consider that this data is sufficient for a new drug application and would provide significant benefit to a community with an unmet medical need.

Lucia D.
My son is fortunate to be on the open label extension study. He was in part 2, we believe on the placebo, because now on the open label extension we see improvements. He is no longer choking while eating, his small motor skills have improved and his speech is much clearer. We now have hope of him getting a job, he just completed a computer science degree at UMass Amherst. Something that would be infinitely more difficult if he was unable to speak clearly.

Simon D.
Our son F. is on the open label extension - although we recognize it is obviously not a “cure” our experience suggests it has significantly slowed his progression - we believe we have seen noticeable improvements in his ability to swallow as well as the clarity of his speech - and F. continues to be able to cover short distances with the use of a stick rather than requiring full time use of a chair, all of which result in a significant improvement in his quality of life - both physical and emotional. We have seen absolutely no evidence of any downsides or undesirable side effects to taking omaveloxolone and strongly support its being made available to to others as well as allowing our son to continue taking it.

Drew E.
Yes, we would like to participate. Our son participated in the trial. Our experience was very good and we are hopeful that the drug has helped him.

Michaela E.
Part of the moxie study.

Sarah E.
My sister-in-law has been taking MOXIe as part of the clinical trial, and we have been able to notice significant delays in her progression. Yes, if this regimen works and continues to have proven efficacy, I would hope that it becomes widely available to all FA patients.
COMMENTS FROM FA COMMUNITY
Parents & Family Members of Individuals who identified as MOXIe Trial Participants

Anne F.  
Based on the data, my son would absolutely want the option to stay on the drug he has experienced true benefit from the drug. His degeneration has plateaued. His speech is clearer. Use of his hands has improved. He is not in a wheelchair full time. He can still get around with a walker and he is stronger. Fatigue is less. When you live a life waiting each day for a disease to rob you of your independence it is hard to reconcile that adrug that is helping you will be taken away. He is able to pick up a glass, use utensils, wash dishes, shower, the list is endless. Without the drug, it was all slipping away. This is his 3 rd clinical trial. He benefited from the last drug and for various reasons that trial abruptly ended and the drug was taken away. This patient who is a person fighting for quality of life having the same thing happen again. The pain is intolerable. The system takes away hope from these patients. Participating in a clinical trial is grueling work for FA patients, and now with covid, it is frightening. How can the FDA not look at this data and approve omav. These are human beings who every day of their life's have to cope with loss. Think about it. Every day you fear you will not be able to swallow tomorrow. Or tomorrow no one will be able to understand me. Or tomorrow I will not be able to get out of the wheelchair and will be wheeled around like luggage through an airport. Always having people stare at me and quickly look away. Dignity of life is slowly but brutally taken from you. My son started life like most other kids with dreams and aspirations. Playing with other children, laughing and running in the school yard. What he would give to have that time back. Instead he dedicates his adult life by participating in 3 clinical trial, with countless trips to hospitals, countless swabs, countless bloodwork, and just when there is a light at the end of the tunnel the system is about to let him down again. This injustice has to stop. There must be some compassion in the system. Why are FA patients less valuable than cancer patients. If a patient is begging for a treatment that works why can they not have it. This is a critical point in these patients’ lives and the fda holds the key to the beginning of a path to a true cure. Every FA patient should be able to roll into their pharmacy and get a prescription for omav. Enough is enough. Walk in their shoes or sit in their wheelchair for just one day and then you tell me whether or not a drug that works should not be readily available. Stop the bureaucracy. I beg you for my son and for the FA community approve omav now.

David F.  
Yes, we have seen the improvement in J's ability to care for himself and live independently.

Kristina F.  
We have seen our nephew J. make continued progress thanks to the omav drug. We hope and pray that the FDA will make its decision to approve its use soon. Thank you.

Lucas Levi F.  
Part 1

Mary Claire F.  
To Reata and FDA: I am J's Godmother and Aunt, Mary Claire F., PhD. I have known J. his entire life. Everyone in J's family loves this beautiful, intelligent and gifted young man very deeply. But I was especially privileged to have J. as an integral part of my family. My 2 children shared so much of their childhood with J. He was sandwiched in age between them so they were very close cousins. There was much love, adventure, joy and laughter. He is at the heart of our family. It broke our hearts watching J. struggle as this brutal disease began stealing his function. Our only solace was our family’s heroine, my sister, his Mom, Anne F. She refused to accept any level of defeat. She bolstered the emotional resilience of J. and his Dad, B. She hunted and searched. Determined that there would be answers. She found Dr. L at CHOP. A man tirelessly dedicated to eradicating FA. J. became committed to every detail of the protocol of a new drug. Accepting the emotional challenge of placebo or not placebo. Finally, Omaveloxone (Omav) was developed. Once J. was on Omav for a sufficient time the results were so significant and heartening. I saw this first hand at a family event. Normally the fatigue of FA, having to choose his wheelchair or to try to walk, the struggles with speech and coordinating eating would have limited his participation or prevented it. Now J. walked a fair distance unaided into the party. He sat with us and ate. Speech, cognition and fine motor skills all clearly stronger. J. is a Philosophy major at Drew University. He and I got to have a deep philosophical discussion. Improvements were so evident. J. was head erect, speech and cognitive focus much more rapid and clear. But that broad J. smile was back. Affect and energy so improved. It was such a delight. This disease is a thief. Please don’t steal this drug from him. Thank you for your attention to this letter. Thank you in advance for your support of an NDA for Omav.

Michael F.  
My nephew was diagnosed with FA in 2017, when we began to witness the onset of loss of balance and difficulty walking, loss of coordination of movement in the upper and lower limbs, and fatigue. We have all been heartbroken for my nephew to see him with compromised balance, gait, upper limb function, and speech. My sister and my brother-in-law dedicated themselves extraordinarily to supporting my nephew for years. Specialist after specialist, extraordinarily painful surgery after extraordinarily painful surgery, searching for medication and treatment -- all of it. They, my nephew and we all are the kind of folks who do what is necessary -- and we worked on this, especially my nephew, of course. Then hope arose, with a trial. Then we saw SOME unexpected and gradual improvements in activities of daily living, such as walking, quality of sitting position and swallowing. Through a lot of hard work my nephew was able to complete college; the family has been able to establish a place for my nephew to live, in some privacy and with some company. Indications are that omav will help my nephew. Do we want him to have the option of taking omav, the drug/medicine that helps him? Speaking calmly, shouting, begging, demanding, hoping, crying -- whatever way it will take for you to hear it -- please hear me when I say a resounding YES YES! YES!! YES!! -- YES. Thank you for the opportunity to say YES.
COMMENTS FROM FA COMMUNITY
Parents & Family Members of Individuals who identified as MOXIe Trial Participants

Sandra F.  My answer is yes. I am a parent of an FA patient who has been able to participate in the trial, and open label extension study. It is difficult to gauge progression of disease and loss of function because we have nothing to compare it to. I do not know where he would be as far as progression of disease goes if he was not on drug. I can say, however, from first hand experience and observation, that he has more energy than when he was not on the drug. As both a scientist, and a nurse, I am very astute at assessing for signs/symptoms in my son. I have not observed any adverse events from being on omaveloxolone, but did observe that he seemed less fatigued. For that reason, I would hope he could continue on drug, and perhaps expand the trial to include more participants.

Tessa F.  My brother participated in the MOXIe study and would like the chance to continue taking the drug. The hope and potential benefits it brings him and many others outweighs the almost nonexistent negative side effects.

Brian G.  Moxie part 2

Brian G.  Yes, having seen the positive effects from the drug study directly. My wife participated in the study and I have seen the improvements in function and balance.

Erica G.  My younger brother, D., has FA. He was in the Omav trial. He lives a couple hours away from me so we would talk on the phone. In the past few years it had been getting rather difficult to understand his speech. At times I had to ask him to repeat everything he said. Since taking the Omav, I am able to understand everything her says as if he didn’t even have FA. This drug is amazing.

Horacio G.  My son participated in the Moxie trial. Despite he had some side effects it is related with traveling a lot from Argentina to the USA. But it improve his physical status.

Jane G.  My granddaughter participated in the same trial and also experienced improvement.

Katie G.  Yes. He is on the open label currently and we feel it has slowed his progression.

Kimberly G.  I would very much want my daughter to have the option to continue taking Moxie. She has been involved in the trial and I am thrilled and grateful at the increase in her energy level and fine motor skills. Her handwriting improved significantly, enabling her to write legibly. It has been a gift. Please allow FA patients like her the opportunity to take this very beneficial medication.

Liz G.  Yes. My son participated in part 2 of the Moxie study & is in the open label extension study. He feels Moxie has slowed his progression. We are encouraged that Moxie is the first drug to show positive results for treatment of FA in a clinical trial. We're hopeful Reata will submit the NDA & FDA will approve Moxie for treatment of FA, given the positive trial results, the rapid and devastating progression of FA, and the small patient population.

Ciara H.  My brother has been taking the drug and it has helped with his energy throughout the day and his balance!

Craig H.  My daughter has been taking this medication and is in part 2 open label. The results have been a dramatic improvement in her walking and balance. This has also provided her a renewed desire to explore her world and has lifted her emotional spirits.

Faith H.  Yes, my sister was a part of the trials for omaveloxolone and experienced incredible results. I have other siblings with FA and I believe they would like the option of taking the medicine as well.

Jared H.  My sister was part of the MOXIe part 2 and has seen positive results as an outcome. I would love to see this become a drug that is available for all people who struggle with FA and hopefully have a positive impact on their lives as well.

Jennifer H.  My youngest brother has FA, and been on several drug trials. He is currently on the Part 3 open-label extension trial for MOXIe (aka Omavaloxolone). He noticed it has slowed the progression significantly while he has been on it, so feel strongly this should be an available option for others with FA until there is a cure.

Kyle H.  I would 100% have my wife take the medicine. She has been on the trial for over a year now and has seen wonderful results. She is not progressing nearly as much as she was before the trial. She is falling substantially less too.

Laura H.  My sons participated in the double blind portion of the trial. My older son had to withdraw for unrelated medical reasons. My younger son continues to take Moxie as part of the open label extension. Although we have not seen significant improvement on Moxie, I have seen it make a difference for other FA family members. I think it should be approved for use for the treatment of FA. The patient and his/her doctor should then be able to decide if there is a benefit. Just like antidepressants, what works for one patient may not work for another. That does not mean that no one should have the option to see if it works for them.
COMMENTS FROM FA COMMUNITY
Parents & Family Members of Individuals who identified as MOXIe Trial Participants

Michael H.  My son was diagnosed about 7 years ago. He is slowly losing his fine motor skills and has a heart condition. He can still walk but stumbles quite a bit. He was diagnosed at a slightly later age than the average FAer and so he still lives independently. He has done a few trials, but this one was different. For the others, he would tell us he didn’t think they were working. In this case, a few weeks after he started the trial he said he could feel the difference. He has moved on to the open label portion of the study so is quite fortunate to still have access to the drug. While we still see that he is losing some of his mobility as he trips and falls regularly, we know that it would have progressed more rapidly had he not been the drug. So as a parent of a child with the disease, I can tell you unequivocally this matters. It matters to my son and will matter to the thousands of others affected by this disease. We know its not a cure, but if we can slow the progression down while we wait for a cure, that would be life changing for many.

Michelle H.  The 26 year old participated in part 2 and extension.

Paula H.  absolutely as having one child on the drug and see her improve on many levels and affecting all areas of day to day living and then the other child not on the drug is progressing and every day is harder and harder.

Samm H.  My sister in law participated in part 2 and ongoing

Sean H.  Yes, my brother participated in a clinical trial and I saw a benefit towards his balance and energy levels and no side effects.

Shelby H.  Yes my sister in law has been on a trial and has noticed differences in her symptoms.

Kathy I.  Yes my nephew is participating in a trail

Marisol I.  Part1

Bradey J.  Yes, my brother had many benefits with the drug. Not needing to nap once every twelve hours was on benefit of many.

Kayla J.  I met my boyfriend during freshman orientation at college. We became friends, we played coy, we hit it off, we argued, we grew, and we remain together now 8 years later. This doesn’t sound like an unusual story, but only because you haven’t considered FA as a factor that played a role in each moment, every movement, and any plan for the future. When a loved one has a condition described as “incurable, untreatable” the distinction between daily struggles and insurmountable obstacles is thin. The MOXIe study built this buffer up stronger than ever before. My partner has lived with the symptoms of FA since early adolescence, and definitely tends to be cynical about promises of “treatments” or the gleaming hope of the refrain “Cure FA!” Even still, while participating in the MOXIe study, we felt we noticed benefits. We live together and I often find small changes difficult to detect, yet his family noticed immediately from our more punctuated meetings that his speech seemed clearer, and his level of mobility didn’t seem to deteriorate over this period. As a participant in both Part A and the Part B Extension phase, my boyfriend did not experience any adverse event that could be associated with omaveloxolone. Instead, he felt a small sense of control when agency over his own body can sometimes feel impossible. He felt a small hope that this one drug won’t hurt and just might help. The ADA wasn’t passed in 1990 along partisan lines, but was pushed through by legislators who had disabled loved ones. All it takes is for you to understand what this means, and to actually care. Based on the available data, why WOULDN’T you, your child and/or your family member want the option of taking the drug/medicine? Please explain your response. We would be interested to hear.

Kristen J.  Yes, my family member participated in the study and has benefited from this medication.
COMMENTS FROM FA COMMUNITY
Parents & Family Members of Individuals who identified as MOXIe Trial Participants

Rosemary J. My son participated in the MOXIe clinical trial. He believes he had the placebo during the trial, but has been on Omaveloxolone since positive results were seen during the trial and all participants given the drug. He’s seen a significant slowing of the progression of his disease over the last few years. This disease is relentless, and it is our plea that a drug that is making a difference for FAers taking it be made available as soon as possible to all people with FA whose physicians believe it should be prescribed to them.

Wendy J. My son participated in part 2 of the study and the extension study and is now taking omaveloxolone. He most definitely wants to continue and I would also like him to keep taking the Medicine. Any improvement in his movement and stability is a great thing and this drug has been shown to improve my sons quality of life. This drug - Omaveloxolone, that can decrease the rate of physical decline, I believe should be made available to all FA patients who would like to take this option.

Anthony K. & Debra K. Yes, my son-in-law has been on the trial and has benefited from this medication. It is hard to quantify the benefits since FA is progressive, but prior to getting the drug he was rapidly declining. Over the time he has been on the medication his FA progression has slowed and even improved in some aspects. He has had no adverse reactions and would choose to be on this medication for as long as it is available to him.

Esmé Louisa K. Participated part 1and 2 and open study.

Jessica K. My son participated in the trial and is interested in receiving the drug.

Ana L. My daughter is currently participating in the Reata trial and I can’t imagine her, or any other FA patients, not having access to this drug. While it is not the cure we all are desperately seeking, it is a start. She absolutely has felt and seen beneficial improvements related to energy levels and increased dexterity (all without side effects), and as her mom, I have too. No one watches her or analyzes her every move and mood as I do, nor is there any test that can truly measure the benefits of even slight improvements. Daily life is the true test, and the benefits are undeniably there. She clearly has seen an increase in energy levels- she now uses a walker 3x week, sees a physical therapist weekly and attends grad school and works, all without significant fatigue. And while dexterity improvements may be less noticeable, she hasn’t experienced any substantial decline in her abilities over the past several years that she has been on drug, something that her physical therapist regularly attests to as well. Please make this available to all with FA, it is a must for our community and serves as a much needed and beneficial place holder until a cure is finally pushed forward.

Debbie L. My FA daughter has been on the trial and is now able to work full time without extreme fatigue. She was devastated, and inconsolable with the thought of going back to life without this drug! Heart wrenching to watch her decline with FA let alone take away a medication that has improved her quality of life (mentally, emotionally and physically) with absolutely no side effects. We ask you “why would you take this away from our FA children”? Would you take this away from your child?

Jennifer L. My son wants to take Omaveloxolone because he participated in the Moxie trial Part 2 and we have noticed a significant improvement in his overall health. He is currently taking Omaveloxolone as part of the Extension phase of the trial and he will be devastated if he cannot continue to take the drug because it has given him hope for the future.

Marcia L. Yes, absolutely! My son benefited from being on open label. He walked better, speech was better and his coordination overall was better.

Maryann L. My cousin has FA, has participated in three clinical trials and has benefitted from the drug “omav”. I therefore strongly support and urge approval of the drug.

Amalia M. Yes. My son has been taking Moxie for 3 years and has had noticeable improvement in his gait, fatigue and motor coordination. There is no doubt the disease progression has been kept at bay if not cut back.

Armando M. My stepson is taking omaveloxolone. Before I had to ask him to repeat what he just said. In a conversation I may had to ask him five or more times to repeat what he just said. Since taking the drug, I noticed I may have to ask him once during a conversation. I also noticed he is not chocking with liquids or food as often as before. He needs this drug to have a better quality of life. FA is devastating, but not having hope is deadly. I’m afraid that is this drug is not approved our only hope will vanish.

Cheryl M. Niece participated in study. She would like the opportunity to reap the benefits of this drug as it is the only hope she currently has for a cure.

Cody M. Yes! My wife has FA and was in Phase 2 of the trial.

Gerald M. Yes. My nephew was part of a trial in California of omaveloxolone and believes it has slowed the progression of the disease.
**COMMENTS FROM FA COMMUNITY**

Parents & Family Members of Individuals who identified as MOXie Trial Participants

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**Kathleen M.**
Participated in part 2. Extremely interested in taking this medication.

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**Nina M.**
Yes. He participated in the trial.

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**Raelynn M.**
Yes! My sister was on in part one and the open label extension. I helped.

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**Scott M.**
Yes. MOXie has made a noticeable difference in my partner’s condition.

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**Shelley M.**
Already taking it.

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**Dirk N.**
Our children took part in the MOXie study part 2 and are also taking part in the extension study. Our son, whose disease progression is stronger, received placebo in part 2. Our daughter the active ingredient. In the extension study, our son also receives the active ingredient. At the moment we can only say that the course of the disease has not worsened. However, we don’t know what it would be like without Omaveloxolone. So we assume it will help. We hope the drug will be approved for use in other patients with FA too! We hope so much that this dire disease can be cured soon !!!

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**Kay O.**
My oldest son is on this med and has experienced improvements with his functional level especially his speech ! !

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**Esra Ö.**
I do not have Fa disease. But my girlfriend is a Fa patient. She takes the drug omav, and is satisfied that it brings her a lot so we want it to be approved.

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**Isilay Ö.**
I do not have Fa disease. But my aunt is Fa patient. She takes the drug omav, and is satisfied it helps her a lot, so we want it to be approved.

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**Cherie P.**
Yes, my brother participated in the study. My brothers ADLs improved over all, his speech was so clear, phone conversations were amazing. I didn’t have to have him repeat himself, (like before the omave) I feel like the omave really helped him, I hope he can continue to take the medication.

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**Costa P.**
My son is on the Reata Clinical trial at UCL in London is is currently on the open label extension study. His last test showed most factors remaining constant, with slight improvements in some of the measurements.

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**Jarrod P.**
My sister is living with FA and was a participant in the clinical trials. She experienced positive results and improvements with this drug. I support her and the FA community fully! The option should be available to all people living with FA.

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**Jim P.**
Please proceed with approval. We had no issues with the trial. Thanks!

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**Joyce P.**
Yes, we would very much like this drug to be available for our son. He has adult onset FA and is participating in the MOXie drug trial and has found that it has significantly slowed down the progression of FA deterioration. Our son is married with three young children and needs to continue working in order to support his young family. We believe this drug should be made available as soon as possible so he is able to continue taking the drug once the drug trial is over so he doesn’t have to wait for years and lose more mobility--and his job.

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**Mark P.**
Yes, one niece has taken the drug in a clinical trial and did well on it her sister is more advanced and needs this option as soon as possible!

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**Nicole P.**
Yes, my husband has been on the trial and has benefited from this medication. It is hard to quantify the benefits since FA is progressive, but prior to getting the drug he was rapidly declining. Over the time he has been on the medication his FA progression has slowed and even improved in some aspects. He has had no adverse reactions and would choose to be on this medication for as long as it is available to him.

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**Patricia P.**
Yes, I want my daughter to be able to take the drug “Omav”. She participated in the trial and the impact on her daily life has been significant. She has shown measurable and impressive improvement in fatigue, small motor skills, speech core strength and her ability to walk. Thankfully she is still ambulatory and “Omav” has been life-changing for her. Please make this drug available as soon as possible as there are NO alternatives in terms of therapeutics for patients with FA and there is no time to waste due to the progressive nature of FA. Thank you.

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**Beryl R.**
Yes - my TWIN 23 year olds have been part of the MOXie trial, and I believe the drug has helped to keep them ambulatory. They are both still able to work, walk and drive.
COMMENTS FROM FA COMMUNITY
Parents & Family Members of Individuals who identified as MOXIe Trial Participants

Brad R. As part of the MOXIe study, we experienced the benefits of the drug firsthand with our daughter. There were no side effects and it dramatically slowed the progression of FA. Doctors stated that they had expected much worse progression than was seen in her. Had it not been for Omaveloxolone, it is likely our daughter would be in a wheelchair now rather than fully ambulatory. She had to stop taking omaveloxolone for a few weeks due to an interruption caused by COVID and we saw increased fatigue and speech and gait impacts. Please approve Reata’s NDA to allow our daughter and other FA patients to have access to this safe, lifesaving drug that definitely slows progression and gives more time to find a cure.

Chris R. I have two daughters with FA. My oldest participated in the Phase 2 trial and she continues in the open-label study. We believe this drug is working in line with the clinical results seen in the trial. Although this is not a curative medicine, it has shown - through statistically significant data - to positively alter the progression of the disease, and this medicine has benefited our daughter. This medication is very safe and it would be a travesty to withhold it from the FA patient population and their families. Not only is this medication showing some level of efficacy, it is giving our daughter HOPE. Hope that it will keep her FA from significantly progressing this horrific and life shortening disease. OMAV CAN make a difference in all that have FA and help bridge the gap until we can get some of the more curative medicines and therapies through clinical trials. We implore the FDA to rapidly approve this medication. We are currently fighting this disease with supplements, Idebenone, physical therapy, tears and prayers. Approving this medication is a validation that the FDA supports the science behind OMAV, the results of the clinical trials, and more importantly that the FDA is behind our FA community and is with us in this fight for life. The approval of OMAV is the right thing to do. Please uplift all of us and give us HOPE through your actions by the approval of Omavaloxolone!

James R. My little sister (27 years old), N, has been living with FA for 4 years. She was diagnosed with FA during the week of her college graduation in 2016 after she was having trouble running with her friends; she is a late-onset case. Her diagnosis was absolutely devastating for our family and particularly for her twin sister, who is not symptomatic and does not have any indications of onset (they are fraternal twins). After Natalie’s diagnosis, we have raised money for FARA through various athletic events; personally, I ran the New York Marathon and completed a Half Ironman to raise money for FA research, raising a total of $25,000. I have also participated in research studies as a control subject; I spent 3 hours inside of an MRI machine for a cognitive study in Minneapolis. We are not passive participants in the commitment to finding a cure for this horrific and grossly unfair affliction. While we are committed to finding a cure, at the end of the day, we are in desperate need of time and a means of slowing progression. Omavaloxolone provides a glimmer of hope to keep N. out of a wheelchair before her 30th birthday. N. participated in the part 2 and the open-label extension study. Her mobility and energy have drastically improved following her participation in the open-label study; she used to be lethargic and unmotivated to exercise - after starting the open-label study, she has been regularly using an exercise bike and has significantly improved energy. Her speech has also drastically improved - previously, she was much slower in speaking and now is able to speak much more coherently. I recognize the importance of FDA regulations and promoting safety for FA patients; however, I also recognize the core mission of the pharmaceutical industry - providing life-saving and life-extending formulations to patients. To cut off N’s access to omavaloxolone is a terrifying proposition for her and for us and I beg you to extend the lifeline for N. Thank you for your time and consideration - I am grateful for the good work that has been done and know that good work remains.

Jennifer R. Yes, it has helped my cousin tremendously

Lawrence R. Daughter participated in trial.

Mariángela R. Open label extension study
COMMENTS FROM FA COMMUNITY
Parents & Family Members of Individuals who identified as MOXIe Trial Participants

Monica R. My sister participated in MOXIe part 2 and open label extension study. We are so grateful for her participation in the study, as she was only diagnosed with FA less than 5 years ago. She is less progressed than what we imagined when we first heard of her diagnosis and the expected progression. We know that every FAer has a different speed of progression, but we truly believe hers has been slowed due to MOXIe. She is still fully independent and does not use any assistive devices. We implore the FDA to allow for MOXIe to be used by FAers without the need for another clinical trial, based on the safety and efficacy already demonstrated. Our family saw the heavy impact that the travel had on my sister, as she had to take a connecting flight and often stay overnight to participate. Participating in the trial delivered a positive outcome for her health, but we did realize the travel implications and hope that other FAers do not have to endure the same to have equal access to MOXIe. We ask Reata to also submit for a new drug application. We thank you for the incredible work you are doing to improve the lives of FAers.

Nancy R. YES, we heartily endorse the option of being able to take omaveloxolone at this time! Our daughter was diagnosed with FA almost 5 years ago. She participated in the MOXIe part 2 and open label extension study and during that time, progressed at a much slower rate than expected, with no side effects. We believe that taking MOXIe has slowed her progression and given her the ability to continue to live independently without the use of assistive devices. This has been a huge blessing and gift for her and for us as her family. We urge Reata to submit a New Drug Application and for the FDA to approve an NDA for omaveloxolone in FA based on the existing evidence from clinical trials. The time involved in mounting another clinical trial would be expensive as well as difficult, due to the small number of available FA patients. Moreover, FAers who could benefit greatly from the slowing of progression that omaveloxolone has shown, would continue to lose mobility, speech fluency, etc., while waiting for the end of the trial.

Patrick R. Our son participated in both parts of the trial and has now been taking the medication for two years. B’s response to the medication has been a general feeling of well being and the ability to have much steadier walking ability. B takes the medication at the same time each day and then waits an hour for the medication to kick in. B carries on an active life style within the limitations of his FA. B continues to drive a vehicle and help me with livestock production on the farm, he uses a working sheep dog to assist in these activities. B has an active social life and also enjoys forging steel and making knives. B does not smoke and does not take any form of alcoholic beverage by choice. B enjoys camping with friends which he does often, though he struggles to move around in the darkness and avoids this at all times.

Trish R. Yes. My daughter was part of the trial and has had little to no progression and has had no negative side effects.

Bart-Jan S. We been participating in MOXIe for 3 years now and would continue to take Omav as it is our only ray of hope against an otherwise horrible, relentless disease.

Chandler S. He has been participating in the MOXIe study for two years and we have not seen any negative side effects. It is hard to tell if it is slowing progression since he was only diagnosed a little over two years ago.

Chrishna S. We have been taking part in the Moxie study for the past two years. We have not noticed any negative side effects being on the medication. It’s hard to say if the medication is slowing progress. Our son was only diagnosed 2.5 years ago.

Daniëlle S. My sister (who has FA) would very much like the option of continuing to take omaveloxolone. She participated in both the phase 2 study as well as the open label extension study. While she did not notice any effects during the phase two study, her condition worsening within this time, (we assume she was in the placebo-group), she noticed great benefits of taking omaveloxolone in the open label extension study. She could walk greatly increased distances without getting chest pains. Before, she would get heavy chest pains, causing her to need to stop and rest, frequently, after walking for only a few hundred meter / five minutes or so. After starting to take omaveloxolone in the open label study, she could walk distances of up to several kilometers / an hour or so, without getting chest pains at all, for more than a year. This greatly improved her quality of life. When taking antibiotics however, which we think interferes with the positive effect omaveloxolone has, the chest pains while walking would immediately return, going away again once the antibiotics treatment was done. So we are fairly sure the positive effect on her chest pains can be attributed to omaveloxolone. Also, the worsening of her balance and speech, which happens due to FA progression, seems to have slowed down significantly.

Dawn S. My niece L. has FA and was diagnosed @ 7 years ago. She had participated in the recent drug study with major positive results. To make this drug unavailable to her is a disgrace. This amazing drug shed some hope and light in what has been a very dark tunnel for her and our family. Please, I am begging the FDA to approve. My niece’s life depends on it.

Debbie S. Yes. My niece has had great results during the test trial. Her speech, coordination, and abilities overall improved noticeably. What a gift it would be for those who are afflicted by this disease. Finally a treatment!

Don S. We were involved in MOXIe part one and part 2 plus the open label extension study. I fell it has helped our daughters they seem to have more energy and mobility.
COMMENTS FROM FA COMMUNITY
Parents & Family Members of Individuals who identified as MOXlxe Trial Participants

Marleen S. My daughter participates in MOXlxe part 2 and OLE study. We clearly noticed, that after probably being in the placebo-group in part 2, her walking, pain and fatigue improved significantly after taking Omav in the OLE study. She already used a wheelchair for longer distances before taking Omav, because of the chest pains, she got when walking or biking, but was able to walk greater distances again without any pain while taking Omav. She could even walk slopes again without becoming chest pains. Her fatigue was significantly less. The FA progressed more slowly while taking Omav. She is still able to walk after more than a year, although there is a little progress in FA, mostly concerning tachycardia and balance.

Marlin S. Yes! Because he was a part of phase 1 and is on the open label and its helping him.

Monica S. My son participated in the Moxie trial. Despite he had some side effects it is related with traveling a lot from Argentina to the USA. But it improve his physical status.

Natasha S. Shes on the trial.

Robert S. My daughter in law has FA. She did the MOXle last summer. She felt pretty good when she came home, but has taken a turn for the worse since. If this drug would help her, she would most likely take it.

Robert S. Absolutely—Since my son has been on this drug he has shown and maintained vast improvement in his speech, manual dexterity, energy level and use of a walker in the house. He now is able to wash dishes, do his laundry, make himself a cup of coffee, brush his teeth and shave with a RAZOR! The taking of this drug is giving him the opportunity to do daily chores that we take for granted. I believe that one of his proudest moments was when he took his girlfriend, his mother and father for a boat ride on the lake where he lives. He knows that this drug will not cure FA but that it is giving him and others a fighting chance until a cure for this debilitating illness is found.

Samantha S. My husband was part of the trial (and still is) and this has given us hope. We are excited about the future and confident that FA will be cured during our lifetime. Many of our friends and family have commented on the difference they see in my husband, particularly his clarity in speech.

Vincent S. Yes my son would take the drug. He participated in part 2 of the study. We believe his condition could be worse if not taking the drug and have seen some improvement in hand coordination. With no other alternatives and no side effects we feel there is little risk, so would prefer to take the drug for any potential benefits.

Waneta S. My son participated in Phase 2 and is now participating in the open label...it has made a huge difference in his progression...this needs to be available to anyone with FA....please give them something to fight this with!!! Thank you!
COMMENTS FROM FA COMMUNITY
Parents & Family Members of Individuals who identified as MOXIe Trial Participants

Imelda T. Yes. My daughter has participated in MOXIe part 2 and we feel that she has had a stabilisation in her symptoms while she has been on it. She has had no deterioration in her speech at all and she is still walking with assistance.

Jayne T. My Son was the youngest person to be on the Moxie trial and is currently on the extension phase. I would dearly love for others in the FA community to have the chance to be able to try this drug. Time is not something that many FAers have, so they really need to be able to have access to this drug option ASAP. The implication of delaying access to this drug could have extremely severe implications for some people's progression and may also mean that some will no longer be here to even try it. PLEASE let FAers have the option. Thank you.

Linda T. Yes I would want my daughter to be able to continue on omaveloxolone as she really would like to be able to continue with it as she has really improved in so many ways and I could also see much improvement in her when she came home from college.

Virginia T. My daughter participated in part 2 of clinical studies. She has maintained what mobility she's had for a couple years. She remains steady.

Monica V. My son is a participant of the Moxie trial. He is taking the medication since open label. I can see improvements in his speech, balance and coordination. This drug is the only hope for all the people living with FA.

Chris W. I think it should be available to everyone. My wife has taken it for the last couple years and has shown little signs of progression.

Dan W. Yes, definitely! My son has noticed some improvement in his ADLs and has had no adverse side effects.

Jamie W. The participant in the study is my boyfriend. With the medicine he has reversed some of the issues that he has. Stability was the biggest thing that we noticed not long after he began the trial. Then he noticed feelings in different parts of his body that he hasn’t had since he was a teenager, now 39. To see his face when he received a pedicure and could actually feel some of what they were doing was priceless. His confidence also improved. He was no longer worried about everyone seeing him as a drunk that couldn’t walk. He was proud to show off his improvements. He would do whatever it takes to makes sure that everyone with FA could get back some of the things he did. He sometimes feels guilt that he is able to get the medicine when so many can’t...because they either are aged out of the study or could not preform one of many of the requirements for the study. Now with more trials pending, he worries that it will be taken away from him and that he will regress. As for side effects, I haven’t really seen any that I can attribute to the drug, except more freedom to live his life as close to normal as he can with FA.

Joe W. Our son was in the trial and the drug has totally stopped progression of the disease.

Karla W. Yes my son was in the Moxie trial and is currently doing the extended study. We have noticed improvements in his stamina and feel the drug has made a difference.

Rhonda W. Our family member was in the drug trial and is taking the drug.

Becky Y. As the parent of a child with Friedreich’s Ataxia, we would like to express our feeling concerning the path forward for Omaveloxolone. Our daughter E, was diagnosed with FA 12 years ago. We, like many others, had never heard of the disease before then. She was 12 years old, presenting with many of the initial symptoms, walking and balance problems and fatigue. We were told to “take your family vacations now”. We were told there was no treatment or cure available. We were given the phone number for FARA. I still remember the first phone call we made to FARA. Twelve years later, FARA has proved to be the resource that provides hope for us EVERYDAY for a treatment and cure. E. has participated in several clinical trials. We know first-hand the mental and physical anguish that comes from not having a medical option for this disease. E. began the Reata trial in March of 2018. At the end the trial she was allowed to continue on open label. We have seen a definite improvement in her strength and noticeable slowed progression of the disease. We feel that the entire Friedreich’s Ataxia community should have the opportunity to, if so desired, use this drug. We strongly feel that the data shows benefits outweighing any risk. We ask you to consider the data you currently have, and allow the use of Omaveloxolone now. With there being no other drugs currently available for FA, please allow the individuals with FA the option of using Omaveloxolone. For everyone with FA, this truly is a life changing decision. Thank you for your time.

Rick Y. Yes! Our daughter has been in the Moxie trial. It has helped slow her progression and increased her arm strength. Please allow other FAers the opportunity to take this drug. It is not a cure, but it can improve daily living quality! That is life changing for people with FA.
<table>
<thead>
<tr>
<th>NAME</th>
<th>COMMENTS</th>
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<tbody>
<tr>
<td>Alaa A.</td>
<td>Yes, I would take it. I would like to improve my quality of life and pursue further tasks. I would like to hold my baby nephew and walk around the house with him, I want to help him walk his first steps, very much.</td>
</tr>
<tr>
<td>Constance A.</td>
<td>Yes. I would like to take this medicine because it can help me walk better. I want to get better. I don’t want to be bullied for the way I walk anymore. I want to get better and be more like everyone else who doesn’t have Friedreich ataxia.</td>
</tr>
<tr>
<td>Corey A.</td>
<td>Yes I’ve suffered enough. The reward far outweighs the risk.</td>
</tr>
<tr>
<td>David A.</td>
<td>I did not participate in the study. I am hoping to stay ambulatory as long as possible. If not for me, for the sake of my young children. Being there to give meaning to their life(s), is the most important thing to me.</td>
</tr>
<tr>
<td>Emma A.</td>
<td>Willing to take chance with Moxie as my symptoms are progressing and the study results are promising. Want to support testing/trying as it then may be more readily available for my younger brother.</td>
</tr>
<tr>
<td>Halil Ibrahim A.</td>
<td>Yes, we always hear that medicine is useful for me and my brother. That’s why we want to use it.</td>
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<tr>
<td>Kevin A.</td>
<td>I would take the drug without care</td>
</tr>
<tr>
<td>Kim A.</td>
<td>Yes I will take anything to see if it helps slow my progression</td>
</tr>
<tr>
<td>Kim A.</td>
<td>Yes. My body my choice. Anything would be better than living in this shell of a body now</td>
</tr>
<tr>
<td>Marta A.</td>
<td>I would take the drug. I think it has been proved that it works and even if it only works a little it will help me.</td>
</tr>
<tr>
<td>Nick A.</td>
<td>Based on the data available today, I think everyone with FA should be given the opportunity to take this drug. I know from my experience living with FA that my symptoms will continue to progress a lot in the time that it would take to complete another trial. We should all have the opportunity to treat FA as soon as possible. Time is very important.</td>
</tr>
<tr>
<td>Page A.</td>
<td>I have lived with FA so long and have participated in many trials that never gets approval and followed through with. I have been joining trials since I was 28 years old and now I am 50. I will be very willing to take any drug that helps!</td>
</tr>
<tr>
<td>Sean A.</td>
<td>Yes, I want the option of taking Omaveloxolone. Not only are the known results from the current studies promising, but their is no treatment for FA, so this would be the only option. Even if Omav only slows my progression, it will by me time for the current research to find a cure. Please approve this treatment for me and the Family.</td>
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<tr>
<td>Stacy A.</td>
<td>Yes I have Seen Evidence That omav Really helps. Oh my goodness do I need it. Daily living is hard for me. Not only does This drug Give me much needed hope But it Will help me become a person again.</td>
</tr>
<tr>
<td>Vladimir A.</td>
<td>Yes but no trial</td>
</tr>
</tbody>
</table>
COMMENTS FROM FA COMMUNITY
Individuals Living with FA in the US

Alexandria B. Yes I would want the option to participate in the drug because it had promising results in the recent studies.

Alysondra B. I would want the option

Ashley B. Access to omaveloxolone would make a world of difference to our family, especially for our 20-month old daughter. Watching her grow over these past months has been the greatest joy for me, but also very difficult. It is hard to have to watch her experience new things that I am unable to be a part of. It is hard to listen to her cry for me to hold her and carry her from her crib, without her understanding why I am unable to do so. It is hard when she asks me to hold her hand on walks when I can’t because I have to hold onto my walker to keep from falling. Looking back two years to where I was in 2018 is mind boggling. I was able to walk independently, without an assistive device. I was able to carry in a load of groceries from the car without using walls and countertops to balance myself. I was able to lift my bodyweight at the gym. These are all things I have since had to give up, and mark as yet another defeat to FA. The chance that this drug could revert me back to my stage of progression in 2019 would be life-altering for my entire family. It would improve my abilities, slow my progression, and ultimately allow me to maintain my independence for longer. Most importantly, it would allow me to be a mother to our 20-month old baby girl for longer, and give me the opportunity to experience things with her instead of simply being a bystander. I hope that you will consider the significance that these seemingly small changes would make in my life and others living with FA, as well as the impact that they have on not just us, but our entire families. Being given access to omaveloxolone as the first and only treatment for FA would provide many opportunities that we otherwise don’t have, and would give us years that would otherwise be lost to this debilitating disease.

Barbara B. I HAVE FA, AND SUFFER EVERY DAY. WHEN I GO TO BED I THANK GOD THAT I MADE IT THROUGH ANOTHER DAY. I HAVE HELD ON BUT AT 60 YEARS OLD I'M TIRED OF FIGHTING I'M LOSING THE FIGHT. I WOULD TAKE THIS DUG IN A HEART BEAT! MY FAMILY AGREES. IT IS WHAT WE HAVE PRAYED FOR ITS BEEN 36 YEARS OF FIGHTING WITH NO HELP IN SIGHT. THIS WOULD HELP THOSE THAT ARE YOUNG TO LIVE LIFE TO THE FULLEST, PLEASE PLEASE HURRY TO APPROVE THIS DRUG, TIME IS NOT ON OUR SIDE.

Barton B. Yes, I would like the option to take the drug/medication omaveloxolone. I have been suffering from the progressive symptoms of Friedreich’s Ataxia for over 45 years, and would relish the chance, and assume the risk, to take a drug/medication, such as omaveloxolone, which has proven effective in the clinical trials to-date.

Braden B. I am Braden. I am living with FA. I think this medicine should be approved because it has shown very little side effects with big benefits.

Brendan B. Yes we want to take it

Brian B. Yes. I would do anything necessary to stop or slow down the negative progression caused by Friedreich's Ataxia.

Brianna B. yes. based on evidence, this medicine could improve FA.

Casey B. Yes take it

Catherine B. Yes, because I want to try something as far as medication.

Christina B. I would want the option to take it.

Donald B. Yes I would take the medicine, I have not participated in any studies, I really want to take something that would greatly help me to endure this disease.

Eleanor B. Yes, because I can feel myself losing the ability of being able to walk. I need to hold walls for balance. My hands are beginning to shake more, making it harder to hold things like a pencil. I have been schooling from home since March because of the pandemic. I am high risk and I don’t think traveling for a drug trial safely is feasible right now. Please consider approving Omav immediately, I cannot afford to wait while my body fights Friedreichs Ataxia on its own.
### Elizabeth B.
I would absolutely take this drug as someone who has been living with FA since I was diagnosed at age 15. For the past 18 years, I have experienced my body gradually decline, including heart failure and complete loss of my walk. My entire life and my family's life has been affected by this disease in every imaginable way and then some. Therefore I would be beyond grateful to see the FDA grant permission to authorize this drug as a treatment for patients with FA. Any improvement of symptoms would be welcomed and celebrated by anyone living with FA. Thank you.

### Elizabeth B.
Yes, I have not participated in any trials.

### Gabriella S. B.
Yes, I would most definitely want the option of taking the drug because I would like to be even more independent.

### Hannah B.
Yes, it’s changed my life for the better

### Jessica B.
Please give me a chance to take this drug. Just having more energy would be a blessing. This drug could keep me out of a wheel chair a few more years. Please try and put your self in my shoes and anyone else with FA knowing there is a drug that is safe and can make life easier please please give us omav

### John B.
I would like the chance at a treatment before I die

### Jordan B.
Yes. Please. I have not been apart of any trials but I believe in the benefits of this drug and want to be able to access and use it myself

### Katie B.
Yes I would like to take this drug.

### Linda B.
Yes, I would definitely accept the option to try omaveloxolone. For most of my life there was never a drug that could improve/maintain my quality of life. I would definite try it, hopefully it would benefit in any way.

### Margaret B.
Yes I would love to take this drug. It is getting harder to do anything with very little balance. I was always very active and it’s hard giving it up. Also for children with FA I’m sure it will have a greater benefit.

### Mary B.
I want to take the medicine

### Mary B.
I would love the chance to help my FA

### Paula B.
Yes, I would want the option to take this drug. FA is a debilitating disease and we should have the right to try any drug which could ease our daily struggles.

### Pierrette B.
I would like to participate on the trial

### Raena B.
Yes, I want to take Omav. In fact, I want nothing more than to take Omav. I am an ambitious patient who refuses to alter her plans in the name of this disease, and I have been counting on the availability of this drug to stay on track with my awesome life.

### Rebecca B.
I want the ability to do some stuff on my own. I want the ability to care for my family instead of being the one needing cared for.

### Richard B.
I would take the drug if it would even reduce my symptoms a little. I currently use a walker and about to move to a wheelchair. It’s becoming harder to speak clearly and do my job. I cannot stress enough how much I would like to take omaveloxolone.
COMMENTS FROM FA COMMUNITY
Individuals Living with FA in the US

Sam B.
I was diagnosed when I was 8 years in 1995. I have been living with FA my whole life and this is one of the most promising strides that have been made for a possible cure or treatment for this disease. I was not a part of any of the Moxie trials. I would absolutely want the opportunity to take this medication. I have dealt with a multitude of symptoms and health issues due to FA. These range from the need for the use of a wheelchair to muscle spasms, loss in dexterity, difficulty with speech, atrial fibrillation, atrial flutter, and congestive heart failure. What is most significant to my quality of life over the most recent months and years is my loss of vision. Some of my biggest hobbies are watching television, movies and sports. Since I was a little kid I have always been captivated but the stories, cinematography and editing and the art to creating entertainment. Creating a story with visual effects. This led me to pursue my passion and go to college for video editing. Now 10 years later I can barely see the computer sitting in front of me let alone utilize the keyboard and trackpad to create and edit. I can’t even enjoy watching a football game on my television. My loss of dexterity and most significantly my loss of vision has taken this away from me. Despite these obstacles I have hope for the strides medicine has taken and the future of a cure for FA. This drug is one of the most promising advances towards beating FA. I think this is so important to me, my sister who also has FA and the entire FA community. Please consider those who live with this disease everyday and approve an NDA for Omaveloxolone.

Sam B.
Based on the data available from the trials for omaveloxolone, I would like both myself and my fellow FAers to have access to this drug. I think this drug would help me specifically with my fatigue and speech. If another trial is needed to approve this drug, it will take multiple years to get approved. This is a problem for FA patients because a few years of progression means major life-changing losses in function. From seeing the successful data produced by the trials, I think omaveloxolone should be made available for the all FAers.

Scarlett B.
Yes I think this would be good for me and others so it could help us with our diagnosis to get better

Sean B.
Yes. The data shows improvement in the FARS scores and ANY improvement is better than progressive deterioration that FA promises.

Sharyn B.
Yes, I would like to try it. If drug is successful it would mean - an overall better quality of independent life.

Vito B.
Yes. Having FA, and it progressing at the pace it is; I should have the right to decide whether or not I should be able to take the drug.

William B.
Yes I would definitely take this medication! I am fully aware of the side effects and the safety of this medication. After suffering from FA for 30 plus years I’ve been desperately wanting for a treatment/cure for this horrible disease. Please consider what myself and other FAer’s endure daily. Approving this promising treatment is over due.

Adriana C.
My answer is 100% yes because the omav drug has the ability to improve people’s health conditions and possibly save lives, including myself, my brother, my several fellow FAer friends, and FAers of the future. I was diagnosed with FA in 2013 and became a full-time wheelchair user in 2017. Before I lost my walking ability, my walking was tremendously labored and I required a walker at home. In addition, my fatigue, speech, and hearing has gradually worsened. The omav drug has only proven to positively impact these or none at all, never worsening the participants’ abilities. Even the slightest change in our health will make the biggest difference in the world… and I’m here to tell you why, this life-altering disability had immensely affected my emotional health, as I’m sure it has for every single FAer out there. However I have also become so strong-willed and optimistic that I acquire so much hope that there will one day be a medicine that can help us FAers and it’s finally here! So I ask that you please consider the physical and emotional health of thousands of FAers around the world in your decision. Thank you for reading.

Anthony C.
YES! Definitely, I would take the medicine! Having even the slightest chance to be a more normal person would be incredible.

Deborah C.
Yes, but I haven’t had the opportunity to try Moxie as of yet.
Donald C. Yes I would like to take it. My sister would like to take it also. My dad died from it so I’ll take it because I don’t have to worry about long term effects. I’m 52 my dad died at 60 so I would love to take a chance to live long and a better life than I have now.

Emma C. A thousand times yes! After 17 years of (diagnosed) FA, losing my ability to run and walk, adjusting to being a full-time wheelchair user, getting PCAs to assist me in every activity of daily living from shaving my legs to cooking dinner to carrying a glass of water, losing my ability to handwrite anything (even though I am a writer), chronic fatigue and low stamina, pain related to severe scoliosis, developing diabetes, surgeries to lower the arches in my feet, and countless other symptoms and losses, I’d be eager to try any treatment, even if the results were minimal and side effects severe. But to know that there’s finally a treatment with really obvious positive effects and no negative side effects? It’s difficult to process, let alone convey what that could mean for my life and for others and for future humans living with FA. As I approach the average life expectancy for people living with FA (35, I’m 29 now), I implore the FDA and Reata to work together to approve and release this treatment as soon as possible to the FA community. We do not have the luxury of waiting a year or two or more. A speedy approval could mean more time and more time with what precious people and abilities we do have.

Fiona C. Yes I would!

Jamie C. Yes!!!! My FA has progressed SO MUCH and is getting worse. Omaveloxolone is my only hope to live longer. I urge the FDA to approve this drug for use in the FA community immediately. Time is of the essence.

Jeremy C. Yes, I would love. We need a treatment ASAP!

Joseph C. Yes, I would like to take the drug/medicine Omaveloxolone, ASAP. As a person living with FA, I can affirmatively claim that this disease is extremely an inconvenience on my family and myself. Living with FA has done nothing but cause me pain, physically and mentally. It physically has done nothing good to my body, because of the mussel thickness FA cause, I can no longer walk, so I use a wheelchair, which has caused my family to spend thousands of dollars on remodeling our home to make it easier on my life to move around. Because of FA I could never attend any recreational sports during high school, it destroyed my social life style, I never fully experienced the freedom that one gets when driving because of how unresponsive my legs are from quickly moving my foot on the gas peddle to the break peddle, and on top of all that, FA has given me many heart operations, do to unwanted and faster arrhythmia. Mentally, it has done a toll on me, with always having mental break downs when I am in disbelief that I can no long fit in society, as far as work for example. Apparently an employer 98% of the time, would rather hire someone who is under educated that can walk, rather then someone else who is well qualified, but in a wheelchair. Like I have written before, FA has destroyed me mentally as well with so much heartbreak. So many relationships ended before they even started. So many other women that I tried to have relationships with or approach, see me as someone who is intimidating to even talk to because they see me in a wheelchair, and overthink of the bad things that can happen to us, mentally. In conclusion, Omaveloxolone needs to come out ASAP and not be delayed anymore. It’s bad enough it took away youth and freedom, release it before FA takes my life too.

Julieta C. If course, it is my only hope! Please approve this!

Nancy C. Hi my name is Nancy I have lived with symptoms 30 years and am currently in a wheelchair full time, I have lost my life and my family bears the brunt of it. My husband of 38 years is my caregiver dressing bathing and being all around mom for our 17 year old daughter. My time is running out but how wonderful it would be to brush my hair or blow my nose, scratch an itch. Golly I wish I could......bring us back to life and give us who are affected the option of trying...please.

Rodger C. I would take it, my brother & I have had fa for 85 years combined, its time

Susan C. YES. I was diagnosed at the age of 22 and I’m now 46 years old. I’m READY for a medical treatment and understand the risk involved.

Tara C. Yes, I need/want help now. Any improvement will advance my quality of life which is diminishing everyday

Aidan D. Yes to halt progression

Aj D. Yes I would. Anything to lighten the burden of FA.
Alex D.  I well take the drug

Alex D.  I would love the option to take this drug. I myself have been living with FA for a little over 10 years. Now fortunately my progression is not as fast as others but it still progresses and it still has taking enough away from my life to take a toll on my physical and, most of all, mental well being. It has been a long time since my diagnosis and I would absolutely love to halt the progression as soon as possible before it is too late. Hearing and reading that OMAV has the potential to do this, my excitement and hopes are very high! A little over year a go I learned about the drug. 10 months ago I went to a FA symposium and learned even more and have gotten even more excited and curious for the drug. There isn’t any treatment for FA now and there maybe one here finally. Since I heard and read of it’s potential, I have thought about it every day.

Allison D.  I did not participate in Moxie because of family obligations but I’ve seen that it works through pictures/videos of friends who were in the trial. I also was in Philly when the results of the trial were announced. Almost everyone was in tears including myself. We thought we’d have our first treatment available to us in a matter of months. Fast forward 15 months and there’s been little progress in getting us the medication. Every single day that goes by, I lose more abilities. In the last 15 months, I’ve lost a lot of leg strength and coordination. I used to be able to ride my trike with much smoother cadence. My ankles have gotten weaker and my feet have started to turn in, particularly when I feel like I’m going to fall. I have eight year old twins who surpassed me in physical abilities the day they took their first steps. Not only do I want to be able to do 10% of what they can, but I need that ability as a mom. I played softball growing up and now my girls are into it. I want to coach their team so badly but someone in a wheelchair can’t very well play softball. I don’t care that there may be some unknown side effects of omav or that it may not work forever or even that there are lots of unknowns with a new drug. When I was still able to work, I was a Clinical Research Coordinator. I helped run trials for Alzheimers, Parkinson’s and ADHD. I understand the risks of new drugs but I don’t care. There is no treatment for FA and there needs to be one. Omav WORKS!!! PLEASE, from the bottom of my heart, submit the NDA and approve it.

Amy D.  As a patient with FA (extremely rare as I am 65 so considered very late onset), this disease is horrible. I didn’t participate in the MOXle trial, but have been in the Larimar trial and had amazing results. From what I have heard, the MOXle medicine has worked. It will help so many people. Yes, I know this is a rare disease and in the population as a whole FA doesn’t affect a lot of people. However, those it does affect it is devastating to both the person and the family. If drugs can make a difference in our lives, why not allow it to come to market!!! Please seriously take into consideration approving Moxle and the other meds in the pipeline. Some of them may even cross over to other diseases such as Huntingtons, MS, etc that could help them too. Since most of us are on Medicare due to disability, having healthier patients could also lead to less medical expense. Something to think about. At the trial I participated in, I was the oldest by 12 years. Most of the others were YOUNG (20-35) and all in wheelchairs or scooters, The majority of them were in these devices since their mid-teens. My hope with the development of these meds is that “maybe” most people may be able to sustain where they are at and not reach the point of mobility devices being needed. Then these people could lead somewhat “normal” lives. Once again, PLEASE approve these meds.

Brett D.  I have been diagnosed with the FA for 17 years. I am still living by myself. I have been in heart failure for six years now. It has taken away my right to hope and dream for any kind of future. Please give me and everyone The hope to dream for a better tomorrow.

Bridget D.  I would like to be part of the open label drug trial as my vision is becoming severely affected. I would like to maintain an independent life.

Chandra D.  Yes. There is currently no other option to treat fa.

Christina D.  I would try omaveloxolone because I want too stand up and walk. Even with support (hand rails or a person) it is better than now, I can not go outside, I can not go up the stairs in my own house.

Cindy D.  Yes I am in late stages of FA and have a lot to gain

Dirk D.  Yes! If there is a drug that could improve quality of life with little to no side effects why would I not?

Elizabeth D.  Yes I do

Jack D.  Yes I would very much like to have the option to take the drug because there are currently no other known treatments or cures for FA I for one will take what I can get.
### Comments from FA Community

#### Individuals Living with FA in the US

<table>
<thead>
<tr>
<th>Name</th>
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<tbody>
<tr>
<td>Jennifer D.</td>
<td>Yes I want to take this drug. My time is running out, I have waited 30 years for anything. Please let me have the opportunity.</td>
</tr>
<tr>
<td>Josie D.</td>
<td>Yes I have heard really good results from other patients and my doctor. I think it could really help me and a bunch of others.</td>
</tr>
<tr>
<td>Mustafa D.</td>
<td>I am also a Fa patient, I did not use the omav drug, but I have a friend who uses it and it is a good drug. We want to take advantage, I want it to be approved as soon as possible.</td>
</tr>
<tr>
<td>Scarlett D.</td>
<td>Yes. My priority right now is to slow progression.</td>
</tr>
<tr>
<td>Suzanne D.</td>
<td>Yes! This is the only promising treatment for FA thus far. I personally have waited for this since I was diagnosed in 1997.</td>
</tr>
<tr>
<td>Tina D.</td>
<td>Yes would help</td>
</tr>
<tr>
<td>Alexa E.</td>
<td>Yes I would want access.</td>
</tr>
<tr>
<td>Brian E.</td>
<td>I would take any treatment that stop or eased symptoms from worsening. I have a wife and two young children, caring for them is already difficult but I worry how much longer I will be able to support them. They see me struggle everyday and I can see the concerns on their faces. If the FA continues to get worse I worry will only be a burden to my family. Any hope I can give them, even if it is small, is worth it. FA takes choices away on how you can live. Having a medication at least gives us a choice to offer hope for a better quality of life.</td>
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<tr>
<td>Carl E.</td>
<td>Yes...any level of relief would be greatly appreciated.</td>
</tr>
<tr>
<td>Nan E.</td>
<td>Being recently diagnosed, I would be willing to try any approved drug that would help. I suffered a traumatic brain injury at the age of 10 but Ataxia and other neurological problems are now becoming a problem.</td>
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<tr>
<td>Samantha E.</td>
<td>Yes, I would take it. Anything to help with symptoms and progression is worth taking.</td>
</tr>
<tr>
<td>Susan E.</td>
<td>Yes because I'd rather try it and potentially benefit from it or even suffer negative consequences than eventually die from FA and not try.</td>
</tr>
<tr>
<td>Debra F.</td>
<td>Yes, I want to take it. I lose ability every day. I want it to stop. Please let it stop.</td>
</tr>
<tr>
<td>Jaydon F.</td>
<td>Yes I would like to take it, I feel comfortable with the data showing it is safe and overall beneficial.</td>
</tr>
<tr>
<td>Orrin F.</td>
<td>I would love the opportunity to try Omav and slow down my progression. I have lost so much in the last 2 years, I have lost my ability to walk, stand, write, my speech and swallowing reflexes have been affected, my heart now has damage. I can no longer stand flat on my feet. I would be willing to endure any side effects to slow this progression down, I want to live a long happy life with my family. I would like to go to college and maybe someday have a job at this rate that will not happen. Please consider approving this medication quickly it would give myself and the FA community a chance to live a better quality of life and most of all it would give us HOPE.</td>
</tr>
<tr>
<td>Sam F.</td>
<td>Yes, I am willing to try to do anything to improve my quality of life.</td>
</tr>
<tr>
<td>Wadad F.</td>
<td>Yes, I and my family want to take a moxi treatment because it stopped the progression of the disease and the patient seemed to improve slowly. I believe that stopping the disease is a cure for the patients who started with the disease. Me and my all family have FA went to take moxie.</td>
</tr>
<tr>
<td>Wafa F.</td>
<td>I was diagnosed with FA in 2016, since then my health is getting worse! I have lost so many things in my life because of my health issue, but I always thank god for what I have and pray to find a cure. My family and I were so happy when we heard about MOXI before we know that the FDA did not prove it! Yes, of course I want the option of taking omaveloxolone medicine.</td>
</tr>
<tr>
<td>Agnes G.</td>
<td>Currently do not know enough about oaveloxolone to make an informed decision.</td>
</tr>
<tr>
<td>Andrea G.</td>
<td>I wouldn't take this medicine because as someone who has lived with FA most of my life any possibility to stop or slow this disease will help me physically and bring me hope.</td>
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COMMENTS FROM FA COMMUNITY
Individuals Living with FA in the US

Caleb G. Yes, I would do anything to stop my fa from continuing its path. I don’t want to lose the ability to use my legs to walk.

Christa G. Yes, I am not yet dependent on assistive devices to walk, but I fear that I will be using a rollator walker soon. With Omav, I can potentially avoid that or put it off for some time. I still work, and I would like to continue to do so. I have been following the trials and feel confident in Omav. It would be a life changing treatment for myself and many others within the FA community. I am fortunate enough to have been diagnosed later than most, and I feel that I would benefit greatly from Omav, because my disease progression isn’t advanced. Omav may afford me the ability to live my life fully and completely without becoming wheelchair dependent. I am a mother of 4 active children. Being bound to a wheelchair or walker would be cumbersome, to say the least. I am also a bow hunter, hiker, gardener, outdoorswoman. My freedom is slowly slipping from me. I have not been hunting since before my diagnosis, and I look forward to being able to do that again. I’d like to teach my children to bow hunt and to go on hunts with them. Omav could give that, and so much more, back to me. I fully intend on taking Omav when it becomes available to me.

Christopher G. Yes, in the past 2 months, my movements have become more jerky and stiff. Few more months and I may not be able to walk unassisted.

Darcy G. Yes, I want the option of taking the medication. It is the first medication that ever was to offer more than symptom management.

Doğukan G. I am sick of fa omav I need it very much

Emma G. I would be eager to take this drug. I was diagnosed with FA 3 years ago, experiencing symptoms for 4 years, so I am relatively new to the FA community. That does not change the fact that I have been living with this disease and slowly watching myself decline. It has been tough, especially with no cure or even a drug to slow down the progression. I believe a drug is needed for the FA community because we have struggled without any sort of drug therapy for our disease, so why not give us some hope. I believe if this drug were available to me now that my progression would be slowed dramatically. If I had to wait years for a second clinical trial, I don’t think there would be hope for me. I am 21 years old and I have a future planned for me, but a future with FA without any sort of drug therapy will be difficult.

Julian G. Yes, I would try it because it may stop/slow the Progression of this Horrible Disease!

Kathleen G. Yes, I would take the drug.

Lisa G. I didn’t participate in the trials but I closely read the results of each phase. I would take the drug.

Lucas G. Good

Moira G. Yes. I would take any opportunities presented to me.

Rebecca G. Yes. FA is stealing my independence

Ruben G. Yes, I would.
COMMENTS FROM FA COMMUNITY
Individuals Living with FA in the US

Sean G.  
I would definitely take the drug today. Based on the 5 years of current research, positive results from the studies, and directly hearing from the current participants, this drug is the answer to my prayers and what I have waited patiently for for the past decade. This drug gives me a chance to experience a normal life and I will take that chance everyday of the week. Please grant approval for the immediate use of this drug for the treatment of those with FA. Our time is very precious.

Zachary G.  
I would like the option of taking the drug not only because it can help me achieve my goals easier but also to give people who were diagnosed at a younger age, a chance of not progressing as fast.

Breaunna H.  
Yes, I would love to be able to take this drug.

Brendan H.  
Yes I would like the option of taking omaveloxolone.

Caleb H.  
Yes, I would like the option to take this medication.

Candace H.  
Living with this disease for over 23 years. Giving any relief would be better than what we have now, which is nothing.

Carla H.  
YES......I would VERY [much] welcome the option of this new drug.

Christin H.  
Yes, I would absolutely take omaveloxolone asap. I was not part of the study, yet aware of the results, and eager to try it. My desire is to be independent of daily living caregivers on which I now rely, but even if this drug not a candidate for a progressed patient, such as myself, younger/less progressed patients could benefit. Even a year or two can mark significant progression and limitation.

Clarissa H.  
I would like to extend my life and keep the effects at bay.

Curtis H.  
Yes! I'm ready to try anything that would help out any

Dylan H.  
Yes because omaveloxolone helps people with FA

Eric H.  
Yes. Dealing with loss of abilities from FA is difficult. The possibility of stopping or even reversing the progression is something for which every FA sufferer has long awaited. I request the right to take MOXIe as soon as possible. Every day of delay is devastating. Please, consider approving the use of this drug quickly. Thank you.

Grace H.  
Yes. It seems like a worthwhile treatment.

Jason H.  
Yes I would gladly take this and share my results with the FA community. I have been diagnosed with *Friedreich’s Ataxia since 1996. At that point I was promised there would be a cure or treatment at least right around the corner. 25 years later I’m still waiting. Pausing progression would mean so much to me at this point. I honestly don’t believe that I have several years left even though I’m doing okay right now. But who knows how tomorrow is going to be?

Jeremiah H.  
I HAVE SPINOCEBELLULAR ATAXIA TYPE 3 AND I CAN’T WALK WITHOUT USING A WALKER AND MY SPEECH HAS GOTTEN VERY SLURRY.

Jessica H.  
Yes I definitely would like the option to take omaveloxolone. Any type of relief from living with Friedreich’s Ataxia would be very much appreciated.
### Comments from FA Community

#### Individuals Living with FA in the US

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<tbody>
<tr>
<td>Jessica H.</td>
<td>Yes, I think my quality of life will be improved</td>
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<tr>
<td>Jill H.</td>
<td>I’d like to do more.</td>
</tr>
<tr>
<td>Kati H.</td>
<td>Yes! Would improve my speech, fine motor, etc. FA has taken away a lot and needs to stop!</td>
</tr>
<tr>
<td>Madison H.</td>
<td>Yes, I would love to participate and find a cure for FA so I can follow my dreams and live a long HEALTHY life.</td>
</tr>
<tr>
<td>Mark H.</td>
<td>Please allow this effective treatment.</td>
</tr>
<tr>
<td>Mekayla H.</td>
<td>I would like the option to be treated with MOXle because I am just starting my career as a Data Scientist, and I want to be as successful as possible. At this point, I am using a walker to get around but it would be amazing to slow progression so I can have a better quality of life and have the same opportunities as my able-bodied coworkers. I also have a brother with FA, and he deserves the same experiences as other 26 year olds, MOXle Can help those experiences happen.</td>
</tr>
<tr>
<td>Micah H.</td>
<td>Yes, absolutely, the FA community needs a medicine</td>
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<tr>
<td>Michael H.</td>
<td>I would participate in the study</td>
</tr>
<tr>
<td>Mya H.</td>
<td>yes, I would love to slow the progressions and have relief from some of the symptoms of FA</td>
</tr>
<tr>
<td>Natchez H.</td>
<td>Yes. I listened to my friend S., who participated in the study and showed signs of motor control.</td>
</tr>
<tr>
<td>Rebecca H.</td>
<td>yes, i would</td>
</tr>
<tr>
<td>Sam H.</td>
<td>Yes, I would want the option of taking MOXIE because it has been shown to have some positive results and I would love to take anything that gives me a better quality of life</td>
</tr>
<tr>
<td>Sara H.</td>
<td>Yes I would take this drug because I believe it would help me to live like a teen as more normal and less stressed about the progression of my disease. I am hopeful this drug will help to improve my life and help others also living with this horrible disease. I live the healthiest life I can with this disease by exercising daily and maintaining a full diet, but I believe this drug will help in ways that those cannot. Living life with this disease is challenging with a toll on both my physical and mental well-being, and one that I would not wish on to anyone, however, opening this drug availability will help to improve the quality of life of many within our community.</td>
</tr>
<tr>
<td>Seth H.</td>
<td>Yes I’d want the option! The benefits clearly outweigh any risks as shown in the accrued Omav data and Moxie trial patient reflections.</td>
</tr>
<tr>
<td>Sienna H.</td>
<td>Hi. My name is Sienna H. I have had Friedreich’s Ataxia for 14 years now. I have grown up seeing my brother progress and terrified of what my future will look like. I have been lucky enough to have no symptoms except for mild scoliosis, but that can change at any given moment. I hope this can give a little insight on how my much being able to take this medicine, and have that sense of security, knowing that this might give me a couple more years. Just more time. It might help my brother, maybe he can begin to do things he loves again, like drawing. I truly think this medicine should be given out now. I know I am not even close to someone who needs it the most, but I hope this gives a little insight of how much this drug means.</td>
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</table>
COMMENTS FROM FA COMMUNITY
Individuals Living with FA in the US

Steve H.  I want something while I can still stand.

Tara H.  I do not know in about the drug

Wafa H.  Yes, I would want to take the option of taking the omaveloxolone drug. Please, help us for now and prove it! The passing of time without any treatment is not in FA patients favor at all, because our health get worse by time!! We don’t want this medicine later, we need it now.

Andreea I.  I would try a trial to see the results, even if they are small

Grace I.  I would love to take the drug and give the best feedback I can. I would like to know more about it and results though before hand

Tiziana I.  Yes!! would take medicine progression so much worse would take for even 5% improvement.

Abby J.  I would like to take it.

Amber J.  I would love the option of taking this drug

Claire J.  I am 13 and I am living with FA. I was diagnosed four years ago (because my brother was diagnosed), and my FARS scores were perfect. I could stand on one foot with my eyes closed for 60 seconds, and my FA symptoms weren’t showing at all. In the 4 years I’ve known about FA, I’ve seen my FARS scores increase. I’ve seen my symptoms get worse and worse. It’s scary. If my FARS scores could improve by 2 points, my symptoms would be almost nonexistent again. I would love that. So, please, approve OMAV now. I don’t have time to wait.

Don J.  I would like to take it.

Drake J.  Yes, I’ve been wanting it for a long time

Emma J.  I have seen videos of individuals who are taking omav and there is noticeably a difference. The worst part of living with FA is knowing it is progressing and being at the mercy of others to wait for a cure or even to slow progression. To have access to omav would be amazing as there is currently nothing. Waiting years for another trial, is also years of progression that may never be able to be reversed.

Jacob J.  I would take it.

Jake J.  I have FA and desperately want to have MOXie. Everyday, whether at school, or at home, or even just walking around, I need assistance, and have to sit on the sidelines as my friends play games without me. I want to go and run and walk and play sports again, and as of right now, MOXie is one of the only things that can help me do that.

Jordan J.  I would definitely want to take omaveloxolone when it becomes available based on the empirical evidence currently available demonstrating the efficacy and safety of the drug. I find it amazing that omaveloxolone can pause the progression of FA; that would alleviate so much anxiety for me if my FA would not get worse. It would be phenomenal also if this drug could reverse the progression of my current state of FA two years. I could have a more biomechanically correct gait, which would allow me to ambulate around places easier. I hope I can get omaveloxolone to see what it brings me and the FA community.
Karina J.

I have FA, am 48 years old, have been living with the symptoms for over 30 years, managed to become and serve as a college professor [with an accommodation], and share the custody of my 2 daughters with my ex-husband. I want to take the drug omaveloxolone because I have been following its development since 2015, and have been present at many scientific speeches, and in contact with many people that have taken it. In my findings: the risks for the drug are low, it slows down the progression, and it adds energy, and it even restores some function. I need 4.5 years until my second daughter graduates from high-school, and am barely managing to live independently, work, pay my bills, and pay my help. I have no choice but to live alone, and every day is a struggle. My illness is advancing very quickly because of my age: a year and a half ago, I could shower on my own. Now, not only can I not safely shower, but also, I miss transfers, and end up on the floor for hours waiting for help, sometimes in a wet or soiled diaper. I have urgency issues, and wet the bed (clothing, sheets, wheelchair…) even though I use pull-ups and a pad, or I am constipated, which really hurts, or I have taken one too many laxatives, and end up having explosions in my diaper that take all day to clean. UTIs follow. Retention, constipation, explosions and UTIs did not happen last year. My fatigue has also gone through the roof lately. In the month of December 2020, I started sleeping 15 hours per day. I suddenly cannot afford to accomplish much in one day. Which is why I fear for my job suddenly. Losing my job entails: not seeing my kids, having to move to a distant and cheaper area with no help and during covid, not being able to afford health insurance, losing the wonderful community of doctors, therapists, nurses, aides family and friends that make my days possible. Losing my job entails not being able to afford help, losing the very few friends that I have, losing touch with my sister (one of the few people that treats me like a human), losing my accessible apartment, and losing my reasons to get up in the mornings. My voice is difficult to understand. Five years ago, I could make recordings for my online classes. I could spell my name over the phone, and place orders. My hearing is affected, if I go out to a restaurant or bar it is impossible for me to hear others. Choking is an everyday occurrence, and drinking 2 glasses of water per day is my daily chore. Eating is a chore, as I am insensitive to most foods, and swallowing is difficult. This is all very recent – past 3 years. If it weren’t for covid which turned my job into telework, I never would have been able to teach this semester due to my fatigue, intense spasms and incontinence. I only have help for 5-1 hours per week. And the fact that I can only shower when I have help, makes my incontinence very hard to manage. I know I have made a difference in the lives and education of my children and students. I would like to be able to continue working, paying my bills, paying my health costs, and staying out of my mother’s life so that she can survive taking care of my brother, who has FA, and had a stroke 7 months ago. She is 80 and my father left us when the FA started manifesting itself in my brother and I [It is common in disabled families for the father to leave]. Rehabilitation homes turned my brother down after his stroke last March. His wheelchair looks like a stroller, he can no longer speak and screams 4-5 times per night to call for my 80 year old mother to his bedside to relieve his pain. He blasts the TV all day to watch sports, and maybe hear something as his hearing is extremely affected. I am not sure he understands much of anything. He urinates, and has bowel movements in his diapers and in his bed. He is mouth fed by my mother and drinks out of sippy cups. ½ of his food or drink ends up on the floor or on himself, as he has severe swallowing issues. Most of this was not the case last year. I visited them a few weeks ago, and seeing their state made me temporarily lose my mind. To be the cause of so much suffering in the ones closest to you, is the reason why I signed a DNR and insist on living alone. I will become a vegetable waiting for omaveloxolone to be approved by the FDA, and watch my brother die. And many lives will be affected. Please approve it now. This society does not need yet another weight to carry on its shoulders. I know I am not the president of the united states, but there are so many like me who are even younger facing similar & countless losses. Slowing down those losses, will make them so much more manageable for us the individuals, for our family & friends, for our communities, and for our society. I am not scared of Covid. Covid looks like a joke compared to FA. It is scientifically possible to avoid covid, not FA. The imprisonment [getting around is a luxury for us], the isolation [few actually want to hang out with us as we need so much assistance financially and physically], the depression [we smell, look like skeletons… few will touch us unless we pay them or beg], the food scarcity [we have so many food restrictions, and we can usually only buy food online, which is often out of stock, overpiced, and a hassle to store], the poverty [in a bad economy disabled people are the first to get fired and the last to get hired], the low salaries [disabled people are paid the least, and we work twice as much to produce the same amount as a normal person, who needs less sleep, has few medical issues and can live in any home or hotel s/he chooses – we are limited by access], the daily losses [death of family, death of function], temporarily caused by Covid is what FAers live on a daily, degenerative and permanent basis. When my neighbors complained that they couldn’t use the pool last summer, when it’s been more than a decade that I have not been able to use one, or that they couldn’t go on vacation or go to bars, or on dates, I realized that living the way I do, is simply not acceptable for the majority of people that inhabit this world. So by approving omaveloxolone, you will be curing some people’s covid, and allowing FARA to focus its efforts and finance on other drugs that will be more effective. I am just asking for more time, and for more energy in a time when identifying to us, FAers, is actually possible. Please approve this drug that will slow down our losses, or at least give us some hope so that we can continue fighting. It’s been 30 years that I’ve been living with FA.

Kelly J.

Yes I would! Anything to hopefully cure my illness.

Laura J.

Yes would like the option to take omaveloxolone because I am anxiously waiting for a treatment that would improve the quality of my life.
COMMENTS FROM FA COMMUNITY
Individuals Living with FA in the US

Lily J.  Definitely! I have had FA for several years and would take anything that would slow the progression!

Monica J.  I would definitely take it.

Patrick J.  My Wife S. wants the option to take this drug right now. We have been married for 30 years and for the last 8 years FA has deteriorated S’s mobility and overall physical and mental health. Month after month FA is winning, we need this drug to slow the advancement of this horrible genetic disorder. We need a solution quickly…FDA please get this done.

Shawna J.  YES! the effects of the treatment show promise

Shirley J.  Yes, I would consider using the medication

Tiffany J.  Yes, omaveloxolone, to my understanding, brings hope to: new and older people being affected or may soon begin to be affected by FA. Therefore instead of just letting our functions deteriorate, an FA patient should be offered a drug that shows a prominent opportunity in facilitating and increasing chances of a better lifestyle. In other studies- read, the increase in exercise and mobility has shown a positive effect, and with drugs such as omav, we can improve our mobility.

Vijay J.  did not participate

Alyssa K.  Yes I am newly diagnosed but have been living with symptoms for 10 years. I’m still able to do all ADLs independently. Any chance of being able to regain some basic movement would help tremendously & feel we all deserve the opportunity!

Andrea K.  Yes, I am willing to try taking this medication for treatment of FA. The study shows some slowing of progression with individuals that are not as progressed as I am. I am interested to see what this medication does in someone that is more progressed.

Crystal K.  Yes, I have tracked this research, investigated the mechanism of action and reviewed patient success. I worked for a Statistical Analytics Software company for 15 years before Friedreichs Ataxia took away my livelihood. And I consider myself blessed because it started later in life for me. A statistically significant result of this level can provide young patients with time that will enable them to develop skills and experience for a brighter future. Energy is the currency of life. The mitochondria are the power house of the cell. The more time you allow to pass, the more uncertain their future. How many carbon bubbles pop in your seltzer before it is flat? That is happening in a child’s body before anyone knows there is something wrong. You cannot understand the frustration with the lack of urgency if you do not experience this. But what if it was $1 taken from your bank account every hour. When it hits $0… There are real monsters under the bed. Hurry the clock has started on a child that doesn’t know it yet!

David K.  I would like to have the option of taking the medicine. I have not had any effective medication for my Ataxia. I’m 58 and my symptoms are accelerating, so I would really like to get something to help. My 14 year old daughter has not been diagnosed and does not appear to have any symptoms, but I would want to determine if there is something to help her if she is ever diagnosed with Ataxia.

David K.  Yes: if there have been signs of improvement with it, I would try it.

Destiney K.  yes i would take it!!
Jeannie K. Possibly but I would rather someone whose symptoms are not at my stage have it. I was lucky enough to have later onset. I’m older now but early onset faers oxidize so much quicker. I feel that your medication may allow them to have much fuller longer lives.

Jolin K. I am fortunate to be where I am today. I have a wonderful family and great friends who all support me. My husband of 18 years is my rock, he is always by my side and I can not imagine life without his love and support. My 5 children are helpful and good natured. I am 38 years old and started using a wheelchair full time 2 years ago after falling several times while pregnant and requiring medical monitoring. I have comprehensible speech and maintain upper body control. If there is a chance that I could stop progressing or regain control in anyathomable way, it will be worth the risk of taking Omaveloxolone. It is hard, even for me to imagine losing control of currently functional limbs, speech, bladder, etc. Listening to the testimonials from people who have been living with this devastating disease scares me so much. I do NOT want my family to watch me decline and I do NOT want to be a burden to everyone I love. If Omaveloxolone could stop us from losing any more, the risk would be outweighed by the benefit(s). I am probably overly cautious about all medications. I have taken a total of 2 Tylenol in the past 5 years. I have never had a flu shot in my adult life and I will be happy to wait a while to see long term effects from the Coronavirus vaccine. I volunteer to be the first person (outside of the study) to take Omaveloxolone. Thank you for your time and consideration.

Lilly K. Someone that I go to therapy with is on the drug and has seen extreme improvements. I unfortunately wasn’t old enough to be apart of the trial when it was happening. If we got this treatment it would make me so happy!!

Loretta K. Have not participated.

Maddie K. Yes, I would like to have the opportunity to try to extend my life. Wouldn’t you?

Mehtap K. I have FA since 20 years and FA stole the best years of my life.

Michael K. Terrible to try and live with this.

Scott K. I was diagnosed about 12 years ago with FA and my symptoms have progressed steadily since then. In the last few years my progression has lead from requiring no walking assistance to using a cane to a walker to an electric scooter. The next step will require use of a wheelchair. However, I believe omaveloxolone will prevent this progression from happening, based on clinical trial results. Please make this drug possible to obtain so I can prevent this last event from occurring. FA has already robbed me of so much, please approve it now so it doesn’t have a chance of robbing more.

Shannon K. I have been living with FA for 30+ years. I have sat here and helplessly watched my quality of life be taken from me. I am asking the powers that be, The FDA, have the decency to do the right thing here and allow MOXie to skip further clinical trials and make this treatment/slow of progression available to those of us that have been dealt the ugly hand of Friedreich’s Ataxia.

Shaylyn K. Yes! The positive results of the trial are perfect & I am very excited for the first FA treatment to occur!!

Sierra K. I would definitely be open to taking the medicine. From what I’ve seen, it makes a huge difference for a person with FA and their symptoms. It could help me keep control of certain symptoms for longer than I thought possible.

Sue Ellen K. Yes, I would like the opportunity to take Reata’s drug as a chance to improve daily functioning.

Vishruth K. I have FA, that much improvement is walking and slowing progression is a lot got us to ask , please approve to help us maintain our function.

Annette L. I would need more information about the medication, but I would consider it.

Christine L. I will for sure take Omav! When I first heard of the news the there was a possible Treatment for FA, I was ecstatic! When I heard the news on Tuesday night that the FDA will not approve the medication, I fell into a hopeless feeling. I am praying the someday soon I can have high hopes!!

Donna L. A treatment that would improve my quality of life would be life changing. I need to stay independent so I can take care of myself and not burden society. Fatigue, strength, speech, vision, pain could be helped by Moxie. Please expedite approval for FA patients.
Jada L. Yes, it would change my life.

Joshua L. Yes. I need a pause in symptoms before they get more severe. Please approve this.

Laura L. I want the option please!!

Megan L. I would take the medicine. I want to be able to feel independent and not needing to rely on people or wheelchairs or walkers to move or stand. This drug has shown amazing effects to help people with FA who primarily struggle with these simple tasks.

Michelle L. Yes, my time is running out.

Nygel L. I want to try this drug. It is safe and should improve my life and daily living. I have seen very encouraging data from the study and have witnessed friends taking the drug before and after. What I have witnessed and read looks like we have our first therapy.

Preston L. Yes I want to take the medicine because it would give me the opportunity to do so many more things that I thought I lost because of FA

Renae L. I was not apart of it but I am willing to try anything that might help me!

Wes L. Yes, I would. Stopping progression with some improvement would be amazing. I work out everyday knowing it really won’t help FA. Having medicine that actually helps, no matter how much, would be a dream come true.

Alex M. Since there have been no therapeutic treatment option so far, I would absolutely take any approved medications to help with the symptoms.

Angelina M. I did not take part in the trail but would love access to the drug.

Antoinette M. I have been living with this horrible disease for over fifteen years. My mobility is deteriorating; in last four years I have gone from using walking sticks, to a cane and now to a walker. The recent progression is concerning. I currently work full time and live independently which I desire to do that for the rest of my life. Clearly without some medical treatment, my ability to live independently may be impaired. I implore Reata & the FDA to move forward now with approval. This is urgent as there currently is no pharmaceutical treatment for this debilitating disease which is life shortening.

Barbara M. I have lived with FA for 30 years. I was so happy when Reata announced clinical trials on Moxle. I have followed the science and believe Moxle will definitely help me fight the devastating and potentially life threatening as well as the extreme suffering caused by FA. I hope with all my heart, we will be given the opportunity To purchase Moxle. Thank you.

Brian M. Yes I’ve heard many positive results!

Carly M. Yes. While I appreciate the FDA’s advise I’d rather the drug be approved now than in couple of years for another clinical trial and more loss and tormenting progression.

Chris M. I have been diagnosed with Friedreich’s Ataxia for over 20 years. The symptoms of the disease are devastating. Let’s slow and stop the symptoms with Omav. Please give me access To this life-changing drug!

Christian M. I would take it
COMMENTS FROM FA COMMUNITY
Individuals Living with FA in the US

Crystal M. I did not qualify for this study but eagerly awaited the results. It seems like it had very good results and no major side effects. I am definitely interested in taking the medication. At this point in my life, FA has affected more than just coordination and ability to walk. A list of complications that I handle on a daily basis will be too numerous to include in this letter. But I seem to progress more everyday. Every day we go without a treatment is a day that I progress as do thousands of others. We, as a community, have been eagerly awaiting a treatment for FA. I am hoping the FDA will approve the drug without a second clinical trial. The FA Community has a huge urgency for this drug, because every day we go without any type of treatment is a day that we progress even more, becoming trapped inside a body that does not do anything that it is instructed to do. I personally, would love to get some of the functions back that I used to have that I have lost. I realize I’m older, and being in a wheelchair at this time, I might not walk again. But if I have a drug that can help improve some of the functions that I have lost, or even slow progression so that it does not happen as quickly, I would take it today. Also, for the younger patients that are still walking, this drug gives them so much hope to not end up in a wheelchair and lose the functionality that many of us already have. I implore you to approve Omav, which is so eagerly awaited!

Dylan M. I am not on omaveloxone currently. I remain in relatively good health and believe with the aid of this drug I would be able to continue with a much higher quality of life.

Eli M. Yes. Because I want to get better and stronger.

Elizabeth M. Yes, I based on the evidence, I do want to take Omav.

Harold M. I would welcome ANY FA treatment or medications to slow down the symptoms, if not reversing the disease itself, since there is currently no medications for FA.

Hayley M. Yes! Anything to help!

Isabel M. Yes I would take this medicine so I can start feeling better and have start feeling stronger!

Joey M. Yes. Anything promising! I NEED HOPE THAT ILL LIVE PAST 35!

Jordan M. Yes I would like the option to take Omaveloxolone. It has been 14 years since my diagnosis. I have not qualified to participate in any trials. The existing evidence available supports both safety and effectiveness and that is enough for me to say I would like to have this available for our FA community. Time is of the essence here. At my diagnosis I was still able to run, play volleyball, swim, be a kid. Those abilities were rapidly taken by FA and now at 26 I need assistance with every daily task, have both vision and hearing impairments and the disease still continues on. Please approve this drug based on the existing data and help our community now.

Lindsay M. I’m fighting FA daily! This drug sounds promising and I’m hopeful FDA will reconsider so I can maintain a health quality of life.

Maia M. I don’t understand English but I would like to help T.

Marc M. YES........Anything that would help.

Megan M. I have Friedreich’s Ataxia, and I would like to have the option of taking the drug Omaveloxolone. One of the most frustrating symptoms I have of FA is fatigue. This affects my ability to work because my levels of fatigue vary throughout the day. I believe I would benefit by taking Omav so that I can have a job and be a contributing member to society. I also struggle with daily routines such as preparing meals, getting dressed, and getting up from the floor from falling. I often have to ask for help because it takes me a long time due to loss of coordination and strength in my arms and legs. I believe taking Omav will alleviate these neurological symptoms so that I can do things for myself and live on my own.

Megan M. Yes I am living with FA and I would enjoy the option to take this medicine now to have something to help the symptoms I live with on a daily basis.

Michael M. I would like the option of taking Omaveloxolone. The initial studies seem safe. If I can get even mild improvement and stave off complete dependency on others I would be grateful for FDA approval now.

Mitchell M. Yes I want to try anything and open to pause the progression

Nora M. Yes anything to slow down progression is so needed.
### Comments from FA Community

#### Individuals Living with FA in the US

<table>
<thead>
<tr>
<th>Name</th>
<th>Comment</th>
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<tbody>
<tr>
<td>Sandra M.</td>
<td>Yes. I would like to receive this drug/medicine to help treat my FA.</td>
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<tr>
<td>Sharon M.</td>
<td>Yes I would. I was patient for a drug study in the past.</td>
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<tr>
<td>Srikanth M.</td>
<td>I was diagnosed in 2020. Ever since my diagnosis I was waiting to go on the drug and is definitely beneficial for all the FAers in the world.</td>
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<tr>
<td>Tiffany M.</td>
<td>Any drug that is available to help with FA symptoms I’d like to have the option to take it.</td>
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<tr>
<td>Tiffany M.</td>
<td>Yes I would take. I tried to participate in the trial but I could not pass The peg test.</td>
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<tr>
<td>Tricia M.</td>
<td>Yes absolutely! I screened for this trial but was not chosen to participate due to my high arch feet and limited trial participants. This drug has proven it is safe and well tolerated, while slowing the progression of this dreadful disease. My life and so many others could benefit from trying Omav while there are no other options for us.</td>
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<tr>
<td>Tricia M.</td>
<td>Yes, anything to help me lead a more normal life!</td>
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<tr>
<td>Tyson M.</td>
<td>As with all those with FA, I am slowly dying and there are precisely no treatment options. This stuff works. As such, I (and the rest of us, too) desperately need access to this drug as soon as possible. Without it, there will be progression of neurological symptoms, loss of quality of life, increasing cardiac events, and many needless deaths. Please do the right thing.</td>
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<tr>
<td>Zachary M.</td>
<td>Yes. I struggle with everything. This year I’ve lost more control of my hands where it’s even more difficult to play my phone or games which is pretty much all I could do before. I’d love to be able to be better, even a little bit would be great.</td>
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<tr>
<td>Alicia N.</td>
<td>Yes I consider taking the medicine I have never being been on any drug for FA. I have had this debilitating disease for 37 years</td>
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<tr>
<td>Claudia N.</td>
<td>I want the option to take the medicine as I want to be able to slow down the progression.</td>
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<tr>
<td>Daniel N.</td>
<td>Yes, I would like the option of taking the medication.</td>
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<tr>
<td>Kailey N.</td>
<td>Did not participate in it but am familiar with the data &amp; it is vital to maintaining my independence that I have access to this life changing drug. I have friends who participated in the trials &amp; they have ALL benefited from it greatly with no side affects. The longer this takes to be approved, the more abilities I lose forever.</td>
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<tr>
<td>Keli N.</td>
<td>Yes, I want to try.</td>
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<tr>
<td>Kim N.</td>
<td>Yes! I would love to live longer!</td>
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<tr>
<td>Carlos O.</td>
<td>Unfortunately, I am at the level of progression with FA where I am incapable of performing most of the tasks required in the MOXIe clinical trial. Therefore, I cannot provide information of a personal experience with the study. However, I am involved in two separate clinical trials which are not directly associated with the MOXIe study. Thus, I can admit with certainty that the safety protocols which are in place before, during, and after each study to ascertain the safety and subsequent efficacy of each study’s results; make me absolutely confident that omaveloxolone is very safe and effective. Therefore, yes, based on the data currently available, I would take omaveloxolone. Because I know the method used to ensure the strict safety regulations, and the rigorous analysis of effectiveness, were used to validate the data for omaveloxolone.</td>
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COMMENTS FROM FA COMMUNITY
Individuals Living with FA in the US

Erin O. I would absolutely take Omaveloxolone. It is cruel to have a drug that works, even slightly, to not give it to us. I have been declining frFA for a very long time and do not have much time left. I certainly do not have time to wait for a new trail.

Gavin O. Yes, I would like to try OMAV, but not in the hopes of walking. The effort from you guys to create urgency out of ability to walk is amazingly naive. I’d love to halt my declining communication skills. I’d love to stop my malformed limbs. I’d love to halt my worsening heart disease. I’d love to halt my bladder issues. I’d love to avoid the chronic pain and extreme fatigue others in the community with FA report. The inability to walk is not the world-ending idea you lot are pushing.

Haley O. Yes I would like to try and see if it has any positive effects on my daily life.

Katie O. With a condition that gets progressively worse, even a slight improvement in symptoms or halting decline would be life changing. I do not have another five years to wait.

Mary O. This disease is awful, any drug that could help should be made available!

Sharon O. I would take Moxie if I could take it along with Intelence.

Shauna O. Yes, I would take omaveloxolone. I have heard only positive things about this drug and how it has slowed progression. This drug could be the deciding factor on whether I end up in a wheelchair, whether I will be able to continue my line of work, keep my voice, etc.

Steve O. I would most definitely be agreeable to trying this medicine. Life is passing me by as I am wheelchair bound due to this disorder that I never even heard of until I got it. I still do PT but the ataxia makes it very difficult to complete as my extremities are not responding to messages from my brain. A drug that could give me some improvement would be a miracle!

Alison P. Yes. I was not able to participate in the trial. Each year my symptoms get worse. I am worried about my speech and people not understanding me. I don’t have a lot of energy. My heart is affected and I have been in a wheelchair for 5 1/2 years. I hate FA and want to do things that other people my age do.

Frankie P. I was recently diagnosed with Friedreich’s ataxia at a mere 18 years old. It was 2 weeks after my birthday and 2 weeks before Christmas, what a gift right? I started to think and plan my future: where I would continue my education, what my career would be, having children, and getting married were just a few of the many experiences that were at stake. When I was diagnosed with FA I felt like my future was ripped out of my arms. What I have worked for my entire life was now going to be realistically unattainable for me to achieve. In 5-10 years I will probably be in a wheelchair and unable to speak, so how in the world could I realistically plan to go to medical school. How can I save other people’s lives when I am fighting for my own? How can I take care of children when I will struggle to take care of myself? I yearn to WALK down the aisle at my wedding, but I’m the later years how realistic could that be? With omaveloxolone, I have hope. I am completely Capable of MOST of my motor functions, but the struggle is definitely apparent. Omaveloxolone could help save my physical abilities that otherwise I am inevitably going to lose; I could attend medical school, walk down the aisle at my wedding, and raise my children if we could stop the progression of my symptoms. Omaveloxolone gives me and others like me a chance in life. To LIVE and not merely survive. Our dreams wouldn’t be out of reach; however, the longer we wait the more that is tipped from us. The FDA and Reata pharmaceuticals has the ability to give us HOPE and to give me a future worth wanting and worth living. My future lies within the decision of Reata and the FDA; however terrifying this situation is, a treatment is on the brink of availability and I pray each and every night the access to this treatment will be granted in a timely manner. I and patients like me do not have a second to waste.

Isabel P. I would absolutely take Omav if it became available to me. I was unable to participate in the trials because I can no longer walk. A treatment for FA would mean the world to me.

Jamie P. Yes, I would be excited for the opportunity to start taking this medication!

Janet P. I have had FA for >50 years and would like the opportunity to take omaveloxolone to keep the FA from progressing further and have less fatigue to enjoy my life more. Hopefully it will help me stay independent for a longer period of time.

Justin P. Yes, it would help me be able to function better as my balance isn’t good. I use a cane and wheelchair when I need to walk for long periods of time. A walker is something I may need to resort to.
Kennith P. | Yes------anything that would improve FA would be wonderful

Kimberly P. | There are so very few medications available to help people with this horrible disease. We desperately need science to develop products to help.

Marlee P. | Yes, I would like to not live with the pain and hope something can help me not feel like I’m losing control of my body.

Matthew P. | Yes I would take the drug

Megan P. | Yes - anything is worth a shot to help FA

Melissa P. | Yes, I would take the drug Omav. The reason for taking the drug is because I feel strongly that it has been proven to be safe and effective in treating FA. Currently there are no other drugs available for use in treating my disease. I am very excited to try Omav to treat my FA symptoms and look forward to the day that my condition would improve. I have been diagnosed with this disease for 25 years, so if there is anything that would help treat my disease I would eagerly try it. My prayers are that Reata will prepare the NDA and that the FDA will consider the great need of many patients who have waited years for a treatment and will approve this application for Omaveloxolone.

Michael P. | I have never been treated for FA and I am open to try it or help anyway I can

Nina P. | Yes if it could potentially help. I would be willing to give it a try.

Nina P. | Yes, I would want to take this drug

Renee P. | Yes- the sooner the better

Stephanie P. | Yes. Currently doing the Biohaven study with Triluzole and nearing the end. Will no longer be on drug. Scary to me when I have been on it for a year. This drug has no side effects(according to the girl who posted) so why not let those of us who suffer from FA take a drug that helps us? It’s almost like saying to a hungry person “here’s a plate of food… but you can’t eat it”. Please consider releasing this drug for us!

Todd P. | Yes. Chance for disease improvement.

Jess Q. | Yes. Side effects seem minimal to non existent so it can’t hurt and may even help.

Allison R. | Yes. Absolutely yes!

Amber R. | I would take it in hopes of improvement.

Angelina R. | Yes I would. I’d take anything that may help with FA

Besarta R. | Yes, I want the option of taking the medicine. I was 4 years old when I felt different from the rest of the children. I could not run as fast as them, my gait was odd and I started to experience problems with balancing. I was born in 1988, in a country that did not have neurologists, orthopedists, available therapies or knowledge about rare, neurodegenerative diseases. Thus, my symptoms progressed as I got older and my questions about my body kept piling up. In the year of 2020, my family and I moved to America and I believed that I would finally have answers. I dreamt that there would be a pill that would get rid of all my problems. Instead, I finally saw a neurologist when I was 12 for the first time in my life and he diagnosed me with Friedrich’s Ataxia. Then, I had to have surgery to correct my scoliosis and I never walked again. Today, I am 32 years old and severely disabled. I can barely speak, I can’t use my hands and I don’t have a social life. I need assistance with every aspect of living. I have a younger sister with FA who is 23 years old. I fear that her future will be like mine. I am aware that Omaveloxolone is not a cure, however it is similar to the pill I used to dream of. This drug has the ability to help my sister and so many other people with FA. This drug will help improve the life of my sisters and so many others.
COMMENTS FROM FA COMMUNITY
Individuals Living with FA in the US

Bill R.
My understanding is that the body's response to Omav is similar to the response I received from a clinical trial of EPI-743 even though the drugs work differently. My experience with EPI-743 was very positive. No side effects and my balance, coordination, strength and stamina improved and got better the longer I took it.

David R.
Yes, and it's positive effect on kidney function is reason enough for me.

Emily R.
Yes! This has been shown safe and effective as a treatment for FA. My body is dying and this drug will give me a chance! I shouldn't have to worry about planning my funeral at the age of 25. This medicine is hope. Please don't take away our one fighting chance we have to live at this time!

Fatjona R.
Yes, I want the option of taking the medicine. My sister and I were born with FA... we are 9 years apart. My symptoms began at age 12 and they keep on getting worse. Every year, I lose the ability to move a certain way, to speak coherently and most of all, hope. My sister was diagnosed at age 12, but her symptoms began at age 4. She dreamed of a pill that could make her better when she first came to America. However, doctors diagnosed her with a rare neurological disease that has no cure or treatment. She did all she can do which was therapy. My sister exercised at home, as well... but, her disease progressed rapidly and it continues to debilitate her body and spirits. My mother has the most difficult time coping with this disease. She slowly watches her daughter weaken physically and emotionally, which has broken her heart. My mother accepted that my sister and I have FA, however she has not accepted how horrible the lives of her two daughters have become. Furthermore, my family knows that Omaveloxolone is not a cure for FA, but it is similar to the pill that my sister dreamt of... let her dream become an ounce of reality and let Omaveloxolone heal my mothers aching heart.

Geraldine R.
Yes, I would gratefully take the medicine. If the study has shown promising results (which it has), I'd be more than willing. As someone who's lived with FA since childhood, I'm sure I can speak for ALL FA patients in saying that if there is just a small sliver of a chance this medication will help, I'd do it.

Jhettlyn R.
Yes I want to be able to receive this medicine in hopes that it might help lessen the symptoms of my disease. I would like the option of trying this as it's not fair to sit around and do nothing.

Kestyn R.
Yes please! I need help!!

Kim R.
Yes I feel that we deserve the right to at least try anything to pause, reverse, or stop any stage or symptom of this horrible disease.

Regina R.
I would absolutely take this treatment!! I have friends that are in the study and have only said positive and helpful things. I'm more than ready for a treatment that could better my quality of life. It's needed and long over due for us to receive the care we deserve.

Robert R.
I did not participate in any clinical trials. However, I would at least like to try the drug to see if it helps. Having something to try has got to be better than just letting Friedreich's Ataxia run its course unopposed. Even if the drug doesn't work for my specific case, Omaveloxolone would be a great place to start for researchers to develop other drugs that might work across a wider group of patients later on. Either way, I would consider it a win-win for research and development. No journey can begin without taking a first step.

Sean R.
i really need this med

Shirisha R.
Yes my child would love to take it to decrease the progression of this disease.

Vishu R.
Keep the progression slow. We see rapid progression even 1 year delay is a lot to me.
Wenceslao R. Yes, I would jump to the opportunity to take it. I want to start enjoying life the way able bodies do. Whether or not it the drug works, we have to give it a chance. Please approve it. Imagine your child had FA.

Cindy S. Yes, because I feel as if it would help me with my everyday life.

Alan S. Yes, I would like to have the option. Currently there is no treatment for FA and the drug offers some hope at least.

Amanda S. I would like the opportunity to take the drug/medicine. I want to slow or reverse some of the symptoms I have now to live an overall better, happier life. Any hope that FAers can get for this disease that has no treatment options is welcomed.

Amy S. Yes. I am older but stopping the progression would definitely impact my quality of life going forward. I want to be as functional as possible to be a grandma.

Ashlea S. I have suffered from this disease for 22 years now. It has taken virtually everything away from me. I am ready for things to change.

Ashley S. I’m willing to try it even though my hopes have been up before just to be let down again but hopefully yall will pass this because nobody should live like this!!!

Barry S. No due to my age and other health conditions

Bethany S. I would take the drug. I would do anything possible that might make my life different than it is now. Even if it’s a small change or no change at all, I would still take the drug because there might be a chance it might make my life better and easier and worth living.

Briana S. Yes. I’ve heard great things about this drug.

Caroline S. Yes, I would take the drug! It has strong data to support that patients who take Omav make and maintain improvements in their functioning and quality of life, with few side effects. Patients who have taken the drug have consistently reported improvements in their gait, postural stability, and fatigue, which are symptoms that affect me greatly.

Chelsea S. Yes! I’d love to have my life back!

Christopher S. Yes been waiting for something to help.

Collin S. Yes, I would definitely take this drug. I was diagnosed with FA in 1997. This wicked disease has stolen the prime of my life. I have been in a wheelchair since 15 after scoliosis surgery to install rods in my back. My gradual decline has been exhausting for both me and my family. My speech, eyesight, hearing, swallowing, sleeping, and almost every normal body function has deteriorated significantly. I am unable to even scratch my nose. All this with no sign of a cure on the horizon. Omaveloxolone is the 1st viable treatment for this horrible disease. Although I am late stage FA, I am hopeful it can somewhat stall my decline. Any side effects would be tiny compared to what I am suffering through now. I also want to see the futures of other FA kids & families improve to be better than mine with this new breakthrough drug.

Danica S. I would absolutely take omaveloxolone because I have heard of the positive results from MOXie participants. No treatment currently exists for Friedreich’s Ataxia so I (and thousands of others living with FA) have nothing to lose and everything to gain. This disease is killing us. We deserve the opportunity to improve our quality of life through taking omaveloxolone, for ourselves, our families, friends, and caretakers.

Darla S. Yes, I would definitely take it. It has been proven to show results. We have the option to beat this disease or set back down in our wheelchairs. Please allow us to stand up and fight this debilitating disease!

David S. I would take it if ot helps
**COMMENTS FROM FA COMMUNITY**

Individuals Living with FA in the US

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**David S.**  
Yes Absolutely yes I want Omaveloxolone to be available to take. I already lost a brother to FA and I also continue to lose daily functions from FA. I am a father myself, please don’t let me lose more and don’t let an innocent little girl lose another piece of her daddy. I’ve waited over 20 years with FA for a possible treatment and already buried a brother with FA. This is a closest thing we’ve seen to a treatment, it took this long for a drug with good results for any kind of improvement. I do not have enough time left to wait for more trials to be done. Omav can pause or slow down progression and I need that right now. We can build on other treatments from this but we must start here and now so we can find a cure. Please approve this drug now so people, our future, our children and me do not continue to lose function and live.

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**Dawson S.**  
Yes, I would love to be able to take this drug because it may change my life. I have progressed a lot lately and to try to stop that would be amazing and even to get some ability back would be great.

---

**Ellen S.**  
I have had FA for over forty years and would like the chance to improve my quality of life.

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**Erin S.**  
It cannot hurt to try.

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**Evan S.**  
Yes. Since it progressively gets worse, I figure if I don’t at least try the medicine then I’ll definitely never get better.

---

**Francis S.**  
I would like the option of choosing to take omaveloxolone, or any promising treatment or drug for this nasty disease. I have been living with FA for a quarter century now! That’s a very long time when you wake up every day and struggle to do life’s “simple” things - like walking and talking. My grandkids marvel at seeing me in an old video clip, and watch me swinging a softball bat, throwing a frisbee, or just standing freely - with no walker, or wheelchair, or anything else to help me stand! And not falling over! They’re equally amazed as well at hearing what I used to sound like, with my Real voice! I realize there’s now a treatment, which will apparently help with (even some of) my many physical challenges due to FA. So I’m asking you, to please, please expedite its release! Not in years to come, no, but right NOW. Yes, I’m 71, but I want to ‘live’ again!!

---

**Hannah S.**  
I would want the option of taking omaveloxolone. I was diagnosed with FA at the tender age of 6 and have been living with its symptoms for 11, almost 12 years now. Even if I started taking the drug now, there’s no way it would reverse all my symptoms. However, there are some abilities I have lost over the past few years that I would like back. If we keep on waiting to approve this medication, FA’ers will keep on losing abilities forever.

---

**Jatin S.**  
Yes. There have not been adverse effects, so I’d like the possibility of either stopping the deterioration, or maybe even slight reversal of the disease progression.

---

**Julie S.**  
Yes! Someone should always have the option to take a drug, particularly if it can potentially save lives. FA is a life-shortening disease. This med has been proven to be effective.

---

**Karsen S.**  
Yes I would want the option of taking it

---

**Katie S.**  
Yes, I have heard very good things about MOXie and would love the chance to have a treatment for FA, I’m 16 and would love to have more opportunities and a longer safer future!

---

**Kimberly S.**  
I am willing to try any medication that will help me in my daily life.

---

**Levan S.**  
Yes I would like to have the option of taking the medicine. Instead of thinking I have an incurable disease id prefer having the option of taking a medicine that can help stop or improve the symptoms

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**Libby S.**  
I have FA and want to take this drug to alleviate my symptoms and slow progression.

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**Luke S.**  
Yes please rush FDA approval

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**Michael S.**  
I would like to try this medication. I don’t have time to wait for another trial. To slow the progression and regain 2 years of lost abilities would have a huge positive impact on my life! FA has already stolen my ability to walk, stand, and my independence!
COMMENTS FROM FA COMMUNITY
Individuals Living with FA in the US

Morgan S.
When I was little I did gymnastics, ballet, and dance. Yet I have never learned to ride a bike. I have never been able to have a sleepover. I have never been able to hangout with my friends without being restricted by my disability. As I grow older I have to watch everything that I enjoy doing taken away from me, and I cannot stop it. It is called Friedreich’s Ataxia; a neuromuscular disease that causes me to lose my muscle and abilities over time. This treatment drug, Moxi, can tremendously slow down the progression of my disease so I can retain my abilities, and not just have to sit there and watch every single thing being taken away from me. As of right now I am fourteen years old and in a wheelchair. I try my best to live life day by day because I probably will not get to do most thing that occur in people’s lives: having a family, getting a job, even driving. But getting this drug would be life changing for me and many other Friedreich’s Ataxia patients.

Nicole S.
Yes- any help is needed.

Paul S.
Yes, been waiting on something, anything, for more than 20 years.

Sarah S.
i have not been a part of any studies; however, I have read many positive comments from both FA patients and researchers. I am hoping this will help with my recovery until the gene therapy is available.

Sean S.
Yes of course. None of the side affects are worry some considering the possible benefits.

Sean S.
Yes, I have seen the results it has provided for members of the FA community and the level of safety demonstrated. I would 100% want to be on Omav as soon as possible knowing its effects and that it could save me from becoming wheelchair bound. I’m Sean and I am 21 years old. I was diagnosed with Friedreich’s ataxia at age 19 but have been experiencing symptoms of FA for 5 years now. Omav should be available to individuals with FA immediately because our health and condition get worse every single day and taking Omav will prevent us from losing more of our abilities, such as the ability to walk, which is currently in the process of losing. However, that isn’t the only thing I am losing. I recently lost my dream of becoming a professional pilot to FA. I put in years of hard work, dedication, and tens of thousands of dollars into flight training. I earned my commercial pilot and flight instructors license but now that I can’t fly, I have practically nothing to show for all my effort. I might have lost my dream but it isn’t too late for many other FAers and Omav can make the difference for them in achieving theirs. Many others in the FA community are facing additional issues like fatigue, heart disease, lack of muscle coordination, speech impairment, inability to work, and trying to maintain independence. Currently, Omav is the only drug we have to combat symptoms of FA and I am hopeful that the FDA will find the MOXle trial data sufficient for consideration of approval and understand the importance of the benefits omav has for FA patients.

Shari S.
Yes. I would like the opportunity to take a drug to treat FA. I would like to experience an improvement of my disease. It would be a huge benefit to everyone living with FA and their families. This drug would improve lives.

Sophia S.
Haven’t sampled it but definitely want to have the option.

William S.
Yes, I would certainly take MOXle. I am 49 years old and living with FA has been an adventure I would not want anyone else to have to experience. For this reason, I chose never to have children. This is a lamentable sacrifice, but I did not want to continue faulty genes. I believe we are making progress in editing the genome and MOXle have the potential to buy time until an absolute solution is developed. This is my and many other peoples hope - that the underlying cause of FA is corrected. A step in that direction that could buy more time to get there justifies my sacrifice.

Zaheer S.
I want my life back!
COMMENTS FROM FA COMMUNITY
Individuals Living with FA in the US

Brooke T.  I did not participate in the MOXIe trial, but I have friends who did. I do not think it's fair to say that the MOXIe is not efficient because it has overall stopped symptoms. There are no other medications out that have been proven to help and our FA community needs something. This has helped encourage everyone and stopping the progression is very important to me because right now, while there is no gene therapy out, slowing the progression is very important because my symptoms have just started to worsen and I am doing good RIGHT NOW. But that is the key thing, right now. No one knows how much my symptoms will worsen and if we don’t get something like MOXIe out, then I will find out much faster how bad my symptoms will get.

Christina T. Yes, I would like to try this drug. I need some hope before things get worse for me:

Daniel T. Yes, I feel the benefits would out weigh any risks

Emily T. I would like the option of taking the medication. I believe it would help with living with symptoms of FA.

Jacob T. Yes. The results are positive and this drug can help us live more fully

Kalyn T. Yes! It would potentially mean less fatigue so that my quality of life can improve! Instead of having to go straight to bed after work because all my energy is gone I might be able to enjoy time with family and friends or do a little more to manage my household independently. In addition I would feel safer walking without having to hold onto walls or furniture.

Kelly T. Yes, I will definitely take the omaveloxolone when it becomes available. I have been affected in every possible way including now I am almost blind.

Morgan T. Absolutely! Not doing anything at all scares me a lot more than ANY risk a medication may or may not have.

Rondall T. Yes, I have tested positive for Ataxia which is a hereditary disease. Maybe if I am allowed to take drug, the results would minimize conditions of future patients.

Sandra T. I would want the option. My child also has ataxia and I want to do anything I can that might help someone else so they don’t have to go through it.

Stephanie T. I want the option

Tolga T. Health

Yanni T. Yes, I would like to better my quality of life. Every day is getting harder and harder.

Ayse U. I am 36 years old and have been sick for 15 years. Please, I want this drug to be approved and used.

Deanna V. Any, ANY, relief from the symptoms is wanted & much needed! Please understand that this disability takes so much more from us than just the ability to walk.

Joseph V. Yes I still try to work and I think it’ll help tremendously

Julie V. YES!!! The opportunity to slow / stop progression of FA is not even a question. As an adult onset patient, it is hard to describe how difficult it has been to lose my ability to do many of the things I love. The opportunity to stop losing is a welcome relief! Thank you for your consideration.

Melody V. I have lived with FA my entire life, and currently somewhat progressed to a point where confined to a wheelchair and need help with everyday care. I would be greatly appreciative for any an all drugs or treatments to be accessible. Thanks

Michele V. Yes I would try it.

Alena W. Yes. Anything is better than what I have been going through. I am anxious for any type of improvement or even if it means that I won’t get any worse than what I am now.

Alex W. Yes! When you live with a progressive disease, desperation and risk are common.

Brad W. I would be willing to take it. I’m ready for anything to help with my balance.
<table>
<thead>
<tr>
<th>Name</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brendan W.</td>
<td>Yes I would love to take omaveloxolone because I want to slow the progression of FA and have future generations have the ability to slow the progression</td>
</tr>
<tr>
<td>Christi W.</td>
<td>Yes, even though there may be some unknowns involved with taking a newly developed drug, without it, the outcome is certain and I really want to be there for milestones in my children’s lives: graduations, weddings, grandkids, etc. and if this drug can offer more time then I feel it’s availability should be expedited.</td>
</tr>
<tr>
<td>David W.</td>
<td>Yes, any possible help is a positive.</td>
</tr>
<tr>
<td>Jackson W.</td>
<td>I was diagnosed with FA 4 years ago, but I had balance issues a few years before that. In the past 5 years I have gone from walking, walking with a cane, using a rollator to now using a wheelchair. I exercise 6 days a week and eat healthy, but everyday FA takes something else away from me. I would love to have the opportunity to take Omav to help slow my progression. Right now it’s our only hope. Please consider our request and help make this available for me and the others affected by FA. Thank you!</td>
</tr>
<tr>
<td>Jean W.</td>
<td>YES I would want to take Omav! I was diagnosed with FA over 39 years ago, which means I’ve been symptomatic for over 40 years. That is a long time to be sick. It is! But the most brutal thing about it has been 40 plus years of loss after loss, both my functions and friends. Along with all my friends in the FA community, I’ve had innumerable days of trying to do things, big or small, put one foot in front of the other, legibly and efficiently sign my name, be understood on the phone and much more and no longer being able to do it or to do it as well. Sometimes the loss is temporary, you have the flu and things get worse, but often the loss is just is your new normal. Even worse, we lose friends to this disease. People who are vital and strong contributors to our FA community and, of course their broader community. Loss of friends (especially to the disease one has) is really hard to bear. At this time in my life, my focus is on doing whatever bit I can to prevent a young person from enduring the relentless losses of FA. In my younger days, I just wanted cure. I didn’t appreciate what slowing the progression would mean. What if my voice stayed clear as a bell for five years longer? What if I could walk for longer? What if my constant shadow fatigue didn’t grow so fast? While I know it is hard to value something you haven’t yet lost over something you have, my 40+ years of FA have shown me that the things you haven’t lost yet -- every little ability you still have -- is important. So, I think it is vital that we have access to Omav now, that the 15 year-old who comes to our teen hangout (that I love) does not have to endure two more years of loss as she waits for a drug approval. Most importantly, slowing progression could mean we lose fewer friends. We can’t wait 2 years for that to happen…it is too important.</td>
</tr>
<tr>
<td>John W.</td>
<td>Yes, it provides some hope to providing energy to mitochondrial function for much needed energy production.</td>
</tr>
<tr>
<td>Kimberly W.</td>
<td>I would really like the option to take omaveloxolone as a treatment to help with FA symptoms. Living with FA makes almost every aspect of daily life difficult and the potential to gain a little back is so important to me.</td>
</tr>
<tr>
<td>Lauren W.</td>
<td>Yes! I would be so happy to take the drug and work towards a treatment for fa.</td>
</tr>
<tr>
<td>Paul W.</td>
<td>Any person living with this rare disease should have a treatment available now, like the current Covid19 vaccine was made available very rapidly.</td>
</tr>
<tr>
<td>Name</td>
<td>Comment</td>
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</tr>
<tr>
<td>Shannon W.</td>
<td>Absolutely because this disease is not just physically, emotionally, and mentally exhausting for me but my family and Friends as well.</td>
</tr>
<tr>
<td>Shelby W.</td>
<td>Yes, I would be willing to start taking it. However, I did not take the drug or any related drug in the past.</td>
</tr>
<tr>
<td>Teresa W.</td>
<td>Yes. To alleviate symptoms</td>
</tr>
<tr>
<td>Victoria W.</td>
<td>Yes I would take the drug</td>
</tr>
<tr>
<td>Abby Y.</td>
<td>Yes because I want to slow my progression</td>
</tr>
<tr>
<td>Brooke Z.</td>
<td>Yes. I feel it would benefit.</td>
</tr>
<tr>
<td>Landen Z.</td>
<td>I was born normal. Nothing was wrong with me at all. I would run normal, play with friends, play soccer. Then, in elementary school my teacher noticed my hand tremble slightly with my writing and told my parents. I saw my doctor and they diagnosed me with hypothyroidism and I was put on levothyroxine and we thought that would solve all problems. I started walking slightly funny, my dad would yell at me because he didn’t understand that I couldn’t help it, he thought I was purposely walking funny. My friends started calling me names because of my walking. At the time it was very slight and minor and I was mostly normal and capable of everything. Then I found myself struggling with plugging my appliances into the plug or anything that required straight and direct movements. I was then in middle school and my body was having a mind of its own. It’s as if I try so hard to walk straight but my body goes awry. I started getting tired more, I needed glasses as my vision changed, and my spine was crooked. I was normal at one point and I was deteriorating. I couldn’t do most things my friends were doing any longer. Quickly my FA progressed and I could barely walk up two steps without stability. My friends had to carry me discreetly during school programs up the steps. My voice also changed and I hated so badly to present publicly. I started going to every doctor for every different body system. I had no energy after school, yet this is how my life would become. I remember going to physical therapy and the lady told my mom that he should just stop coming here because I’m not going to get better. I know she’s right, but this is the only medicine that I have right now. I can’t even walk normal anymore, I may not be able to drive, my eyes are getting worse and shaky, I had to have scoliosis surgery. I am losing all parts of myself. Within a few months things drastically change and I am scared. Researchers always extend deadlines for their studies and Reata was my only hope until now. Please don’t take this away from me. Please help me get medication that can help me. Any improvement is better than none. We have nothing else and I don’t have much time anymore.</td>
</tr>
<tr>
<td>Mali Z.</td>
<td>I need a drug to ease if not better living with FA</td>
</tr>
<tr>
<td>Zac Z.</td>
<td>Yes please! I feel. This drug can help others like me! Let’s stop talking about it and get it done! I’ve heard for years we will have a cure since I was 7. I’m now 25 and am losing ability - let’s give people with Fa some help so we can pause on this progression. If you were in our shoes - you would feel passionately about making this happen! Put yourself in our shoes and our wheel chairs!</td>
</tr>
<tr>
<td>Zachary Z.</td>
<td>Yes, from the results of those that have taken omaveloxolone and the results from the study I would take it without hesitation.</td>
</tr>
</tbody>
</table>

Footnote 1- 87 signers commented- “Yes”, “Absolutely”, or “Absolutely yes.” Footnote 2- 4 signers commented- “No” or “N/A”
### COMMENTS FROM FA COMMUNITY
Individuals Living with FA Outside of the US

<table>
<thead>
<tr>
<th>NAME</th>
<th>COMMENTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alberto</td>
<td>For me and other people to have some treatment against this devastating disease</td>
</tr>
<tr>
<td>Abderrahim A.</td>
<td>Yes, i WOULD take it. A data showing a drug to be safe and efficace plus being a statistically significant and showing mFARS improvement of 2.40 pionts after 48 weeks of randomized, double-blin, placebo-controlled is a MIRACLE!</td>
</tr>
<tr>
<td>Alejandro A.</td>
<td>She needs the medicine to try to have a better quality of life</td>
</tr>
<tr>
<td>Ana A.</td>
<td>yes, of course</td>
</tr>
<tr>
<td>Andresson Carlos A.</td>
<td>For me and other people to have some treatment against this devastating disease</td>
</tr>
<tr>
<td>Annie A.</td>
<td>Yes, I would like to take and get the medicine to improve my chances and get better</td>
</tr>
<tr>
<td>Beyza A.</td>
<td>None of my family has this disease only me.</td>
</tr>
<tr>
<td>Danielle A.</td>
<td>Yes. Because i hope to improve my health condition and overall quality of life</td>
</tr>
<tr>
<td>Dante A.</td>
<td>Yes. Because i hope to improve my quality of life</td>
</tr>
<tr>
<td>Gilberto A.</td>
<td>Yes if is secure</td>
</tr>
<tr>
<td>Hadj Salem A.</td>
<td>I did not participate</td>
</tr>
<tr>
<td>Hasan A.</td>
<td>A friend uses omav, he said it was good for him, I want to try it, I want it to be legal and accessible</td>
</tr>
<tr>
<td>Henrique A.</td>
<td>Do not partipate the clinicas trial</td>
</tr>
<tr>
<td>Higino A.</td>
<td>I'm not sure if I participated in MOXle but i would like to be a volunteer at any stage of the research. So I am 21 years old I live in Brazil in the state of Minas Gerais and I do polka things with the help of someone, I have been in a wheelchair for 5 years.</td>
</tr>
<tr>
<td>Ian A.</td>
<td>Yes, any improvement to my quality of life would be more than welcome no matter how small. I like to try and do things myself and that is becoming more challenging. I also have severe scoliosis making things even more difficult. I use a 'handy move' hoist that I can operate independently for things like transferring onto my bed, shower, etc... Being able to have some dexterity to do simple things would hopefully help in my daily life.</td>
</tr>
<tr>
<td>Joselyn A.</td>
<td>It is a drug that I have been waiting for since more than 15 years to improve my quality of life and that of all who suffer from FA.</td>
</tr>
<tr>
<td>Julie A.</td>
<td>I have FA and want the option of taking the drug/medicine (Omaveloxolone).</td>
</tr>
<tr>
<td>Linda A.</td>
<td>She wants take moxie just she hope it can help her to live better she dosent want any opinion</td>
</tr>
<tr>
<td>Maria Beatriz A.</td>
<td>It has a lot of hope not for me, but for my sister. I am 43 years old and my sister, 30.</td>
</tr>
<tr>
<td>Maria Beatriz A.</td>
<td>Yes. I really want to participate!</td>
</tr>
<tr>
<td>Mark A.</td>
<td>Yes. Life is very difficult so any benefit is worth a small risk.</td>
</tr>
<tr>
<td>Maxime A.</td>
<td>i do want to participate, this is the only chance at a cure i have</td>
</tr>
<tr>
<td>Mohamed A.</td>
<td>Yes, sure. I want the drug for myself.</td>
</tr>
<tr>
<td>Name</td>
<td>Comment</td>
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<tr>
<td>Murat A.</td>
<td>Yes, because there is currently no alternative</td>
</tr>
<tr>
<td>Nakay A.</td>
<td>My parents are carriers of FA, but they do not suffer from it. However I am a carrier and I suffer from it</td>
</tr>
<tr>
<td>Osama A.</td>
<td>I heard from my friend about it so I would definitely try it</td>
</tr>
<tr>
<td>Raghda A.</td>
<td>Yes, I will definitely start taking it</td>
</tr>
<tr>
<td>Ross A.</td>
<td>Yes, I would definitely take omaveloxolone. I am a 60 yr old man who has been symptomatic since my early 20’s. I have used a manual wheelchair since my late 30’s and I moved to a power wheelchair 5 yrs ago. My life now consists of sitting in a motorized reclining chair with a laptop computer. I have to have assistance for every daily living task, including transfers, especially toilet transfers. My speech has slowly declined to the point that I am hesitant to talk on the phone. This short text is taking an hour to write. I’ve fought against FA almost my entire adult life with no drug to slow or halt progression. Now, through the extraordinary effort of researchers and the FA community, a drug does exist that can at least slow down the progression of this heartbreaking, insidious disease. I need to do something, anything to slow this down and try to hang on to what little quality of life that I have left. I ask for the help of Reata Pharmaceuticals and the FDA to act quickly to bring omaveloxolone to market. Thank you.</td>
</tr>
<tr>
<td>Rukiye A.</td>
<td>I want to have a cure for FA</td>
</tr>
<tr>
<td>Sama A.</td>
<td>Yes I want taking the drug/medicine?</td>
</tr>
<tr>
<td>Serpil A.</td>
<td>I want access to use the medicine.</td>
</tr>
<tr>
<td>Sheryl A.</td>
<td>I live in South Africa &amp; to my knowledge, we have not been included in this study. I am 51 &amp; am a late onset FA patient. I’m recently engaged for the first time &amp; prior to diagnosis (2015), my health was good. I was normal. MOXIe will give myself &amp; many others of all ages hope. Return us to being able to be independent &amp; contributing to society please?</td>
</tr>
<tr>
<td>Sónia A.</td>
<td>These patients should be entitled to this free medicine. Enough limitations ; it is a very expensive medicine</td>
</tr>
<tr>
<td>Waleed A.</td>
<td>Yes, of course, we wish we had the medicine available</td>
</tr>
<tr>
<td>Yordy A.</td>
<td>Yes, this drug can help many people including my family member. I hope you take our answers into account. Thank you very much.</td>
</tr>
<tr>
<td>Alice B.</td>
<td>I would like to try this treatment which can stop the disease and degeneration. I have been taking antioxidants since 2008: they help me gain more energy. Studies say that Moxie is similar to antioxidants but has more efficacy and strength against degeneration. We need a therapy that is accessible to all of us especially in this moment of Coronavirus emergency: time is extremely important to us because every day we lose our skills and we need this drug that has been studied for years.</td>
</tr>
<tr>
<td>Andrew B.</td>
<td>I would want the option. There is no alternative, just ongoing deterioration of nerves and muscles. Given the safety has been established I’d try it in a heartbeat. There is NO alternative but wasting away.</td>
</tr>
<tr>
<td>Anthony B.</td>
<td>Yes I would. A small chance I could be like you, is better than no chance. Don’t forget about us FAers, or the future generation.</td>
</tr>
<tr>
<td>Bernard B.</td>
<td>I would be prepared to take the medicine.</td>
</tr>
<tr>
<td>Brodie B.</td>
<td>Yes I’d want that option, because if it helps I’m interested</td>
</tr>
<tr>
<td>Cally B.</td>
<td>Yes I would want it</td>
</tr>
<tr>
<td>Carrie B.</td>
<td>For over 25 years I have helplessly watched my body beaten, contorted and traumatised in an unimaginable pain. The thing about FA that is not so obvious is that the emotional turmoil inflicted is every bit as debilitating as the physical one. It is one thing to live with a future of worsening symptoms causing death, but another to live without hope for the future at all. We know that this medication is not the almighty cure. But perhaps the hope for a life were we no longer witness our bodies weaken and die before our eyes. A tomorrow too plan for and look forward too.</td>
</tr>
<tr>
<td>Catherine B.</td>
<td>Yes, I’ve heard only positive things from FA patients who have been in trials for Omav</td>
</tr>
<tr>
<td>Connor B.</td>
<td>Yes as there are no other treatments for FA.</td>
</tr>
<tr>
<td>Erivan B.</td>
<td>Yes, I wish I didn’t have access to the tests!</td>
</tr>
<tr>
<td>Federico B.</td>
<td>Have never taken any medication for FA so I would be totally willing to take this new drug</td>
</tr>
</tbody>
</table>
## Comments from FA Community

**Individuals Living with FA Outside of the US**

<table>
<thead>
<tr>
<th>Name</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Filipe B.</td>
<td>Yes, I would take it, even if the results are minimal I would do everything to improve my life and of my family.</td>
</tr>
<tr>
<td>Ierotheos B.</td>
<td>I would like to try the drug omav!</td>
</tr>
<tr>
<td>Jane B.</td>
<td>Yes, convinced by research findings</td>
</tr>
<tr>
<td>Jeet B.</td>
<td>Yes, I want to have it for myself</td>
</tr>
<tr>
<td>Jennifer B.</td>
<td>Yes, I would definitely want to take omaveloxolone, this condition takes over your life, so as it has proved in this long study that it makes a vast improvement in the symptoms would be fantastic before it is too late for people, please think again you could stop people dying!! Thank you.</td>
</tr>
<tr>
<td>Jiorgos B.</td>
<td>Based on the available data on the safety and efficacy of omaveloxolone I would like to provide this treatment.</td>
</tr>
<tr>
<td>Joseph B.</td>
<td>Yes, I want the opportunity to access the only treatment available for FA.</td>
</tr>
<tr>
<td>Juliana B.</td>
<td>I need this medicine to live</td>
</tr>
<tr>
<td>Karl B.</td>
<td>Definitely I would use it!!! In a heartbeat!! I don't have time to wait &amp; nothing to lose! I'm 53 with FA.. How Ridiculous is it that Covid Vaccines are rushed through &amp; such a debilitating fast moving disease like FA has years of Red Tape! Gladly sign something to confirm it's totally at my Risk! Covid Vaccine companies do not stand behind their products &amp; the world excepts that!</td>
</tr>
<tr>
<td>Kerry B.</td>
<td>Yes because it gives me hope of a better future.</td>
</tr>
<tr>
<td>Kevin B.</td>
<td>Yes, to get back a less complicated daily life</td>
</tr>
<tr>
<td>Laura B.</td>
<td>Yes, I would be very interested in any sort of treatment for FA!</td>
</tr>
<tr>
<td>Lauren B.</td>
<td>Yes, I want hope.</td>
</tr>
<tr>
<td>Lee B.</td>
<td>Yes I would like to have the option of having omaveoloxone - but more important to me would be to option to pass my inclusion to have this drug to some one on the start of there F.A condition to slow or prevent there degeneration of this disease. So they would be able to have a better quality of life. From my first signs of F.A to now is 24 years and counting !!! F.A is a wicked and nasty disease.</td>
</tr>
<tr>
<td>Lucila B.</td>
<td>Yes I would take omav medicine as the results form the trials were good and I am hopeful of improving my life with this medicine</td>
</tr>
<tr>
<td>Luisa B.</td>
<td>Yes I would like. I have had the disease for more than 20 years and only this year I started using a wheelchair. I believe that the medicine can help me a lot.</td>
</tr>
<tr>
<td>Mandy B.</td>
<td>Yes. Am desperate for some kind of treatment</td>
</tr>
<tr>
<td>Mario B.</td>
<td>I only take Idebenone. I have not participated anything!</td>
</tr>
<tr>
<td>Michelle B.</td>
<td>Yes - a cure would mean everything to me. I can't even put into words what this would mean.</td>
</tr>
<tr>
<td>Milena B.</td>
<td>I would like to take omav, my sister and me live with FA and it's very hard. We want and need to stop loosing functions and to have a better life quality with independence.</td>
</tr>
<tr>
<td>Murat B.</td>
<td>I am a Fa patient. My brother-in-law neurology prof u had a positive effect on omav activities, but he was not on the market.</td>
</tr>
<tr>
<td>Murvy B.</td>
<td>Yes. I even requested Reata Pharmaticals to supply me omaveloxolone on compassionate grounds. Reata agreed provided the request is made on my behalf by a physician. So far the physicians I have contacted are reluctant to assist me. Unfortunately, I did not get the opportunity to participate in any clinical trial.</td>
</tr>
</tbody>
</table>
**COMMENTS FROM FA COMMUNITY**
**Individuals Living with FA Outside of the US**

- **Richard B.**
  - There's a hope.

- **Rogier B.**
  - I would definitely take it. Even stopping the progression after 24 years would be wonderful.

- **Samira B.**
  - Have never participated in a clinical trial.

- **Shannon B.**
  - Yes. Definitely. Life is a burden...it should be a gift! Every day produces new challenges that could be elevated by this drug. I am daughter, sister, friend and mother. This life affects more than just me.

- **Yunus B.**
  - Not.

- **Abner C.**
  - Yes, can't keep waiting.

- **Aimee C.**
  - Yes because it could potentially ease symptoms and I want to help other FAers.

- **Alalia C.**
  - I would definitely want to try this drug because I want to do so much more in my life but fear I will not be able to do even even half of things I want do with my current condition and I will be able to even less if/when it gets worse.

- **Antoine C.**
  - I would take it because omav offers the best results and the lowest risks yet. Also, I want to live fully, and I can't do that with FA.

- **Argyro C.**
  - I want to take omav because I want to be healthy again as I was before. Please only you, can give me the chance to live my life like my friends!! I want to study, to get married and to have my own family!! Please, give me my smile back again!! Thank you!

- **Canan C.**
  - The debilitating effect of FA on my friends daughter and the emotional turmoil it causes his family leaves them wanting the option of taking the drug to provide their daughter with the best opportunities in life.

- **Carina M C.**
  - I would like to be able to take the medicine.

- **Carla Izadora C.**
  - I would like it, it is a medicine that can help me stop the disease, or even return some movements.

- **César C.**
  - As mentioned I think that any medicine or drug that can help me feeling better and more independent would be very helpful.

- **Charlotte C.**
  - I would like a medicament because I want live! I am an ECE prep and I have doubts about my future life. I would like to have a normal life, I am afraid of the future, currently I survive I do not live. The necessity of a medicine becomes extremely urgent. If there is no medicine I doubt my will to live... it is too hard...

- **Ciara C.**
  - I would really want the option to take this drug/medicine. As I'm in college, work a part time job and training to be a teacher, this drug would make my busy lifestyle a lot more do-able for me. A drug that can ease my symptoms would be extremely helpful for me!

- **Cintia C.**
  - Yes, I would want the option of taking omaveloxolone since safety and efficacy are found in that medicine.

- **Cristiano C.**
  - Despite not having participated in tests I believe in efficacy and I see hope in medication.

- **Desiré C.**
  - I'm open to everything for fighting FA.

- **Elise C.**
  - Yes - as FA is progressing quickly, I am willing to try anything that might halt/help symptoms.

- **Harshita C.**
  - Yes I would like to take the medicine.

- **Helen C.**
  - Yes I would like the option to take the drug/medicine because anyway the debilitating effects of FA can be slowed down or cured would be a godsend to me and my family.

- **Jacko C.**
  - I would like to take it as I have been following closely the trials and research and honestly believe the option of taking this drug is the best hope I have so far of being happy. It is about hope, not neccessarily results. Although results would be great too. : )

- **Juan David C.**
  - Yes. I would like and am willing to participate. So far I have not had the opportunity to participate in any clinical trial for FA.

- **Kaelan C.**
  - I would definitely choose to take the drug/medicine I have really think this truck has much potential as my parents have spoke to people who have been part of the Moxie trial and they said they are able to stand again their speech improves their energy levels increase ext... personally I am about to get a dog and Take care of him. I am hopeful but unsure about my mobility down the road and I think with moxie I will be able to get some mobility back.

- **Kaysan C.**
  - Because based on the available information, I believe that omaveloxolone is safe and effective for the treatment of Ataxia, which will result on the improvement of my motor coordination (a symptom of Ataxia). Furthermore, the treatment will minimize daily criticism and the consequences of bullying, enhancing my self confidence and providing me freedom of life.
Khalid C. I need the drug to be better

Lambert C. I am 71. I think it’s too late for me!

Laura C. Yes, I would try anything that might improve my situation.

Lauren C. Yes I want to try it and see if it improves my symptoms

Lígia Maia C. Yes, I’d like to have more skills and independence in my daily life

Marjorie C. Yes, I want to take this medecine as soon as possible. My life changed drastically with FA and I want to have the possibility to be excited about my future again. Hope is what I am looking for, hoping for a better future. Not a miracle but still.

Megan C. I would but I didn’t take part in the study

Njomza C. I desperately want to try it. My life got very hard. I’m in a very bad condition.

Øystein C. In a heartbeat. FA has made my life crumble at breakneck speed for 10+ years. I would try anything that has even the slightest chance of helping.

Patricia C. I would be keen to try it

Rebecca C. Having freidreichs ataxia for the last 19 years of my life, it controls every single aspect of my life, after seeing the results of this trial and seeing such positive results, taking this is a no brainier. Anyone with Fa will do anything to get our control (lives) back please please please help us. We only need to be able to shower by ourselves and have the dignity others take for granted. Thank you for reading

Rita C. Yes, I would because I want to live and love and walk and dance like I did before

Ronan C. Yes, of course I would.

Seamus C. There is no known treatment for FA, so yes absolutely!

Sheinila C. Yes. Because is secure, effective and Will minimize the crisis.

Sheinila C. Because base on the information available I believe that omavelozolone is safe and effective in the treatment of Ataxia and it will improve the motor coordination of my family members who are suffering from this disease and as well as bullying because of that, taking away their freedom to fully live their youth.

Silvana C. Based on the data currently available on safety and efficacy of omaveloxolone, I would like the option of taking it. I’ve been living with FA for more than 15 years. Over the years, FA: took plenty of my physical abilities; caused me physical discomforts and pain; made me miss a lot of opportunities and limited my life, and it keeps doing so. But, I still manage to keep my spirit up; to appear strong and happy. FA limited my life, took so much from me already, and it’s time for it to stop. I don’t want to get trapped in a body that doesn’t function and my only sensation to be pain and/or experience a premature death. I read the research article about MOXIe study and I believe that it can stop the progression of FA, and it would be possible to reverse some damages done. With omaveloxolone in light, it would be devastating for it not to get approved and the option of taking it be denied. Time is of the essence, and every FA’er is running out of it. The sooner omaveloxolone gets approved, the better. I do not doubt that you will make the right decision. Best regards!

Silvia C. Yes, because it would be the only effective therapy for me

Sophie C. I have been living with this condition for 3 years, within a matter of weeks I lost my mobility and now fully rely on my wheelchair. I also have scoliosis of the spine which will be operated on in 6 months time. I feel if there is medication out there to stop or slow down my symptoms then FA sufferers need to be given this to prolong our lives and give us some quality of life.
Susana C.  
I would love to have the option to take it. It is a right

Tanya C.  
Yes because FA sucks

Vailza C.  
Yes, I want to be free

Yasemin C.  
I have FA. I am living with it over 10 years. I would like to participate on the study’s and give a try

Adi Č.  
I’d like for anyone with FA to be able to have an option whether they are willing to receive medicine that could improve their quality of life and slow down or even reverse progression of FA or not, so I’d like the same for my brother (who is diagnosed with FA as well) and myself. If someone has any concerns about possible side effects or that it isn’t “efficient enough” or have some insecurities about the way the research had been conducted, they should have an option to refuse it, but there should be an option to take this possibly life-changing medicine as well. Long story short, I’d want to have an option of taking the medicine, but I’m not sure if I would choose it, at least not straight away, as I’d probably wait for our country’s health organization to include it in the list of drugs for FA (though whether that will ever happen is debatable).

Alen Č.  
It would be nice to have a more normal life.

Aaron D.  
As a teenage boy I would relish the opportunity to have any treatment that can make a difference in my life, in the quality of my daily living. Losing abilities slowly month on month is soul destroying as a 14 year boy.

Alessandra D.  
The medication is very important because it gives us the hope of having a better quality of life, a retarded progression of FA as well.

Andrés D.  
Yes, absolutely. I have no other option to give me hope

Betül D.  
I want to join but I am a little worried.

Brenda D.  
I have been living with FA for over 53 years and I’m progressing very rapidly now. I just want the last years of my life to be a bit easier

Brigitte D.  
I would like to have the option of taking this medicine. I would like to be able to stand up more often.

Caroline D.  
What’s the worst thing about living with FA? After 36 years I can honestly say: “the lack of control.” Your head is saying “yes”, while your body is saying “no”. It stopped me from going after the things I like: a partner, a family of my own, a career in acting … The fear of my body giving up, just when I need it the most – made me opt out of many things my peers enjoy. To a point where you live so cautiously, you don’t really feel alive at all. You’re missing out on so many things and the quest for ways to handle your disease, becomes a way of living. You try everything you can for even the smallest result: dietary adjustments, expensive robotic therapy, acupuncture, homeopathy … every time you try something new, there’s hope again. You have to, because without it, there’s really nothing left. But every so often that hope is shattered, and with it the dream of ever living a normal life again. Omaveloxolone brought some of that hope back – if only for a brief moment. Until it was announced that more clinical trials were needed. And once again, I had no control over the matter. Without detriment to the expertise and intellect of every FDA member, it saddens me that people who are not living with FA take it upon themselves to decide what’s best for the entire FA community. A community that’s been waiting so anxiously for that little beacon of hope. One that has fought so vigorously over the years to gather the necessary funds to conduct much-needed research in the field. A group of fighters, now left out in the cold. Drug development is a very slow and cumbersome process. Many FA patients simply don’t have the time for a do-over. Our disease progresses fast and possibly irreversible. Knowing that there is a drug somewhere that might slow down this process – and to which we have no access – is extremely frustrating. Surely, there are no guarantees. But even if we were to test again, on a larger group of people this time, there will always be unknown factors. But our condition is too serious not to take the risk. Therefore, allow us access to Omaveloxolone, so we can at least dream again, and remain able just that a little longer.

Cihan Sahan D.  
I want the option of taking the drug/medicine.

Dallas D.  
I would want to take this medication. FA is so incredibly difficult to live with and I can’t fathom how much a treatment would change my life. Not only would it hopefully improve my physical health, a treatment would drastically improve my mental health.

Danilo D.  
Yes. I just want to have a chance of stopping the progression of my symptoms and more quality of life.

Denise D.  
I would like to take the medicine so as not to worsen the symptoms.

Emma D.  
Yes we would Accept with enthusiasm since the amazing results, especially the significant difference with contro groups.
Georgios D.  I would like to have the option of taking this medicine because I am in good condition despite the disease. On the other hand I require assistance with activities of daily living, something that is not my character. Maybe this drug is a milestone in my life.

Heather D.  I would be willing to take it as there is currently no treatment.

Huseyin D.  I want options of taking drug. I’m patient with FA. I hope that we who all FA community will hear good advancements about drug or medicine or gene therapy options for FA treatment at near future.

Isabelle D.  If omaveloxone improves or stop the progression of FA, it would definitely give me a better expectation of my life.

Jamie-Lee D.  Participate.

João Paulo D.  For me and other people to have some treatment against this devastating disease that is FA.

Jonathan D.  Yes. Any treatment that would slow the progress of this condition would be of great physical and psychological value.

Konstantina D.  I haven’t participated, yet everyone worked so hard in this drug and I want to give it a try. Plus, it’s very important as it’s the first treatment ever for FA.

Kosta D.  Yes, the drug would be the first treatment for FA and the drug the same as to impact the lives of people with this disease very positively.

Laura D.  Of course I would want the option.

Lucas D.  Of course.

Maria De Fátima D.  Yes. I have nothing to lose, do I?

Marina D.  I am waiting for take MOXle and have the possibility of living with uncertainty and anxiety about a badly future. Also, I would have the possibility to improve my activities and be more productive for the society.

Matheus D.  Yes. There are few remedies related to AF and this would be a good hope.

Megan D.  Yes, I would like the option to take OMAV. I am currently living with FA. The nature of degenerative disease is cruel in its interaction with time. Everyday I grieve the mobility I am continually losing. I would like the opportunity to try OMAV to potentially pause my degeneration, so I can catch my breath among amid my grief and begin to once again emphasize the joy, gratitude, and mobility I do have.

Nick D.  Yes I would want to take the drug as the trial has proven it’s safety and efficacy.

Phoebe D.  I need the drug.

Robert D.  Yes. Today there is no medication for AF and it is very difficult to live with a degenerative disease.

Rodrigo D.  Yes, I would like to have the option of taking the medication, because we have to hope for improvement.

Samantha D.  Yes I would take the drug to maintain my symptoms and hopefully improve some.

Scott D.  Yes. Everyday a little part of me is taken. This may be speech, balance, fatigue, hearing, heart, independence, the list goes on. Without fail a part of who I was and what could of been is gone. I’d do anything to be able slow the progression or even just for a little hope.

Talita D.  Yes, I would like to take MOXle.

Tanya D.  No, I have not participated.

Thomas D.  I am 35 years old living with symptoms of FA for more than 15 years and I definitely want the release of the drug so that there is a prospect of taking it. The main reason is that I want a change when almost my whole life plagued - and threatened as well - by this disease and for years I expect something to help. At the same time I am completely dependent on others to meet my needs and it is a nightmare. So I have not something to lose and I believe it is time to start overcoming the monogenic diseases.

Violeta D.  Yes, I would want to receive the chance to take Omaveloxolone for FA. The present data from clinical trials is very good and positive! This is chance for life for me and for all FA suffered people! Please, give us this chance!

Ybele D.  Yes, FA is very limiting my life. If a cure may help to stabilize or even better the diseaze, I will participate.

Bertei E.  Yes I would like to be able to take the drug in hopes of limiting the course of Friedreich’s Ataxia.
COMMENTS FROM FA COMMUNITY
Individuals Living with FA Outside of the US

Burcu E.  Yes, but I did not participated.
Connie E. I would want the option of taking this drug as it is the only drug available that has shown to be effective for Friedreich’s Ataxia. I would also want it available in Canada.
Deniz E. I am also sick but I could not use the drug. But I have a friend who uses it, and he’s satisfied with omaveloxolone. We expect it to be approved as soon as possible.
Elly E. I want this medicine because I want to stay stable. I can walk a little. So I want it because I am afraid to not be able to walk again.
Hilal E. I would like to test the medicine.
Jan Fiete E. Yes absolutely! It would be great if this disease could be slowed down and I wouldn’t be tired all the time!
Jaqueline Dutra E. Yes. It is an alternative treatment for a degenerative disease.
Kathryn E. Yes. I did not take part in the trial, but have been observing it via the FARA page. I need something to slow down this dreadful downhill spiral that I am trapped in. The drug looks to be a positive to my future.
Lesley E. I would definitely take it! There are currently no other options.
Maia E. This drug is very important for my future quality of life. Therefore, the approval of the drug is very important to me.
Marie E. Yes this trial showed promising results currently there is no cure and it even showed reversal of symptoms!
Mehmet Nuri E. I want to access and use the medicine.
Michael E. Yes, I would take the drug. There is not a treatment available for FA and the results of the phase 2 trial were promising. Given the rare nature of the disease it is difficult to gain critical mass for clinical trials.
Pınar E. I want to access and use this drug.
Pınar E. Yes I want to use the medicine.
Selma E. I have been suffering from FA for years and want this drug to be approved because I believe it will improve.
Şirin E. A friend of mine has FA and those who use the drug are very satisfied. I want phase 3 of the drug to be completed.
Şirin E. I did not use the drug, but I have friends who use it, and they are halfway to stopping the disease and have had good results.
Suat E. I want to access and use the medicine.
Utku E. If the drug is safe to use.
Andrei F. I would want the option of taking omaveloxolone. Based on the data currently available, omaveloxolone significantly slows down the progression of the disease, which is important for me as an advanced FAer.
Apostolos Panagiotis F. Immediate approval of omaveloxolone is very important for me. Time is precious for me and for all patients with FA.
Cristina F. NO, I LIVE IN SPAIN
Elizabeth F. My family member wants the option of taking the medicine.
Els F. Yes, stop the disease.
Emily F. Yes, this is the first treatment shown to have proven results.
Filippo F. Yes I want the opportunity taking the drug because I believe that there’s a rational for its efficacy in FA.
<table>
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<tr>
<th>Name</th>
<th>Comment</th>
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<tbody>
<tr>
<td>Geoffrey F.</td>
<td>Yes, whatever could help to decelerate or stop the evolution of the disease had to be tried</td>
</tr>
<tr>
<td>Lakis F.</td>
<td>We are a family of six where my brother and I have fa. Of course I would like this drug since there is no other treatment. I did not participate in any clinical trials.</td>
</tr>
<tr>
<td>Luke F.</td>
<td>Yes I’m currently on a placebo drug trial in Perth, Western Australia</td>
</tr>
<tr>
<td>Maria Victoria Félix Teixeira F.</td>
<td>I was unable to buy the medicine, but I would really like this opportunity to try to improve!</td>
</tr>
<tr>
<td>Niklas F.</td>
<td>I am living with FA. I would take the drug/medicine if it’s available here in Germany, because when it makes daily life actions better, living will be more valueable.</td>
</tr>
<tr>
<td>Nikolas F.</td>
<td>yes of course and I would!!! no I did not participate!</td>
</tr>
<tr>
<td>Paolo F.</td>
<td>Yes. I need something to help me</td>
</tr>
<tr>
<td>Saadet F.</td>
<td>I don’t know any information about the medicine.</td>
</tr>
<tr>
<td>Shahbaz F.</td>
<td>Yes based on the results of trial and the improvements that people have noticed, I would be happy to take it</td>
</tr>
<tr>
<td>Susana F.</td>
<td>My family member need the option to take the drugs.</td>
</tr>
<tr>
<td>Tony F.</td>
<td>Yes I would like the option as I’ve was really excited about the potential of omaveloxolone and the results which were published which then led to saddle and confusion as to why a drug proves to not only slow the disease but improve it was not approved.</td>
</tr>
<tr>
<td>Virginia F.</td>
<td>I would like to walk well</td>
</tr>
<tr>
<td>Wesley F.</td>
<td>Yes. I hope that I have better conditions to live.</td>
</tr>
<tr>
<td>Alain G.</td>
<td>Yes, I would like to be part of the trials because I believe risks are very low.</td>
</tr>
<tr>
<td>Amy G.</td>
<td>Yes I definitely want the option to slow the progression of my FA with the medication.</td>
</tr>
<tr>
<td>Anita G.</td>
<td>To take part in taking the Omavaloxolone drug would enhance the quality of my life, I wouldn't just exist, I’d take an active vibrant role in society.</td>
</tr>
<tr>
<td>Aoife G.</td>
<td>Yes. I would want the option to take omaveloxolone because not only would it hopefully improve the progression of the ataxia, it would also give me hope for a normal future. I would be very happy to take omaveloxolone.</td>
</tr>
<tr>
<td>Caterina G.</td>
<td>I have atassia from 8 years</td>
</tr>
<tr>
<td>Cheyenne G.</td>
<td>I would like to have the opportunity to try this drug. I have never had a clinical trial</td>
</tr>
<tr>
<td>Eliza G.</td>
<td>had a brother, sister with fa, iv had it 44 years think im too old now but for the younger ones</td>
</tr>
<tr>
<td>Elliott G.</td>
<td>Yes I need this treatment as do all 22,000 people world wide living with this debilitating condition.</td>
</tr>
<tr>
<td>Esteban G.</td>
<td>OK ... I’ll take everything what could help to stop the progression of the disease!</td>
</tr>
<tr>
<td>Frankie G.</td>
<td>Yes I would take omaveloxolone as a treatment for my Friedreichs Ataxia.</td>
</tr>
<tr>
<td>Ginger G.</td>
<td>My sister has never received any treatmnt and would like to access one.</td>
</tr>
<tr>
<td>Giovanna G.</td>
<td>Yes, based on the results of the studies, the medicine appears to be effective and promising.</td>
</tr>
<tr>
<td>Guillaume G.</td>
<td>yes I want to take the medicine as soon as possible and / or participate in a clinical trial</td>
</tr>
<tr>
<td>Jasper G.</td>
<td>I would love to take the medicine, this would be a chance for me to travel a lot further I really need the medicine otherwise my FA will get so bad I have to be in a wheelchair. I’m hoping everyday that this drug will come available for the public.</td>
</tr>
<tr>
<td>Joaquim G.</td>
<td>Live and have a better life with Freidereich’s Ataxia</td>
</tr>
<tr>
<td>Juliana G.</td>
<td>i would love to take this medicine</td>
</tr>
<tr>
<td>Katia G.</td>
<td>Yes I am willing to try any treatment approved by the FDA.</td>
</tr>
<tr>
<td>Leila Cristiane G.</td>
<td>My brother and I have AF. I would love to participate in any test. I am available to participate.</td>
</tr>
<tr>
<td>Name</td>
<td>Comments</td>
</tr>
<tr>
<td>---------------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Leonora G.</td>
<td>Yes, I would be willing to take the medicine. I have been living with FA symptoms for a very long time and I have also taken several other drugs that were not efficient to combat the disease. Therefore, of course, I would love to leave my wheelchair aside and get better. The omaveloxolone is my ultimate hope.</td>
</tr>
<tr>
<td>Leslie G.</td>
<td>For I have a bettle live</td>
</tr>
<tr>
<td>Liliana G.</td>
<td>I did not use it</td>
</tr>
<tr>
<td>Lukyn G.</td>
<td>Yes. I have FA and currently it is the only option.</td>
</tr>
<tr>
<td>Manuel G.</td>
<td>Yes, I would like to help people and I get better</td>
</tr>
<tr>
<td>Monique G.</td>
<td>Yes I would like to take. I have never taken this medication. I have cardiac problem. I am diabetic and in a wheelchair. I never love to live.</td>
</tr>
<tr>
<td>Musa G.</td>
<td>I am a FA patient, I did not have the opportunity to try and use the drug, but we hear positive things from those who use it. and we hope it will be approved as soon as possible.</td>
</tr>
<tr>
<td>Mustafa G.</td>
<td>I am a FA patient, but I did not have the chance to try the omaveloxolone drug. I heard from a friend. We want it to be approved as soon as possible.</td>
</tr>
<tr>
<td>Nicolas G.</td>
<td>Although I already have sequelae, it seems that the evidence of the efficacy of the drug is high and I would like to take it to prevent the disease from worsening my symptoms. And that’s good too if it can improve them.</td>
</tr>
<tr>
<td>Romain G.</td>
<td>OF COURSE!! to find a treatment and for science</td>
</tr>
<tr>
<td>Rui G.</td>
<td>Yes, there’s what, one approved drug I can take here in Portugal (Amizal)? Been taking it for years, don’t feel like it does much, even though it costs a lot, any other options would be more than great.</td>
</tr>
<tr>
<td>Sabine G.</td>
<td>Want to help</td>
</tr>
<tr>
<td>Scarlette G.</td>
<td>Nowadays we don’t have any treatment. This drug effectively stops the course of the disease. There are publications that support it. Please ask FDA to help us making the criteria more flexible so all FA patients can access this drug</td>
</tr>
<tr>
<td>Simone Aparecida G.</td>
<td>yes, because it is comproved the efficiency of the medicine; my life could be much better with this medicine.</td>
</tr>
<tr>
<td>Simoneaparecida G.</td>
<td>I souls take the frugal if I hás the opportunity because the volunteers had improved their lives.</td>
</tr>
<tr>
<td>Thomas G.</td>
<td>Yes, the data shows the drug is safe, well tolerated and drug efficacy is significant in terms of quality of living</td>
</tr>
<tr>
<td>Tracy G.</td>
<td>As this is a progressive disease I would like to be given the choice to try omaveloxolone. I have very late onset FA and have already I have lost my independence. I can no longer walk unassisted and am unable to work. I have been self employed most of my working life, my business had to close last June due to FA. I have watched my cousin, who has now passed away due to FA, deteriorate so I know first hand on how this disease progresses. I would like the opportunity to stop this disease or reduce symptoms before my quality of life reduces further.</td>
</tr>
<tr>
<td>Trim G.</td>
<td>Yes, I would be very happy and thankful is Moxie is finally on market</td>
</tr>
<tr>
<td>Windy G.</td>
<td>No and i dont want to take part in the study</td>
</tr>
<tr>
<td>Yara G.</td>
<td>No, but I have to because my family wants me to take it. My sister says I have to write: „Yes, because it could help me.”</td>
</tr>
<tr>
<td>Name</td>
<td>Comment</td>
</tr>
<tr>
<td>-----------------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Zak G.</td>
<td>Yes, because my symptoms are worsening and it is preventing me from living my life to the fullest. Giving this medication a chance is better than nothing.</td>
</tr>
<tr>
<td>Zoë G.</td>
<td>Yes I would take Omav because I want my FA to slow down</td>
</tr>
<tr>
<td>Alexander H.</td>
<td>Yes, i want take Omav</td>
</tr>
<tr>
<td>Angela H.</td>
<td>I want take the drug because I am living with fa 12 years and I fell bad. I need a drug.</td>
</tr>
<tr>
<td>Antonio H.</td>
<td>I would like to take the medicine and unfortunately I did not participate in the experience.</td>
</tr>
<tr>
<td>Brianne H.</td>
<td>Yes, I would take the drug/medicine. If it helped my progression in any way, I’ll take it no hesitation. I’m tired of watching my body no longer be able to do what I know I’m capable of doing. I don’t want to get any worse.</td>
</tr>
<tr>
<td>Carol H.</td>
<td>I would like to receive this drug if proven to be effective at slowing down this illness</td>
</tr>
<tr>
<td>Carter H.</td>
<td>Yes, I haven’t participated</td>
</tr>
<tr>
<td>Emilie H.</td>
<td>Yes, it is very scary to know that there is nothing we can do about this disease. The time is a big issue in this debilitating disease and in one year from now I might not be able to do the things I do today. It is very hard on my mental health and very depressing too. I think everyone in the FA community is sharing a feeling of being left aside.</td>
</tr>
<tr>
<td>Georg H.</td>
<td>I want to have the option of getting a promising treatment. I did not take part in the moxie study and require more information on its effects (positive and negative) before I consider taking it.</td>
</tr>
<tr>
<td>Julie H.</td>
<td>I need it to keep me alive</td>
</tr>
<tr>
<td>Leo H.</td>
<td>Yes, as any chance of helping my case and the cases of thousands of others worldwide must be taken. The severity of this disease cannot be misjudged and the effects it has had on myself, my family and undoubtedly the families of thousands of others have been widespread. I would like to be able to take back some control over my own life and fight this disease.</td>
</tr>
<tr>
<td>Lynnette H.</td>
<td>Yes. At this stage, I have nothing to lose and may gain a few useful years with my family.</td>
</tr>
<tr>
<td>Madhavi H.</td>
<td>I was not part of trial. But I would like to be a part of trial</td>
</tr>
<tr>
<td>Maisie H.</td>
<td>Yes I want to take omaveloxolone no matter what</td>
</tr>
<tr>
<td>Maria H.</td>
<td>I want the option of taking the drug because currently we have no option and no drugs for our disease! Any possible tiny improvement is huge for patients.</td>
</tr>
<tr>
<td>Max H.</td>
<td>stay strong</td>
</tr>
<tr>
<td>Melek Ayyüce H.</td>
<td>I want it</td>
</tr>
<tr>
<td>Meryem H.</td>
<td>I know a person who used that drug told that this medicine had good effects on her. And so I also want to use and try that medicine. And I hope to see this medicine’s effects on FA will be improved as soon as possible.</td>
</tr>
<tr>
<td>Miguel Angel H.</td>
<td>Yes, to improve my quality of life since the disease I have is getting worse and it is difficult for me to do my daily activities and as a patient I would like you to approve it please.</td>
</tr>
<tr>
<td>Nicholas H.</td>
<td>Yes. I have seen the data along with the dramatic improvement among the individuals that were part of the clinical trials. The evidence is there. This community knows this and denying this drug at this stage would just be cruel.</td>
</tr>
<tr>
<td>Norman H.</td>
<td>I would like the option to take omaveloxolone. As my condition is starting to impact more and more on my abilities. I would like the opportunity to slow/stop the progress of the illness. I am a young man and want to lead as normal a life as possible. I wish to be independent and to have a long happy life. From the research I have read on the medication I am convinced that it can help to improve my life and my future.</td>
</tr>
<tr>
<td>Ph H.</td>
<td>Yes id love to have the option of taking this medicine. I am 33 yrs old, confined to wheelchair now. I face cardiovascular issues every now and then. Id love to have access to a drug that would help ameliorate my symptoms especially if it helps me walk again and improves my speech.</td>
</tr>
<tr>
<td>Rhane H.</td>
<td>Yes I would take this medication. My thoughts are that if the drug is deemed safe for human consumption, why not. You may as well take with the possibility that it can help then not try at all, that’s the only way we can find treatments and or cures.</td>
</tr>
<tr>
<td>Rui H.</td>
<td>It’s my wife o have freidreich ataxia and she is more than happy to take that new medication. No questions asked</td>
</tr>
</tbody>
</table>
COMMENTS FROM FA COMMUNITY
Individuals Living with FA Outside of the US

<table>
<thead>
<tr>
<th>Name</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Shona H.</td>
<td>I would like to slow the progression of the disease so I can maintain some quality of life</td>
</tr>
<tr>
<td>Tony H.</td>
<td>yes I would like to have information to then test the drug</td>
</tr>
<tr>
<td>Ana I.</td>
<td>I absolutely would because I freaking need it</td>
</tr>
<tr>
<td>Jenna I.</td>
<td>YES! Anything to help increase the symptoms of FA!</td>
</tr>
<tr>
<td>Kerem I.</td>
<td>Please help me to take this medicine</td>
</tr>
<tr>
<td>Özge I.</td>
<td>Yes I would like the option to take medicine</td>
</tr>
<tr>
<td>Acina J.</td>
<td>Why would I like to have the option of taking the medicine? -Because based on the available information, I believe that omaveloxolone is safe and effective for the treatment of Ataxia, which will result in the improvement of my motor coordination (a symptom of Ataxia). In addition, the treatment will minimize daily criticism and the consequences of bullying, increasing my self-confidence and providing me with “</td>
</tr>
<tr>
<td>Adam J.</td>
<td>Yes, I have ataxia and am prepared to take any treatment that is deemed safe.</td>
</tr>
<tr>
<td>Aleksandra J.</td>
<td>Yes. For the last 20 years I’ve been waiting for any drug that would treat FA, watching as my health steadily deteriorated. Omaveloxolone is the first drug giving me hope to stop this horrible disease. Listening to people who participated in omaveloxolone trials I have no doubt about it’s efficacy and the possible side effects are insignificant in comparison to the devastating effects of FA.</td>
</tr>
<tr>
<td>Angela J.</td>
<td>Yes. It will give me back a bit of independence</td>
</tr>
<tr>
<td>Anna J.</td>
<td>I would like to have the option of taking this medicine. I would like to be able to stand up more often.</td>
</tr>
<tr>
<td>Bossuroy J.</td>
<td>I was diagnosed at the age of 12. When I was 25 years, I was already using a walker then at 31 I was already in a wheelchair. The disease has been progressing since more than 20 years and still no cure. I cannot have any project to realize, no dreams. I can literally say that FA has destroyed my life, because of FA I have no professional nor personal life</td>
</tr>
<tr>
<td>Caroline J.</td>
<td>I would try any kind of drug that would cure FA</td>
</tr>
<tr>
<td>Endrit J.</td>
<td>We are waiting and you are ready to take the medicine, we beg you to have some mercy towards us with the FA, we are tired of life, we also need to live better, think of your children or you to be in our country. Regards</td>
</tr>
<tr>
<td>Harsh J.</td>
<td>not available here</td>
</tr>
<tr>
<td>Kalleb J.</td>
<td>I am interested in the drug but I did not participate in the study</td>
</tr>
<tr>
<td>Nikolas J.</td>
<td>Yes I would, from the test and study they have done show that the drug helps. I don’t know what the possible negative are but I reckon the positive of omaveloxolone greatly out weight the negative. Also I know that some people won’t survive another 2 or 3 year so they might of well have the drug</td>
</tr>
<tr>
<td>Renaud J.</td>
<td>We need this treatment</td>
</tr>
<tr>
<td>Rose J.</td>
<td>Yes. I am 15, and I was diagnosed with FA when I was 13. Compared to many people with this disease, I have had to live with the disease for a relatively short amount of time, yet I’ve had symptoms 4-5 years. But I’m now fully aware of the ramifications so to a degree I’m affected by the knowledge, too, of the ramifications. The results of this drug trial have made me hopeful. I understand the risk of not conducting the second trial, and making the drug available now. But I am comfortable accepting those risks and believe that other members of the FA community should be able to make that same choice in consultation with their doctor and family.</td>
</tr>
<tr>
<td>Sana J.</td>
<td>Yes I want the option of taking the drug/medicine</td>
</tr>
<tr>
<td>Bara K.</td>
<td>Yes, I hope to take a drug which would be able to help me to find back some abilities. Even if it won’t heal me, I think it’s already a big step!</td>
</tr>
<tr>
<td>Beyza K.</td>
<td>Fa patient is the only one in my family. I have never used the drug, but my friend is using it, he is very satisfied. We are waiting for approval as soon as possible</td>
</tr>
<tr>
<td>Brona K.</td>
<td>I would like the option if there is chance it will stop progression before I get any worse. Also based on the results so far there is a good chance.</td>
</tr>
<tr>
<td>Christoffer K.</td>
<td>Yes, preserve status and slowing down of further degradation</td>
</tr>
<tr>
<td>Ciaran K.</td>
<td>Yes as I want to be able to walk better again and be able to play like a child and run around.</td>
</tr>
</tbody>
</table>
COMMENTS FROM FA COMMUNITY
Individuals Living with FA Outside of the US

<table>
<thead>
<tr>
<th>Name</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Emily K.</td>
<td>Yes, so i can live a good life</td>
</tr>
<tr>
<td>Esma K.</td>
<td>O am a fa patient but It did not haber chance tou try the omavexolene drug i heard froma friend.We want it today ve approweed.As soon as possible</td>
</tr>
<tr>
<td>Esra K.</td>
<td>I am excited for asking for approval to use this drug</td>
</tr>
<tr>
<td>Fatbardha K.</td>
<td>I have not used drugs specifically for FA because I have read that there is no concrete medicine for this diagnosis, but I did stem cells therapy twice but no results. I really hope that soon will be a cure for FA.</td>
</tr>
<tr>
<td>Goran K.</td>
<td>I would like to take the drug/medicine because I am ready to try anything that can help me even a little bit. I want to fight this desease with any weapon I can get.</td>
</tr>
<tr>
<td>Gueffai K.</td>
<td>If the medicament was not expensive and it would be currently available on safety and efficency of course I will use it</td>
</tr>
<tr>
<td>Halit K.</td>
<td>I have been sick for 25 years. I want this drug to be approved in order to try it.</td>
</tr>
<tr>
<td>Han K.</td>
<td>Yes my sister is now living With alot of pain. It Would vw perfect to try something that make the live positief</td>
</tr>
<tr>
<td>Hasret K.</td>
<td>Now I want to heal and want this drug approved</td>
</tr>
<tr>
<td>Helen K.</td>
<td>Yes I would like to take it. Even though I have pad symptoms for more than 15 years I would benefit from the drug. Since my diagnosis at 13 I have been really passionate about exercise because I want to keep my body going so when a drug comes I have the chance. I have a lot of disability but I still have managed to create a life for myself and a drug would enhance that</td>
</tr>
<tr>
<td>Hussam K.</td>
<td>I did not share .. the best drug experience .</td>
</tr>
<tr>
<td>Jean-Patric K.</td>
<td>I have followed the trials on behalf of Omaveloxolone since quite some time. The results seem interesting enough to give the medication a try. Dearly hope that it gets approved very soon from the FDA! Good hopes keep on living...</td>
</tr>
<tr>
<td>John K.</td>
<td>Yes even though I am independent I would like to keep my independence as much as I can for as long as I can.</td>
</tr>
<tr>
<td>Lisa K.</td>
<td>I want to take medicine</td>
</tr>
<tr>
<td>Marin K.</td>
<td>I would like to use it. I have read the research on it and I have hope.</td>
</tr>
<tr>
<td>Mary K.</td>
<td>yes course i would love to recieve the drug to help with fa</td>
</tr>
<tr>
<td>Mihribbon K.</td>
<td>I want to access and use the medicine.</td>
</tr>
<tr>
<td>Nevzat K.</td>
<td>I have been suffering from FA for years and now want to recover and want this drug approved</td>
</tr>
<tr>
<td>Nicole K.</td>
<td>I didn’t take part in it though my answer is yes.</td>
</tr>
<tr>
<td>Nienke K.</td>
<td>I hardly don’t know anything about this drug, but If it does any good; i’ll take it</td>
</tr>
<tr>
<td>Pia K.</td>
<td>Yes, i would take the drug, because the more options the better!</td>
</tr>
<tr>
<td>Sabine K.</td>
<td>I would like to take the omaveloxolone!</td>
</tr>
<tr>
<td>Thomas K.</td>
<td>FA has fundamentally changed my life. I have never given up hope of being able to determine and organize my own life again.</td>
</tr>
<tr>
<td>Zehra K.</td>
<td>Now I want to heal and want this drug approved</td>
</tr>
</tbody>
</table>
Aurora L.  I wish I could have the option to take the drug/medicine hoping it will slow down the course of the disease and improve the quality of my life. I wish that this was also possible for my brother, also he living with FA for 10 years. I hope that this drug will makes us more autonomous and independent.

Björn L.  Yes anything to be better

Christian L.  I would gave them the medicine, because it will help them and gave them new opportunities to do something new.

Darren L.  Yes I would like the option to use this medicine. It may slow down the progress of FA and give me a better quality of life. I have 4 children and would like to have as much time as I can to have a meaningful life with them.

Emily L.  Yes. If it may help me why wouldn’t I take it? The possible side effects are a lot less than effects caused by disease progression

Fabrice L.  I’ve seen positive effects on friends how participate ton MOXIe part 2, and it could be great to have almost one drug to slow down the evolution of FA.

Fernando L.  Yes. I would like to have the option to take the medicine

Fiona L.  Most people who endure FA would prefer to lose a limb than to live with this progression and all the pain of FA. Based on the lack of side effects and the promising results I would love to take this drug.

Flavia L.  I want to take the medicine. It’s very sad to live with FA and not to be able to perform simple daily activities. The drug may not bring the cure, but it will bring improvements in life quality. The medicine brings strength and hope to people who live with FA.

Fred L.  I am a patient. I would get you a chase? to improve my life

Gunnhild L.  Absolutely. The studies show good safety. The risk of not having any treatment for FA is certain: FA is 100 % unsafe. We are all facing degeneration and dependence. A life in wheelchair and life threatening complications. It is time to starte treating FA now the we have studies with a safe drug profile.

Josué L.  Yes! The medication has benefited low-income patients, yes I want to.

Kiara L.  Yes it could alleviate my fa

Kristina L.  Yes. It would mean everything for me if I had a chance to get better. Better quality of life.

Lucas L.  Yes, he would take the medicine in order to try to slow/stop/help with the FA. He just graduated dentist, and the hand skills are highly required, since we discovered this disease, we follow all studies about it, and we are willing to try any possibilities!

Nebojsa L.  Yes, I want the option of taking the drug to improve my quality of life to get bac my independance .

Paula L.  I want to try ornaveloxome

Pautrieux L.  I want

Prerna L.  I have not participated in the trial but don’t have any problem in taking the drug

Ricardo L.  Absolutely yes, I’m all in.

Robbe L.  No medication yet

Rosa L.  Clearly yes. As a suffer of FA with no available treatments for my condition that is neuro-degenerative I am a strong advocate for being given the choice of taking omaveloxolone. Not only will it provide me hope of a treatment with therapeutic benefit, the trials indicate it is safe and well tolerated. Please do not deny me this opportunity.

Sofía Mercedes L.  Yes, I ooks promising

Troy L.  I would want to take the medication so it improves my daily living, walking, fatigue for every day tasks.

Vasilis L.  I am the patient myself ... For me it is very important that there can be something positive through this medicine.

Adel M.  Yes i want to take the medicine

Ad’M M.  If this drug works for my body, of course I’ll take it. I’ll actually be able to stop watching my body fall apart.
Adriana M.  
I would like to have the option of taking the medicine. I have been following the development of the medicine and its effectiveness, also seeing how many people have already managed to improve with the medicine, and I wish I could have that possibility.

Alena M.  
Yes, I would want the option of taking the drug/medicine as the benefits are far greater than the risks.

Alexandros M.  
Yes i want be part of it

Amandine M.  
I think this medicine can only be good for someone with FA like me

Ana Paula M.  
I did not participate

Andrew M.  
Yes. I hope to reduce the effects on me of FA in my lifetime.

Anne Laure M.  
I would try it!!!

Brad M.  
Yes I would consider the drug after consultation

Caitlin M.  
I would definitely start taking it

Camila M.  
Study

Carol M.  
I have read all the data from the study and would want to take the drug in the hope that it would stop or slow down the progression of my condition. If it were to slow it down at this stage I would be able to continue living my life with a better level of independence with less reliance on other people. In addition, the number of falls I have is increasing and I know the drug has assisted with this element in a number of subjects in the study.

Carolina M.  
Yes, because it seems to me the most advanced and proven, and I want my symptoms to improve

Cristina M.  
Yes, I would take drug/medicine

Dani M.  
I m not sure to take drug immediately but i m interested by research

Dara M.  
Yes, because I can see the benefits and I don’t want to be in this situation

Dylan M.  
Yes I would, and maybe miracles do happen! Tears of joy!

Erika M.  
I need a treatment with omav

Flynn M.  
The medication would mean that I would have to have less assistance in my daily living and that I would be able to see progress in my psysical being instead of always needing to focus on slowing the progression. It would mean a lot for me and the people around me.

Ilva M.  
Getting this medication would save lives! It's no cut but this medication is the first medication made for FA which means it will be available for everyone and it will buy time until a cure comes. Moxie will make our every day life easier! A little help goes a long way.

Imane M.  
Please we need the cure as soon as possible thank you in advance

Jacques M.  
Bref to stop progression of FA great man has been found

Jakob M.  
Yes I would take it. There is no other treatment available and it has been tested very well. It is the biggest hope the community has right now.

Julia M.  
Because it is the first drug tested against the disease, to see if it can at least stop its effects on each of us who suffer from it. I have high hopes for its effectiveness

Kyra M.  
Yes! I really want to start using it!

Lise M.  
I live withFA

Loiane M.  
Yes, i want to take it

Luis M.  
I would take the medicine without any doubt, anything that helps me improve is welcome.

Malte M.  
I want the option of taking the medication

Marina M.  
I would definitely take the drug.

Maritza M.  
I urgently need that drug to help me in my daily life
<table>
<thead>
<tr>
<th>Name</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mary M.</td>
<td>I would be happy to take the drug</td>
</tr>
<tr>
<td>Melanie M.</td>
<td>Yes, I believe it would be extremely helpful</td>
</tr>
<tr>
<td>Paul M.</td>
<td>I really need this medicine to stop the effects of this disease</td>
</tr>
<tr>
<td>Philipp M.</td>
<td>I did not take part in the MOXie study. nevertheless, I am impatiently waiting for omaveloxolone to finally be approved and then of course I will be able to take the drug. I’m waiting longingly for it, after all, the disease is progressing and I’ve been wondering for years why it takes so long to find an effective therapy. I am all the more pleased about this initiative. Thanks!</td>
</tr>
<tr>
<td>Raimunda Reis M.</td>
<td>I would like to have the option of taking the medicine.</td>
</tr>
<tr>
<td>Ricardo M.</td>
<td>Yes, because I want to improve</td>
</tr>
<tr>
<td>Sam M.</td>
<td>Yes, it’s been shown to be safe and effective</td>
</tr>
<tr>
<td>Sophie M.</td>
<td>Having the option is better than having nothing. Having the option means there is hope.</td>
</tr>
<tr>
<td>Thais M.</td>
<td>For me and other people to have some treatment against this devastating disease</td>
</tr>
<tr>
<td>Yessica M.</td>
<td>Nowadays we don’t have any treatment. This drug effectively stops the course of the disease. There are publications that support it. Please ask FDA to help us making the criteria more flexible so all FA patients can access this drug</td>
</tr>
<tr>
<td>Baleur N.</td>
<td>To STOP the evolution</td>
</tr>
<tr>
<td>Crystal N.</td>
<td>MOXie has shown better outcome for those who are still walking/newly diagnosed. I’m in a wheelchair, I don’t see it working for me (PT would take forever, it may stop further progression, but I won’t be “cured”), but it isn’t allowed in Canada until after phase four. Which is completely unfair to FAers here.</td>
</tr>
<tr>
<td>Deniz N.</td>
<td>I WOULD LIKE TO HAVE ACCESS TO THE REMEDY</td>
</tr>
<tr>
<td>Judith N.</td>
<td>Yes, i will try everything</td>
</tr>
<tr>
<td>Katie N.</td>
<td>I have FA. Over the years, this has changed my life completely and taken away my independence. Please give me the chance to take this drug, as it gives me and my sister (who has the same condition) HOPE. Thank you.</td>
</tr>
<tr>
<td>Laura N.</td>
<td>I have been living with FA most of my life. I am now severely disabled and require 24 hour a day care. My younger sister also suffers from the same condition but is currently at a less advanced stage. I strongly wish to be given access to Omaveloxolone. Thank you.</td>
</tr>
<tr>
<td>Nadezhda N.</td>
<td>I would.</td>
</tr>
<tr>
<td>Savvas N.</td>
<td>Yes would take omav, we dont have any other drug available</td>
</tr>
<tr>
<td>Amanda O.</td>
<td>Yes i would really like to try this</td>
</tr>
<tr>
<td>Aysel O.</td>
<td>Omaveloxolone: A friend of mine uses it and says it’s good for him. I want to try it, I want it to be legal in every country</td>
</tr>
<tr>
<td>Geraldine O.</td>
<td>Yes I would like the option</td>
</tr>
<tr>
<td>Guily O.</td>
<td>I need a cure for this desease. Thanks.</td>
</tr>
<tr>
<td>Gustaf O.</td>
<td>Yes. I would very much like to try omaveloxolone. From what I have seen, I think the positive outweighs any possible side effects.</td>
</tr>
</tbody>
</table>
### COMMENTS FROM FA COMMUNITY

**Individuals Living with FA Outside of the US**

<table>
<thead>
<tr>
<th>Name</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Julia O.</td>
<td>Yes, I followed the progress of those who were part of the studies on Moxie through social networks and I could see that after taking the medicine, the symptoms of FA had a noticeable improvement, which is a great advance for the future of the FA community.</td>
</tr>
<tr>
<td>Shanice O.</td>
<td>I will try anything to treat this disease no matter what and I would love to do trials but there's nothing available to me in Ireland.</td>
</tr>
<tr>
<td>Tara O.</td>
<td>Yes, because there is no other treatment to slow symptoms.</td>
</tr>
<tr>
<td>Terence O.</td>
<td>Based on the evidence of the MOXIe clinical trials, combined with results reported by a friend who participated in the phase 3 trial, I hope very much that Omav receives FDA approval for prescription. Once FDA approval is granted, it’s usually both fast and straightforward for approval to be given by TGA and a drug to be made available on prescription in Australia.</td>
</tr>
<tr>
<td>Thilda O.</td>
<td>Yes I would take it, I'm desperate to find something that will improve my health.</td>
</tr>
<tr>
<td>Xavier O.</td>
<td>I have FA, diagnosed at age of 19, no one in the family has it, although my parents are healthy carriers.</td>
</tr>
<tr>
<td>Ainhoa P.</td>
<td>I would love to, cause I've been getting worse and I'm scared of what will happen.</td>
</tr>
<tr>
<td>Aljaž P.</td>
<td>Definitely, because FA makes life hell. I want to cure it regardless of side effects.</td>
</tr>
<tr>
<td>Amy P.</td>
<td>I would like the option to take the drug/medicine and participate in any studies/trials that may help develop treatments for FA.</td>
</tr>
<tr>
<td>Andressa P.</td>
<td>Yes! I want and I need to take it!</td>
</tr>
<tr>
<td>Athina P.</td>
<td>I declare responsibly taking the drug/medicine in accordance with the surveys about the drug. I would like to have the chance for a normal daily life and maybe be able to do everyday activities on my own again.</td>
</tr>
<tr>
<td>Brandon P.</td>
<td>I think the FA community can trust it! Really hoping FDA approves!</td>
</tr>
<tr>
<td>Christine P.</td>
<td>I would dearly love the option of trialing this drug. Having lived with FA for over 20yrs now.</td>
</tr>
<tr>
<td>Claudia P.</td>
<td>Yes I would take the medicine, for improve my life and help to the the study of the medicine, and make the FDA approved the medicine, will be a hope for the people who are sick with this illness.</td>
</tr>
<tr>
<td>Deborah P.</td>
<td>Having lived with FA for 45 years I think that Omav would be my last chance to stop any further progression.</td>
</tr>
<tr>
<td>Eirini P.</td>
<td>Of course I would take the omaveloxolone because as I see and hear it works very good for FA an the results for the clinical trial are very positive, please approve the first treatment for FA as a patient with FA I don't have the luxury of time... Thanks you</td>
</tr>
<tr>
<td>Eirini-Athanasia P.</td>
<td>I want to take the drug but I haven't participated in part 1, 2 or open label extension study.</td>
</tr>
<tr>
<td>Fenna P.</td>
<td>I would definitely take it. I've seen the research and I heard from people on the trials. I am willing to take risks. All I want is just to have something and Omaveloxolone sounds absolutely perfect.</td>
</tr>
<tr>
<td>Giuseppe P.</td>
<td>There is no cure and this seems to me the only choice. Yes, I want to take this medicine. I have not participated in any tests of the medicine.</td>
</tr>
<tr>
<td>Jade P.</td>
<td>Yes I would want to take them when given the chance because I am still at the stage in progression where I can live independently and walk unaided however if I am not given the drug I will deteriorate to the point where my life will have no point.</td>
</tr>
<tr>
<td>Jovana P.</td>
<td>Based on data currently available on safety and efficacy of omaveloxolone, I would like the option of taking it. I hope omaveloxolone would be the right medicine for people with FA like me, and FDA and NDA will continue to explore this medicine. I believe it will be successfully and I will heal and recovery.</td>
</tr>
<tr>
<td>Laura Camila P.</td>
<td>I have FA since I am 17 years old and I am interested in this drug</td>
</tr>
<tr>
<td>Louise P.</td>
<td>Yes I would take omaveloxolone if it were available to me. I was diagnosed with late onset despite my brother having normal onset FA. He is now 41 and very severely impaired. I struggle to walk and have suffered 2 serious breaks from falls in the last 2 years. As a mother of 4 children, any treatment that could slow or improve my symptoms would help me to continue being a mother rather than progressively becoming more of a burden on my family as has been happening for the last 5 years. I would have joined the trial if I had known about it and been able to.</td>
</tr>
<tr>
<td>Lucas P.</td>
<td>Yes because it will make their lives better</td>
</tr>
<tr>
<td>Luizi P.</td>
<td>Yes, I would buy it immediately and use the medicine.</td>
</tr>
</tbody>
</table>
COMMENTS FROM FA COMMUNITY
Individuals Living with FA Outside of the US

Marcus P. I believe the benefits would be significant to someone in my situation.
Maria P. No, I do not know all the scientific data on this drug. But I would like that all patients who want to have it to be able to do so in the best possible way
Miriam P. I am a FA patient and I want to be part of this drug trial
Pedro P. Yes, my family and I can clearly see the benefits of omav, and any opportunity to participate in a clinical trial is most welcome.
Sajmir P. I’m with the FA, I did not get the MOXIle. But I want to get it.
Susana P. Yes, because I need some help and hope. This situation is devastating.
Tess P. I certainly would! As there is currently NO treatment specific for FA, I’d take this medication with hope of even the slightest improvement or slowed progression.
Thanos P. I declare responsibly taking the drug /medicine in accordance with the surveys about the drug. I would like to have the chance for a normal daily life and maybe be able to do everyday activities on my own again.
Vasilios P. I would like the option of taking this medication. The absence of any medications worsens my condition; thus, not taking anything is much worse than taking something - especially, if the medication works and/or is safe to take
Vicente P. As a FAer and PhD student in biochemistry, I believe the results of the studies prove that the possible benefits of MOXIle outweigh the rather small risks and the results of the essays are sufficiently rigorous to consider the drug valuable.
William P. I didn’t get the chance to take the medication, but I am interested in taking it to have a better life condition
Erica Q. Yes I would. I have been living with symptoms for 20+ years and I still do almost everything on my own. I would love a chance to do the same for the next 20.
Montserrat Q. Yes, I would like to participate, this disease makes my life to be difficult, and those we suffer it need a ray of hope.
Adriany R. For me and other people to have some treatment against this devastating disease
Ali R. I was diagnosed at 18 and now 33, I am trying to get a way ever since. It get worst over time and no aspect of my life has gone untouched by this. While I sound a little complaining but it had stayed way too long. I was following Moxie from 2017, and one has no idea how disheartened I was the night I found out it is not going to be approved. It’s in 3rd phase for a reason, please do not take it away from us the chance of LIVING instead of PAIN.
Barry R. Yes. I feel the potential benefits of omaveloxolone greatly outweigh potential adverse effects.
Ben R. Yes. Anything to improve symptoms and improve quality of life. Being more independent would be fantastic!
Benjamin R. I would like to continue taking Omaveloxolone and because of the positive effect this has on my physical condition I believe it should be available to everyone with living with FA. I feel more stable I can move more accurately Generally I just feel better and have noticed no side effects.
Bruna De Conz R. I would love to take it, it would be great to have hope! Thank you for being dedicated to the AF community
Claudia R. Think it is too late for me
Elena R. I would like to try this medecine
Francineide R. Yes, I want the option of taking the medicine.
Giorgia R. Yes I want
Giuseppe R. Help us to live better
Gonzalo R. Sadly i was disselected of a new test drug because i can walk without support
Helena R. If I could choose between being paralyzed from the waste down or fa, I’d choose paralyzed all day every day. Fa is slowly but surely trapping me in a body that can’t talk, can’t write, can’t see, can’t feed itself... Yeah walking again would be cool but it’s the least of my concerns.
Henrique R. Do not partipate the clinicas trial
## Comments from FA Community

**Individuals Living with FA Outside of the US**

<table>
<thead>
<tr>
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</tr>
</thead>
<tbody>
<tr>
<td>Julia R.</td>
<td>The problems encountered so far because of the disease are very hard to heal. That’s why every minute counts. It’s up to us, patients’ community, to decide whether we want to try a drug!</td>
</tr>
<tr>
<td>Karoline R.</td>
<td>I would appreciate to take omaveloxolone to see if it works in my body too</td>
</tr>
<tr>
<td>Katie R.</td>
<td>Yes. Whether it’s a full cure or not, anything to help with having FA would be amazing. Slowing down progression is a massive step forward as it will increase people’s life span too!</td>
</tr>
<tr>
<td>Leonie R.</td>
<td>Yes there is no other way</td>
</tr>
<tr>
<td>Liam R.</td>
<td>As an Fa’er who suffers with a cardiac arrhythmia as well as the worsening heart defect, which is associated with Friedreich’s Ataxia (FA). It is vital for me to have immediate access to the therapy, (Omaveloxolone) which will hopefully do as expected and prevent any long term complications from persisting. This is widely important to me and my Family because we will all be able to take a deep breath and have the peace of mind in knowing that my symptoms may not manifest any further.</td>
</tr>
<tr>
<td>Mª Ángeles R.</td>
<td>I have never participated in a clinical trial but I would like to have the opportunity to try omaveloxolone.</td>
</tr>
<tr>
<td>Marianne R.</td>
<td>Yes i would like to have the option of taking Omav because it could help me in my everyday live even if it would be just a little bit. It would help me!</td>
</tr>
<tr>
<td>Marie R.</td>
<td>I would take the drug. Even the slightest chance of improvement or slowing progression of FA symptoms would be a Godsend.</td>
</tr>
<tr>
<td>Nike R.</td>
<td>I’d take it but would have to discuss it with my doctor about the potential unwanted side effects. But if there is a slight chance for omaveloxolone to cure FA its worth the risk.</td>
</tr>
<tr>
<td>Paulina R.</td>
<td>Yes, because I’ve never tried any medicine that helps me</td>
</tr>
<tr>
<td>Paulo Roberto R.</td>
<td>Yes, I certainly want to participate in this study, to see if I can find a way to improve my life.</td>
</tr>
<tr>
<td>Rita R.</td>
<td>Yes, i want ti take it.</td>
</tr>
<tr>
<td>Ross R.</td>
<td>Yes I would like the option</td>
</tr>
<tr>
<td>Sheila R.</td>
<td>I have never been involved in any trials and would love to try this treatment</td>
</tr>
<tr>
<td>Siria R.</td>
<td>Yes, I want the option of taking the medicine.</td>
</tr>
<tr>
<td>Tessa R.</td>
<td>Yes I’m waiting for it! It makes my life better.</td>
</tr>
<tr>
<td>Thomas R.</td>
<td>I would try it as a study but I have not been involved in trials to date</td>
</tr>
<tr>
<td>Yasin R.</td>
<td>I just want a cure or any treatment to help fight Friedreich’s Ataxia and if Moxie can do that even to help a little bit than I am good with that.</td>
</tr>
<tr>
<td>Aicha S.</td>
<td>yes my bruther</td>
</tr>
<tr>
<td>Ana Clara S.</td>
<td>To have a better quality of life. I did not participate in MOXIe</td>
</tr>
<tr>
<td>Aurélia S.</td>
<td>I need hope and i want to try anything.</td>
</tr>
<tr>
<td>Brittney S.</td>
<td>I would definitely want to take this to help with the symptoms or delay them if possible</td>
</tr>
<tr>
<td>Caitlyn S.</td>
<td>This is the first drug that has got to this stage in trials since my symptoms started 12-13 years ago. My biggest concern is whether it will be permitted by WADA in international para dressage.</td>
</tr>
<tr>
<td>Chris S.</td>
<td>Yes, 100%</td>
</tr>
</tbody>
</table>
**COMMENTS FROM FA COMMUNITY**

*Individuals Living with FA Outside of the US*

<table>
<thead>
<tr>
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</tr>
</thead>
<tbody>
<tr>
<td>Cinzia S.</td>
<td>I want to take the medicine, when available</td>
</tr>
<tr>
<td>Eduardo S.</td>
<td>I wish I could take the medicine, and thus improve my life, being able to do my activities without having to depend on help all the time.</td>
</tr>
<tr>
<td>Enas S.</td>
<td>I haven’t token Moxi before</td>
</tr>
<tr>
<td>Fernando S.</td>
<td>Yes, because it would improve the quality of life of all the people suffering from FA</td>
</tr>
<tr>
<td>Flavien S.</td>
<td>As the existing medicines are totally inefficient (I take Idebenone), I would be ready to try it.</td>
</tr>
<tr>
<td>Flavio S.</td>
<td>I will take</td>
</tr>
<tr>
<td>Francisco Erike S.</td>
<td>For me and other people to have some treatment against this devastating disease</td>
</tr>
<tr>
<td>Fredson S.</td>
<td>YES, I would like to have access to the medicine</td>
</tr>
<tr>
<td>Giorgos S.</td>
<td>I believe that omaveloxolone has positive effect and is a huge hope for the patients</td>
</tr>
<tr>
<td>Giulia S.</td>
<td>Yes, I would want it. It should be my hope to live Better</td>
</tr>
<tr>
<td>Henrique S.</td>
<td>I would really like my friend to have the opportunity to do the tests and take this medicine. I love her. Please</td>
</tr>
<tr>
<td>Hilario S.</td>
<td>I did not participate but I would like to participate and have done something before I die</td>
</tr>
<tr>
<td>Hülya S.</td>
<td>My friend joined the moxie study and is satisfied, I follow the results, I definitely want to use it as soon as possible, it should be approved now.</td>
</tr>
<tr>
<td>Iris S.</td>
<td>I dont understand</td>
</tr>
<tr>
<td>Ismail S.</td>
<td>Yes, I would because I have no other choice.</td>
</tr>
<tr>
<td>Izadora S.</td>
<td>May MOXie be approved to help fighting this terrible disease</td>
</tr>
<tr>
<td>Jory S.</td>
<td>A cure</td>
</tr>
<tr>
<td>Juliana S.</td>
<td>I would participate because i'd rather have an option</td>
</tr>
<tr>
<td>Kathreen S.</td>
<td>I was diagnosed with FA at 15 and have been fighting it every day since (37 years), I have progressed greatly in the past 7 years, when I was having too many falls using a walker and finally gave in to using a wheelchair. If there was a drug to slow the progression my life would be very different as I would not have to feel guilty every single day for how much I now rely on others to get me through my day. I think this drug has great possibilities for all people with FA but especially for people who are newly diagnosed as it would allow them to maintain their independence for alot longer therefore increasing their quality of life. I have been following this drug since its inception (I even applied to be in the trial but I was too old), it had great option for people with FA as there has never been anything else, it had such great trial results and very small possibility of any side effects. At least it would give those newly diagnosed hope. I wish it had been around when I was fifteen. This drug should be available now and not require another trial, that may take another two to three years. Two to three years in the life of someone with FA is major, it could mean the difference between being able to walk and being in a wheelchair. Please make this drug available now! I would take it immediately, I believe the trial proves its safe.</td>
</tr>
<tr>
<td>Katie S.</td>
<td>Of course I’d love the option of taking this medication..I can’t explain how much this would mean to me, I know a treatment will come, I just don’t know when, but we need this now. We deserve the option of having it.</td>
</tr>
<tr>
<td>Larissa S.</td>
<td>Yes, I do</td>
</tr>
<tr>
<td>Lauren S.</td>
<td>I’d love to take this</td>
</tr>
<tr>
<td>Louisa S.</td>
<td>I would honestly it seems like hope for the fa community but I would need it soon before to late</td>
</tr>
<tr>
<td>Lucas S.</td>
<td>We would like to participate and have the opportunity to try this medicine in order to obtain a cure. We know you are still in the realm of possibility, but a possibility of healing rekindles hope</td>
</tr>
<tr>
<td>Luizi S.</td>
<td>Yes.I would love to use the medicine and would definitely buy it.</td>
</tr>
<tr>
<td>Maria Mercedes S.</td>
<td>Of course because there’s nothing else for FA so it’s a hope, every FAer I know is dessesperate for a solution or something that can help with FA</td>
</tr>
</tbody>
</table>
COMMENTS FROM FA COMMUNITY
Individuals Living with FA Outside of the US

Martijn S.  
After getting more detailed information about, and the pros outweigh the cons, I would definitely take the drug. Why is it possible for the Corona vaccine but not for FA? Of course, because there’s less money to earn from that probably... This cannot be a reason to stop the research and the race to find a cure that can help us, FA patients, which suffer everyday more and more, not only in a period of sickness from a (Corona) virus... We suffer until our death, physically, but also mentally... Almost everything in our life is affected by it. I am a 25-year-old recently graduated engineer and currently looking for a first professional challenge. I have been diagnosed with FA at the age of 18, and since then I have noticed a few deteriorations. Although I can still walk on my own a few steps, I am noticing that things like walking without aid, walking in the dark, standing up for a long time and taking stairs are becoming more and more difficult or impossible, while at the age of 18 I had almost no problems with this. My childhood dream has always been to become a firefighter, but because of FA I have had to abandon this for several years now. I have been followed up by the neuromuscular reference centre (NMRC) in UZ Leuven, but after 7 years I haven’t made much progress with that. 99% of everything I know about FA, I have had to look up and learn by myself. This includes everything from origin, mechanism, symptoms, current research, possible therapies, future perspectives... After all this research, I strongly believe a cure must become possible in the near future, both to stop the deterioration (in the first place) but also to heal the disease completely. As an engineer, I strongly believe in the power of science based on the results of research so far that I have read. At this moment, I am looking forward to a challenging job as an engineer. I don’t want to spend whole days at a desk at work just because of the disease, I want to continue to learn, meet people, build a professional network, travel (for work), develop myself to the fullest. FA should have no influence to this! Yet I’m afraid I’m going to miss a lot of opportunities because of the disease, that it will limit me in my job opportunities and job offers, although employers are not allowed to select on this. But if I apply for a job, and they have to choose between me and another candidate, who has exactly the same capabilities in terms of knowledge, experience and motivation, except he or she has no FA, who will they choose, based on what? This is why I am concerned about my future, because I have experienced for a while now that it severely restricts me more and more, personally, professionally and socially.

Megan S.  
Definitely yes. Don’t know too much about this job, I have a young son and I want to be active in his life for as long as possible.

Moira S.  
Yes I would take this drug. I have lived with Fa for 40 years and it is very difficult to look back at what you were once able to do, as well what tomorrow will bring. I have always had HOPE that a drug would be available to stop or slow the degenerative progression. Reata pharmaceuticals have the drug. FDA can now bring HOPE to FA community by approving drug, please.

Nico S.  
Would participate

Okan S.  
hello, my wife frda, we are following the moxie work, i want omav to be approved

Paulo Vinicius S.  
I want to take this drug, I never took any...

Phoebe S.  
I would 100% love the opportunity to take this medicine!!!

Pollyana S.  
I want the option of taking the drug.

Rebecca S.  
Yes, I would like to be on this trial ASAP, even if it only has a small benefit. I would like to do everything within my power to fight the devastating and overwhelming effects of Friedrich’s Ataxia. I am not a US citizen, but as an Australian citizen, it is very helpful bordering on being crucial for Australia doctors to have US FDA approval before they will prescribe the drug.

Tuğçe S.  
There is no medicine for the FA.

Alican Ş.  
I accept the option to take medicine

Camila T.  
Yes, I have suffered from the progression of FA for 13 years. Every day I lose more of my movements, my independence and the ability to live. Having a medicine is the dream of all patients with FA, we demand the chance to try to fight for our lives. I have a 5 year old son and I want to see him grow up and he needs a healthy mother and not an incapable mother. Please, we beg for the opportunity to try

Donna T.  
Yes I would. The chance to be treated would be amazing

Elvis Alexander T.  
Yes I would, as with no treatment options I feel hopeless

Glenn T.  
Yes, I will try anything that has FDA approval.

Guna T.  
Not participated

Iraci T.  
Yes I’d love to
COMMENTS FROM FA COMMUNITY
Individuals Living with FA Outside of the US

Karen T.  Yes I would like to be part of the trial
Oliver T. Yes. 100%, I’m about to take a vaccine for COVID soon that’s been developed in only a small portion of the time that it’s taken Omaveloxolone to get to this stage. I realise that it’s technically, probably like comparing apples and oranges, but I’m ready. Beyond ready. I can’t even begin to explain how much hatred I have for my situation in life right now, and I’m not even the worst off, trust me. I was devastated, disappointed and let down when I read that the original NDA had failed. Would I take it? 100%.
Renan T. Yes, we are hopefully for a drug to care FA
Sandra T. Yes, anything that helps find a cure.
Serkan T. I have not participated. I want the option of taking the drug/medicine.
Shaun T. 100% I would love the option of taking omaveloxolone, people who make the rules for efficacy have no idea just how slow it is for approval, how many 1,000’s of people lives can be improved or progression slowed of this debilitating illness, if it’s safe (which it is) and it improves symptoms or slows progression then make it available NOW!!!! Why the delay?
Zehra U. I have been suffering from FA for years and now want to recover and want this drug to be approved
Chene V. Yes, I’d happily take the medicine to improve my abilities.
Débora V. I would definitely like to take it, I live with ataxia and this medicine gives us a lot of hope to have a different life. It is a major advance for science and we need to trust it.
Dinoia V. yes, I would like to use the drug
Edileuza V. Yes. I wish
Guillermo V. Yes, I would.
Hector V. OF COURSE I WOULD LIKE TO TRY IT. IT IS A TERRIBLE DISEASE AND ANY HELP IS WELCOME
Isabella V. Yes, i would take it!
Leila V. Yes, I want the option.
Miquel V. Yes. I want
Natália Aparecida V. I have FA and I want to take this drug
Richard V. Yes Hope for FA
Vincenzo V. Yes I want to take omaveloxolone. I hope to improve at least a bit my quality of life. Although I am 68, my family still needs me and I want to be there for them
Vivi V. Of course i will take the omaveloxolone, all data are very good, it’s the first treatment for Friedreich’s ataxia
Anastasia W. I have late onset FA. My quality of life is still OK. To even stop progression of symptoms would be wonderful.
Anna W. No, because I don’t think it would do anything for me and don’t want it to prolong my life. And therefore I find it important that medicine is approved, so that other children need not endure life with FA.
Bianca W. Yes. I would like this choice.
<table>
<thead>
<tr>
<th>Name</th>
<th>Comment</th>
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</thead>
<tbody>
<tr>
<td>Cheryl W.</td>
<td>Yes. Anything that would improve my quality of life would be worth a try.</td>
</tr>
<tr>
<td>Florian W.</td>
<td>I want the option of taking the drug/medicine</td>
</tr>
<tr>
<td>Jani W.</td>
<td>I want to try everything so that my situation does not deteriorate further</td>
</tr>
<tr>
<td>Kate W.</td>
<td>Heard great results</td>
</tr>
<tr>
<td>Lily W.</td>
<td>Being a person who suffers from FA, I would most definitely love the option to take this drug/medicine.</td>
</tr>
<tr>
<td>Martina W.</td>
<td>I would take the drug. I did not take part in the study.</td>
</tr>
<tr>
<td>Nandhis W.</td>
<td>Yes, I want it</td>
</tr>
<tr>
<td>Sally W.</td>
<td>I would definitely take it because I feel I have nothing to lose</td>
</tr>
<tr>
<td>Suzanne W.</td>
<td>Yes would like the option</td>
</tr>
<tr>
<td>Theresa W.</td>
<td>I have FA and would take the medication as living with a degenerative condition is very difficult and unbearable at times. Not to mention very taxing on family and friends as well as the welfare system.</td>
</tr>
<tr>
<td>Tim W.</td>
<td>I have been sick for 18 years too. I have never used the drug. I have friends who use it in phase experiments, they said that they are very good and the drug works. I also want to participate in phase trials and get the drug approved as soon as possible.</td>
</tr>
<tr>
<td>Atike Y.</td>
<td>I have been suffering from FA for years and now want to recover and want this drug to be approved</td>
</tr>
<tr>
<td>Ayse Y.</td>
<td>I too am a Fa patient and you can’t understand how difficult and bad it is to live with it. I have never used omevaxolone, but I have a friend who uses it and he is very satisfied. We now want it to be approved as soon as possible.</td>
</tr>
<tr>
<td>Jassim Y.</td>
<td>Yes, I would like to have omav, i did not participate in any trail due to geographical restrictions.</td>
</tr>
<tr>
<td>Kunal Y.</td>
<td>I will take the medicine. I haven’t participated in any clinical trials because there were no clinical trial centres in India.</td>
</tr>
<tr>
<td>Selena Y.</td>
<td>Yes I would take it</td>
</tr>
<tr>
<td>Aleksandra Z.</td>
<td>I am aware that this is not a cure, but everything that could slow down the progression of some symptoms would be extremely important for my life quality now.</td>
</tr>
<tr>
<td>Chrysanthi Z.</td>
<td>Yes I want to take the medicine, because I want to improve my condition of living.</td>
</tr>
<tr>
<td>Κατερίνα M.</td>
<td>I want to live with quality of life whatever this means</td>
</tr>
<tr>
<td>اُملیه</td>
<td>My brother and I want the ataxia treatment</td>
</tr>
</tbody>
</table>

Footnote 1- 200 signers commented- "Yes"  Footnote 2- 10 signers commented- "No" or "Non"
## Comments from FA Community
### Parents & Family Members in the US

<table>
<thead>
<tr>
<th>Name</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aida A.</td>
<td>Yes my brother would want to take it but he was not apart of the trial</td>
</tr>
<tr>
<td>Alejandro A.</td>
<td>Based on the data currently available, I would allow my daughter to take the drug. The drug proved to be safe and has proven some efficiency as well, so it is better than having NOTHING, which is the current situation of FA patients, since there is no other approved treatment for this disease.</td>
</tr>
<tr>
<td>Alexa A.</td>
<td>They want the option</td>
</tr>
<tr>
<td>Alexis A.</td>
<td>Yes my dad is willing to try ANYTHING. We have no options left. I feel like he should have the right to try this under the right to try act.</td>
</tr>
<tr>
<td>Alyssa A.</td>
<td>I think my step father would want the drug as an option. He seems to be out of options and is now losing his sight. He has battled FA for many years now and is 40 years old bound to a wheel chair. I wish he could have his life back.</td>
</tr>
<tr>
<td>Amanda A.</td>
<td>Yes, my relative was one person away from receiving this drug in a study. She would have been two years into it by now, and feels it would have changed her life.</td>
</tr>
<tr>
<td>Amanda A.</td>
<td>Yes. We would like this drug to be approved so that pediatric clinical trials can be administered. Our child has not participated in any clinical research yet as she is only 8 years old.</td>
</tr>
<tr>
<td>Amber A.</td>
<td>Yes, I would like the option of my child taking the drug. I would because currently there is no option. There is no sense of hope. She is 12 and can’t run, barely able to walk any measurable distance without assistance, has T1DM, hypothyroidism, ventricular hypertrophy, profound fatigue, difficulty swallowing at times, loss of bladder control, and I dread finding out what diagnosis the next specialist appointment will add to the list. Please, please, please some sense of hope for my child would mean more to me and her than the world.</td>
</tr>
<tr>
<td>Anna A.</td>
<td>Yes, I have 2 sons with it. They are not yet immobile. But, it’s headed that way. Lord, God I pray for anything that could slow that process.</td>
</tr>
<tr>
<td>Arlene A.</td>
<td>I would like very much to see my granddaughter be able to have a better life. Any progress in her abilities to be able to lead a more active life would be fantastic. She needs the chance. I also believe it would be up to her parents to make the decision and not me.</td>
</tr>
<tr>
<td>Bridget A.</td>
<td>Yes, I would want my daughter to have the option of taking this drug and she wants the option. She has not had a good quality of life since age 15. She cannot walk and has many other health conditions associated with FA. Not only has she suffered for many years we have suffered along with her. She has not even had a chance to enjoy her life and she’s so young. Please allow FA patients the option of taking this drug!</td>
</tr>
<tr>
<td>Carol A.</td>
<td>Yes. I would like my granddaughter to have the option to try it. It has been tested, now is the time to use it. She needs it!</td>
</tr>
<tr>
<td>Christopher A.</td>
<td>Yes she wants the medicine</td>
</tr>
<tr>
<td>Craig A.</td>
<td>We would like to try it.</td>
</tr>
<tr>
<td>Dana A.</td>
<td>Yes. My husband and brother-in-law both have FA. Both have been working out daily to try to retain their independence. If you ever watch someone with this horrible disease, you see it change them as a person. They are both so young and have families. They deserve any chance they can get.</td>
</tr>
<tr>
<td>Darlena A.</td>
<td>My husband has been waiting for a treatment or a cure for over 20 years. While waiting he has maintained his health as much as possible with exercise and diet. He would jump out of his wheelchair at the chance to participate. So please, please, YES, we (he) would love the option to participate.</td>
</tr>
<tr>
<td>David A.</td>
<td>Yes, based upon what we’ve read and heard about the MOXie study, we would encourage our adult son to take the medicine. Our son was diagnosed 14 years ago, and over those years we’ve seen him change from a normal teenager to a completely disabled person, but with a sharp mind and troubled spirit. He needs hope. He needs a reason to keep moving forward. He needs a treatment, so that he can believe a cure is possible, in his lifetime. We don’t want to wait for the perfect treatment, we need to start and gain some positive energy. Our son, like all those with FA need to see that improvement in their quality of life is as important to our Family as it is to the government oversight regulators. Hope is needed now.</td>
</tr>
</tbody>
</table>
COMMENTS FROM FA COMMUNITY
Parents & Family Members in the US

David A.  
I want this medication for my son

David A.  
I’m sure my sister in-law would participate

Doug A.  
Please approve drug

Elizabeth A.  
My daughter is declining rapidly, especially in 2020. I hope that FDA will approve Omalveloxolone immediately based on current data. The government has already approved Friedreich's ataxia as a “compassionate” out disease recognizing that the inflicted have rapidly declining physical abilities and rapidly impending death. Please approve this drug which demonstrates promising results.

Fabiola A.  
Yes we would love to try it. We have been struggling for many years and it is devastating seeing how FA has taken away the ability to do the basic daily activities. My kids did not qualify to participate on this study but for sure they did try.

Gretchen A.  
Yes. This drug will buy my son time, until a cure is found, and in the meantime potentially improve his neurologic symptoms, thus giving him back some of the independence that he has lost in the last couple of years. This is big for him, but HUGE for some of our community’s younger children. The risks of Omav are low. The benefits for my son and others are potentially significant. The choice is easy. As far as I’m concerned, between Part 1 and Part 2, two double blind random trials were performed. The extension study further confirms my beliefs. I am not a parent grasping at straws. If I didn’t truly believe that this drug would help, or if there were potential serious side effects, I would counsel my son to wait. We all need this drug now, so that we can buy time for the “perfect” drug or treatment. The longer we wait for this proven drug (Omav) to go through yet another trial, the more children we will lose to this horrible disorder. Every day, Friedreich’s Ataxia sucks just a little more life out of our kids, cruelly taking away simple abilities one by one. As a parent of a young child, I delighted in my son’s achievements: his first steps, running for the first time, tying his shoelaces for the first time, writing his name for the first time, riding a bike for the first time, getting his first hit in baseball. As a parent of a child with FA, I despaired as I watched these abilities slip away, one by one. I saw him get his last hit in baseball, his last bike ride, his last time writing his name, the last time he could tie his shoelaces, the last time he ran, the last time he walked independently. Added to this are losses to abilities he had at birth, things he didn’t even have to think about: swallowing without worry of choking and getting aspiration pneumonia, having a heart that functioned normally, eating what he wanted without worry of diabetic ketoacidosis. The average lifespan may be 35, but I have had many good friends who have lost children to FA at much younger ages than the “average”. The youngest was my good friend’s 11 year old son. Omav has been in trials since 2015. That accounts for almost half of my friend’s young son’s entire life. Our children do not have spare time to prove Omav’s effectiveness over and over again. They just don’t. Thank you for taking the time to read this.

Gunnar A.  
With 0 treatment options available, there is no hope right now. I have watched my mother essentially deteriorate over the years and know she is on borrowed time. Even if it’s a .01% chance of just maintaining her symptoms so she can see me get married or have children, who is the FDA to deny her that. Let’s give those with FA a chance. Let this drug be available to the FA community.

James A.  
Yes. It seems to be working and making improvements

Janie A.  
Yes, the FA community doesn’t have time to wait as this disease is slowly killing them. They deserve a chance at trying this drug to improve their quality of life.
COMMENTS FROM FA COMMUNITY
Parents & Family Members in the US

<table>
<thead>
<tr>
<th>Name</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Jordan A.</td>
<td>Yes he would take it. The results have show efficacy toward the ability to assist individuals with FA.</td>
</tr>
<tr>
<td>Josefa Quele A.</td>
<td>To have a better quality of life. Did not take MOXIe</td>
</tr>
<tr>
<td>Julie A.</td>
<td>Yes, the person I know with FA would want the option of taking this medicine/drug.</td>
</tr>
<tr>
<td>Katherine A.</td>
<td>Yes - still time to continue working in her field and enjoying her hobbies</td>
</tr>
<tr>
<td>Laura A.</td>
<td>Yes! Unfortunately my daughter was too young to be a part of this clinical trial but it has shown to be safe and effective for people living with FA. I urge you to please consider making Omaveloxolone available to our children and help slow the progression of FA.</td>
</tr>
<tr>
<td>Lee A.</td>
<td>Yes...she's only a child</td>
</tr>
<tr>
<td>Lisa A.</td>
<td>Yes, I would definitely want S. to have the opportunity to take the drug omaveloxolone.</td>
</tr>
<tr>
<td>Maddie A.</td>
<td>Yes. My mother has spoken extensively about this drug and her willingness to take the ONLY drug that is offered to slow the progression of her FA. She is in her 50's and her progression is too extensive to participate in trials and this is one of our only hopes. Please choose to be a support and member of the movement towards the cure of Freidreichs Ataxia, a rare but incredibly impactful disease.</td>
</tr>
<tr>
<td>Michael A.</td>
<td>Yes I want my sister to have the option for medicine</td>
</tr>
<tr>
<td>Michael A.</td>
<td>Yes. FA is relentless and a major piece of the experience is that every day you must change your future to forge a way to best get by with newly lost abilities. If omav can halt or reverse aspects of FA, this grants a major change in mindset. Halting advancing declines in abilities would bring a new hope that is presently not possible.</td>
</tr>
<tr>
<td>Midge A.</td>
<td>Yes if it will save lives</td>
</tr>
<tr>
<td>Osvaldo A.</td>
<td>Yes.....a chance for a better life</td>
</tr>
<tr>
<td>Owie A.</td>
<td>Yes! I want my cousin to extend her years of working her dream job &amp; enjoying the hobbies of her friend and age group and to experience living independently.</td>
</tr>
<tr>
<td>Pam A.</td>
<td>I am the parent of 2 children with FA. The relentless progression of this devastating disease has affected my children physically and my whole family emotionally over the last 19 years. A treatment to slow or stop this endless loss of abilities would make life with FA so much better. I don’t want to wait for another clinical trial for Omaveloxolone while I watch my children’s abilities decline. I would like to see people living with FA have the opportunity to take omav sooner rather than later.</td>
</tr>
<tr>
<td>Richard A.</td>
<td>Yes, It is something my daughter wants and I support her 100%</td>
</tr>
<tr>
<td>Rita A.</td>
<td>Yes, I would take the drug/medicine</td>
</tr>
<tr>
<td>Robert A.</td>
<td>Yes, my wife is an adult and capable of determining risk and her comfortably with that risk</td>
</tr>
<tr>
<td>Rocio A.</td>
<td>Yes, we want the opportunity to see if this medication can help our nephew.</td>
</tr>
</tbody>
</table>
Ruth A.

My son is frankly and humbly desperate for the option to take Omav as a treatment to slow the progression of this relentless disease and to improve the quality of his young life. During the earliest phase of the MOXIe trial, my son was too young to qualify and his window to participate in later trials was closed by the severity of his condition. Although symptomatic at age 3, he was not properly diagnosed with FA until 2010 when he was 10 years old and already reliant on a walker, struggling to coordinate fine motor tasks and coping daily with oppressive fatigue. When I think of the steady decline in his muscle coordination, strength and stamina, I picture a line, sloping down, steep and inverse in its trajectory to that of his friends, siblings and peers, weighted with loss, and abbreviated with the tragic certainty of a shortened life expectancy. Traveling back up that line to signify the two years of improvement in function that Omav clearly demonstrates would mean he could still transfer with only fixed supports instead of needing an aide and a cumbersome lift. It would mean a return to regular versus thickened liquids and a reduced risk of aspiration pneumonia. It would reflect the stamina of years gone by when an afternoon could include therapies, exercise and fun activities to maintain flexibility instead of unwanted naps and increasing doses of antispasmodics to treat painful contractures. Bearing the certainty of loss from FA is a brutal and constant struggle for my son and our family. J. clearly understands and would gratefully assume the risk of treatment with Omav with its robust safety data and clinically meaningful and statistically significant results. We all want the loss to stop, for the slope to lessen and for the entire FA community to have the opportunity to chart a new path.

Sandy A.

Yes. It has been proven to work.

Stephenie A.

S.’s doctor has been telling us nothing but good things about it and anxiously awaiting the release.

Suzanne A.

Yes! The drug is safe and helpful in slowing the progression of fa. My daughter is on the open label extension and we believe the drug is making a difference.

Terri A.

Yes. We have no time to waste!

Todd A.

Our two cousins with FA do want to take the omaveloxolone to help treat their FA.

Tracy A.

Yes, The research that has been done and the information we have received from Doctors encourages us to receive this drug to help our child and many others with FA. The approval of this Drug is very important for the community of FA to help the individuals who are battling this disease.

Troy A.

Yes we would take the Moxie treatment. Why, because I want my daughter to have a chance at a ‘normal’ life. I want her to be able to get out and have friends, have a job that she has gone to college for, find LOVE and have a relationship that could lead to marriage, kids, in other words live out HER DREAMS!! It is like watching an invisible person slowly TORTURE your child and you can do nothing to stop it or HELP!!! PLEASE GIVE ME AN OPTION TO HELP MY DAUGHTER!!!!!

Vanessa A.

Yes. Willing to try it for quality of life.

Vicki A.

My Niece would very much like to try the new drug, omaveloxolone.

Walter A.

I would encourage my nephew to take the drug without hesitation. It would benefit him greatly.

Alice B.

Our daughter, E., was diagnosed at 15. Even though she has completed her education, including her Master’s, she needs help with all daily functions. This would be an answer to our prayers. Thank you, Mom and Dad.

Alice B.

Yes these patients deserve the option to choose whether they want to try a medicine that could potentially help them!

Alicia B.

Yes my child deserves to have a choice in receiving any possible treatment.

Allie B.

Yes he would want the option!!

Allison B.

Please release this drug ASAP

Amy B.

From what I’ve seen it’s promising with incredible results.

Amy B.

Yes. My sister in-law is 50 years old and has lived with the difficult and increasingly debilitating effects of FA for 35 years. She is desperate to begin taking the drugs that will hopefully improve her quality of life.
Anastasia B.
Absolutely, it should be available as soon as possible to all patients. The data provided by part one and part two of the study along with the open label extension shows significant statistical improvement when looking at the activities of daily life and measures on the FARS Scale. This is adequate and sound proof of the efficacy of MOXie.

Andrea B.
Yes, we want the option based on guidance from our physician and progression of the disease on our family member.

Anthony B.
Yes, we would like the option of taking omaveloxolone. J. began symptoms at age 4, was diagnosed at age 6, and now at age 9 he has trouble brushing his teeth, drawing, writing, and color without assistance. J. falls and needs constant observation and assistance. Thank you for your consideration in this.

Arthur B.
Yes, I would want my three children to take MOXie. I believe it has shown promise with little side effects and is safe. My children desperately need the option to take this drug.

Ashley B.
Yes. This medicine is very important for my cousin.

Audrey B.
There is a serious lack of options for medications and being able to have another option would be tremendously helpful. Also if given that this medication has the ability to reverse the affects of FA by two years my cousin might be able to walk again unsisted. so i vote yes.

Barbara B.
Yes. We have been waiting since she was diagnosed at age 13 for something to be available to possibly help her. This is the first time we have heard of this possible treatment. Thank you.
### Comments from FA Community

**Parents & Family Members in the US**

<table>
<thead>
<tr>
<th>Name</th>
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<tbody>
<tr>
<td>Baylee B.</td>
<td>Yes, they would take the medicine because we believe that any kind of way to keep her around longer and make it able for her to have children and watch them grow up is worth it!</td>
</tr>
<tr>
<td>Beth B.</td>
<td>Yes I have been told it would be important to have this option.</td>
</tr>
<tr>
<td>Bob B.</td>
<td>If she feels this will help her I am 100% in support of her.</td>
</tr>
<tr>
<td>Brenda B.</td>
<td>If this drug is safe and shows improvement, why on earth would it not be approved. The chance to improve the quality of life, without a doubt both of my children would absolutely take this.</td>
</tr>
<tr>
<td>Brenda B.</td>
<td>What I have seen is promising to the &quot;find a cure for FA&quot;</td>
</tr>
<tr>
<td>Brenten B.</td>
<td>I want to help my friends mom out</td>
</tr>
<tr>
<td>Brian B.</td>
<td>Yes my family member would like to try an available treatment option</td>
</tr>
<tr>
<td>Brianna B.</td>
<td>My sister has FA and I would like to sign this form for her and want any kind of treatment for her. She’s 35 years old and has been living with FA for at least 20 years.</td>
</tr>
<tr>
<td>Brittany B.</td>
<td>Yes. Anything that could potentially help has to be made available!</td>
</tr>
<tr>
<td>Bronwyn B.</td>
<td>Yes, anytime we can increase the quality of a persons life we must do all we can to give them that chance</td>
</tr>
<tr>
<td>Caroline B.</td>
<td>My cousin has been suffering with FA for many years now. We have seen a noticeable decline from year to year. He has extreme fatigue, loss of balance- so much so that he either needs to hold onto someone or use a cane, he has difficulty doing simple tasks such as tying his shoes and buttoning his own shirts and his speech has slowed. He needs this medication to help prevent further decline. We’d be even happier if somehow this medication would reverse some of the damage.</td>
</tr>
<tr>
<td>Cecelia B.</td>
<td>Yes we do not want A. loosing more of her physical abilities. She is a precious soul and we support help for her and others.</td>
</tr>
<tr>
<td>Celia B.</td>
<td>Not immediate family member</td>
</tr>
<tr>
<td>Charmaine B.</td>
<td>My grandson has FA my daughter in law asked me to sign this. I trust her judgement as to weather my grandson would or should take this.</td>
</tr>
<tr>
<td>Cheryl B.</td>
<td>My nephew’s health is declining rapid! He deserves the right to try this drug to slow or reverse the progression of this hideous malady. He has very few if any options, the “right to try” law should allow him access to this drug.</td>
</tr>
<tr>
<td>Chris B.</td>
<td>Yes, my brother-in-law and sister-in-law desperately need omav as every day they lose more and more of their lives. Omav is the first treatment that shows promise of delaying the terrible loss incurred by C. and K. every day and there are no negative effects. It is essential that REATA make application to the FDA and that the FDA approve omav as soon as possible. Let those who suffer from FA, including K. and C., and their doctors decide whether to use omav.</td>
</tr>
<tr>
<td>Christopher B.</td>
<td>Yes. I believe my cousin should have the right to choose as to weather he should be able to the medication. If from what I heard is true that it gives them 2 years then he might be able to walk again unassisted.</td>
</tr>
<tr>
<td>Christopher B.</td>
<td>This is a potentially life saving drug for my family member. To approve this and save lives only makes complete sense. I would like to not look at my family member and know her days are limited.</td>
</tr>
<tr>
<td>Colleen B.</td>
<td>My son would like to take the drug/medicine to help with some of the issues associated with FA</td>
</tr>
<tr>
<td>Deb B.</td>
<td>Family member is an adult, aware of risk/benefit and wants to be able to take omaveloxolone</td>
</tr>
<tr>
<td>Debbie B.</td>
<td>Yes, I would be willing to take this drug. our son C. died in 2004 from FA and our youngest still lives with FA - we need another warp speed to help end this suffering!!</td>
</tr>
<tr>
<td>Diane B.</td>
<td>Yes. The trials have shown that it can slow progression and we currently have no other treatments available.</td>
</tr>
<tr>
<td>Dina B.</td>
<td>A life depends on it.</td>
</tr>
<tr>
<td>Donna B.</td>
<td>It’s my cousin’s sons.</td>
</tr>
</tbody>
</table>
Dorothy B. My husband and I are FA parents. Our daughter was diagnosed as a teenager, 30 years ago. In those years, the relentless progression of FA has meant that she has had to give up her career, her home, relationships, and independence. She now lives with us and everything in our lives revolves around FA. We devote hours a day to speech therapy, physical therapy, exercise and diet monitoring in an effort to mitigate the effects of FA as much as we can--all in hopes of a treatment for FA. Nevertheless, FA continues its relentless attack. Just stopping the progression would be huge. Reversing even two years of progression would be a miracle. It is our greatest hope that Omav can be approved and made available. It appears that there are minimal risks with this drug. And the rewards, though they may appear small to someone without FA, would mean the world to our family. The thought of two or three more years of trials is so discouraging because, for an FA patient, two years may literally be a lifetime.

Dorothy B. Yes I want my children to take this drug. It seems safe and effective. My children suffered over 30 years progression. This would definitely bring hope into their lives. Please approve this medication. Thank You!!!

Eati B. Yes I want the option of taking this drug. There is an urgent need for this drug to be approved by FDA. A only hope for FA patients.

Elizabeth B. Yes. Yes! It’s the best chance my nephew has. He can’t bathe, ride a bike, go to the bathroom, walk, stand up, sit down or get a glass of water by himself. When he paints with me he only has enough fine motor skills to control a Qtip in his hand. He’s 12. I believe in strong safety measures and science. However, if you look at the outcome living with FA, the prognosis is utterly devastating. 100% fact. Everything is affected, but the mind. It’s a prison sentence. Quality of life is beyond important and life is already short even if you are never touched by FA. Please give a bit of hope now. Any improvement is a miracle. A friend wrote me a note 2 days before he died of an asthma attack: Life is good, life is real, live for the now, the moment is everything. Thank you so much for your consideration.

Ella B. I am the sister of an 11 year old that’s been newly diagnosed with FA. The medicine/drug that would help him would be great. There are so many people suffering with FA. If this drug/medicine was able to help these people I think it should be of use. There are so many things we could do to help these people that are enduring this rare disease. So yes, we would want the option to have it. It’s someone’s choice whether they want to deny it but it shouldn’t be denied to those people that would like to try.

Ellie B. Yes, based on efficacy I would want the option for omaveloxolone available to my family member.

Emmitt B. Yes, M. is 29 and this would make a HUGE difference for her.

Eva B. My granddaughters are ten years old and have FA. In one year I have seen them deteriorate to the point they now need a wheelchair. They need help sooner than later. This disease causes them to deteriorate so fast. Please, please give them a chance and a treatment. I know this isn’t an answer to this question, but a grandparent’s plea for her grandchildren.

Gale B. In question 4, I checked 2-8 years, but his condition has progressed where he needs assistance daily.

Gena B. Yes my family member would definitely take this!
Glen B.  
My son B. is a funny, intelligent, deep thinking young man. He lives independently in a condo he owns, and works as a software engineer and drives his adapted car. He has been in a wheelchair for 8 years. It's been heartbreaking watching his decline in physical abilities, and speech, particularly in the past few years. He has struck his head on a counter edge, requiring a number of sutures, due to an uncontrolled sneeze, and fallen out of his chair injuring his shoulder, both in the past few months, and both due to his declining physical control. Yet he still maintains a positive attitude and his independence. After all of the work we have done these past years, raising well over 120K to support FA research, it would be incredibly frustrating for him, his family and friends, to see Omav NOT become available, knowing that it is safe and effective in pausing progression, and even improves aspects of day to day quality of life. The clock of progressive decline is ticking for B. and many other young adults and children, that deserve to pause their progressive physical deterioration, and improve, even if only a little bit, their quality of life, until the magic bullet comes along to truly cure FA. Please give these children and young adults that opportunity, and approve Omav for use to treat FA.

Gregory B.  
Yes, simply because there is no better option and it wont hurt.

Gwen B.  
Yes, please allow my family member the option to take the medicine.

Haley B.  
Yes. My cousin would love the chance to benefit from this medicine.

Heather B.  
It is a progressive disease and anything that can possibly help save the life of my nephew is worth it. Its heart breaking to watch him deteriorate.

Jacob B.  
Yes, at this point anything that has proven to impact the progression of the disease is worthwhile trying.

James B.  
Yes, I would like as many safe options as possible.

Janet B.  
Because my family wants this option for their child.

Jason B.  
Yes, anything that can be done to improve the life of my wife is warmly accepted and highly anticipated.

Jacob B.  
Yes, Yes, and Yes, my daughter is 11 and potentially unable to receive the drug if approved. However, with the testimonies on the Jan 5th webinar, we are desperate for her and everyone with FA to have access to Omav. This drugs ability to stop progression and give back any amount of what's been lost, for example; muscle control, gate control, less falls, better eye and hand coordination, better sense of living, and most importantly, having confidence knowing this drug will make a difference in every aspect of her life. The sooner this drug is approved the better off FA patients will be. My daughter and all FAer's amaze me everyday with how hard the work and the determination each of them have, not because they want to but because they have to, in order to attempt to keep their functions, keep up with family and friends. Omav has the proven scientific facts of stopping progression and giving multiple function improvements, wether small or significant is still an improvement and I have a very hard time with understanding why the FDA is failing to understand the importance of approving this FIRST affect drug for FA.

Jeff B.  
Yes, we have been together 20 years, She has been waiting for a drug that might help her. She is slowly losing all ability to do anything my herself.

Jennifer B.  
Yes, my family member should have the option of treatment.

Jennifer B.  
Yes. Anything is better than doing nothing.

Jihn B.  
Yes. If it helps she should be able to try it.

Jim B.  
I believe omaveloxolone should be available to all FA patients. This is based on the statistical results of the study and the positive impact it has had on my daughter’s quality of life. Time is of the essence due to the progressive nature of FA. My request to the FDA is that before making their final decision, that they truly imagine that they themselves or a close loved one has FA.

Joanne B.  
Yes, we have followed the research and would be happy to try to stop or slow any part of this disease to give my family a full chance at life.
Jodi B.  Our son has had symptoms for years. We were just diagnosed Feb 14, 2019. I could only wish that we would be able to participate or have available to us Moxie. I would give anything for my son to have any slowness or improvement in this terrible disease. This disease seems to not have the publicity that others diseases have. These individuals deserve the chance to have this available to them for any type or improvement, slowness of progression, or just out right cure of this debilitating disease.

John B.  Life depends on these meds

John B.  Yes, I’d there is any indication that this disease might be cured or slowed, every person suffering deserves a chance.

Joni B.  Yes. My niece wants every option available to be able to live the life of a normal young adult.

Joseph B.  Yes. First interventional med for FA in forever. Time to treat this disease.

Josh B.  I have two nieces living with FA and our entire family has reviewed the results of the study so far and would absolutely want the option to take the drug. Their situation is advancing rapidly and every month that goes by strips the girls of abilities that they once had. We are desperate for any kind of therapies and drugs to slow or stop the progression of FA.

Josh B.  Of course

Judy B.  Yes my sister would be a great candidate

Judy B.  Yes, action is required now to save lives.

Julia B.  Yea. She would be very interested in trying the medication.

Kamdyn B.  I want for people suffering from FA to have to option to have this medication if they wish.

Karim B.  Yes. This medication will stop the progression of the FA and it will help with the balance. There is no other medication available and this medication will help.

Kathleen B.  Family member’s condition is too advanced for treatment to be effective.

Kathleen B.  Yes I would like anyone that is eligible to be able to take omaveloxolone. If there is a medication that would be able to slow down the process of FA and help to extend their independence with little side effects, then yes I would like them to have that opportunity to make that decision to try it and see if they will benefit from it. Thank you

Kathleen B.  Yes. She will be 12 in Feb and at the crux of growth stages where the curvature of her spine is advancing fairly quickly. She tires easily, is holding onto the walls in the hallway more and using a walking stick for outside adventures. She took her first tumble trying to get on the toilet just before Christmas. This was heartbreaking as she needed help up from the floor to complete the task. The progression is happening before our eyes and all the exercise, and over the counter supplements aren’t cutting it. We need Omav before its too late.

Kay B.  I am grandparent. Parent should answer this.

Kenneth B.  yes, I would wish for my child to participate in taking the drug.

Kenny B.  Yes this medicine gives my granddaughter hope that we may one day have a treatment that will slow progression of her disease. It’s too hard to sit back and watch kids slowly lose their ability to walk, stand, and go play with friends. She deserves a chance at something that has shown even the slightest shred of hope that there will one day be a medicine available that manages FA.

Kerry B.  yes this would make a HUGE difference for her life

Kevin B.  Yes, anything to slow the progression is essential to preventing more harm, and even reversing the effects of this disease. The sooner people with FA have access to this drug the longer and healthier their lives will be.

Kevin B.  Yes. Positive results would definitely increase his quality of life.

Kori B.  I don’t know. It is my adult sister who has FA & she would need to make this decision on her own.
Kristin B.  
As the parent of a young adult suffering from the effects of FA it is extremely important for the use of Omaveloxolone to be approved IMMEDIATELY! Our daughter is quickly losing her ability to live and work independently. She needs to begin the use of this as soon as possible in order to slow the progression and maintain her independence long as possible.

Laura B.  
Yes. The decline is very debilitating on the entire family. We absolutely would choose to use the medication for all three of our children who suffer.

Leslie B.  
Absolutely! My daughter is 36 now and has declined to the point that she requires assistance with almost all things. She has 2 children and if this drug could help her at all to keep her with us and to be as independent as possible we are all in!

Linda B.  
Any parent wants a cure, a treatment for a disease that causes such damage to their child's ability to thrive regardless of age. There is hope in this drug that gives back what has been slowly being taken away. When positive results are proven and demonstrated why the FDA needs more proof of being my comprehension. Give it to those in need. Watch the results and continue testing along the way. Build on the known results but to require a second trial that takes years is not helping those with FA today. The Right to Try should be just that.

Linda B.  
Yes, J's value of life is totally dependent upon what others do for him. He can do nothing for himself.

Lloyd B.  
Lost a grandson with FA. Currently have granddaughter with FA. Yes she would want the option.

Logan B.  
Absolutely please

Louis B.  
Yes. I am not aware of any other potential treatment.

Lynda B.  
Please approve this drug to give my family member the best chance of a longer productive life! All the FA people deserve this! The families of our FA people deserve this also!

Lynne B.  
My 29 year old niece was diagnosed at age 8 with FA. Her parents abandoned her and my elderly parents raised her. I was her PCA from the time she was diagnosed until she graduated from high school. She has not qualified for any of the drug trials because she is unable to walk the required distance unassisted. She has lost her eyesight and relies on others for total care. Unfortunately there are some not so trustworthy people out there who have wronged this poor girl. She lives in an apartment with her boyfriend who also has FA. My niece would be very interested in participating in the trial.

Madison B.  
Yes they would take it. Anything to slow the process of this disease!

Marianna B.  
Yes we would.

Marie B.  
I do believe my brother would like having an option. He feels “stuck” right now because there is no other option than to slowly deteriorate. Having the option to take a medication that could help would mean the world.

Marilyn B.  
I do not know enough to respond. I trust my niece and nephew to give me true answers.

Marissa B.  
Yes. There is enough evidence that it can help.
MARK B.
We are desperate for any possible treatment. Our daughter has suffered from the progression of this awful disease for over 22 years.

MARY B.
My three siblings would all take it!

MARY B.
Yes. I would like to have the opportunity for any thing that would help or slow down this disease.

MATTHEW B.
It works.

MEGHAN B.
Yes, progression is fast and she’s young. Would take immediately.

MEGHAN B.
Yes, took forever to find out what my father had, watching the progression throughout the years with FA is very upsetting. I know he would love to get a second chance at doing the things he loves.

MEIGHAN B.
Very much YES! Omav could keep my daughter walking independently. Everyday J. loses an ability she could previously do. No 11 year old girl or anyone with FA should have to miss out on life from becoming more and more disabled and dependent on other when they should be at a point in life of becoming more independent. The FA life span is short please don’t make them wait on a drug that could give them so much happiness. As a parent of a child with FA my heartbreaks everyday for my sweet girl. Please I beg you give her a chance at living a easier, happier life.

MELINDA B.
Yes, he is progressing rapidly. So smart, strongest person i know.

MICHAEL B.
Yes I know my son would definitely want the option of taking OMAV. I have reviewed the results of the clinical trials for this drug and feel it should definitely be made available to the FA patient community. I can see no reason to withhold approval given the positive results and safety demonstrated by the conducted trials.

MISTY B.
Yes. I don’t want my child b in a wheel chair or not have use of her limbs. She wants to b independent and live a full life.

MOMMENED B.
My nephews have this condition and are in dire need of this medicine. I kindly request FDA to approve this, as it is our only hope!! PLEASE!!!

NANCY B.
My cousins daughter is in her late 20’s and has been living with FA most of her life and has been wheelchair bound. She is totally reliant on her parents for her ADL.

NICHOLAS B.
Yes - this is currently the only treatment that has shown to have any real positive impact on those suffering from FA.

NICOLE B.
YES. My son is 6 years old. He is already exhibiting symptoms of FA and is progressing. Anything that can potentially slow down his deterioration to enable more time for a cure is crucial. Omav not only was shown to slow progression in FA’ers but the individuals that participated in the trial and shared their experiences also reported improvement. If there is a way to prolong not only life, but quality of life shouldn’t it be provided? Time is of the essence. I implore Reata and the FDA to approve this medication. My heart breaks every day for every person going through this condition. To see it and live it every day with someone you love and know there is something that could help them but that they wouldn’t have access to it is unfathomable.

PAM B.
It seemed to do her a world of good, not just physically but gave hope and encouragement.

PATRICIA B.
Yes...my niece would be interested.

RACHEL B.
Not immediate family member.

RACHEL B.
Our son would absolutely, without hesitation, choose to take this medicine if made available. Even if it only helped slow progression or provided relief from his endless fatigue. We ask that he be given the chance to decide what is best for him.

RACHEL B.
I want this drug for my sister so much. It is safe and will make her so much happier. She will have energy to hang out with me. Please, please release this drug.

RAFAEL B.
Yes. Yes. It stopped the progress of the symptoms and lessen them significantly.

RANDY B.
We have been waiting for over 20 years for some kind of medicine to help fight this disease...
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<th>Name</th>
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<tr>
<td>Raquel B.</td>
<td>Yes will try anything</td>
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<tr>
<td>Rebecca B.</td>
<td>My nieces want the option to take the medicine in hopes of reversing/ending the effects of FA</td>
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<tr>
<td>Rebecca B.</td>
<td>Yes my cousin D. wants the option of being able to take this</td>
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<tr>
<td>Richard B.</td>
<td>My daughter would want to have the option of trying any safe treatment which might improve her quality of life.</td>
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<td>Ronald B.</td>
<td>I’m asking for the FDA seriously look at this drug and what it can offer, even if it’s only a little. To watch my grandchildren deteriorate to the point that they are unable to walk and are losing their other motor functions is devastating. I hope you can place yourself in our position to watch your grand children lose all ability to walk, talk well, use their arms and hands and face an early death from this horrible disease. If this drug even offers a little help or reversal of symptoms, you must release it for use. Please please please.</td>
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<tr>
<td>Ruth B.</td>
<td>Yes!!! Anything that might help!</td>
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<tr>
<td>Sally B.</td>
<td>Yes we would like an opportunity to provide options for the best probably care to slow progression and improve quality of life</td>
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<tr>
<td>Sam B.</td>
<td>Yes. Promising research.</td>
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<tr>
<td>Samantha B.</td>
<td>Yes. The mother of the child with FA would like access to the drug.</td>
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<td>Sandra B.</td>
<td>Yes, she feels it slows progression.</td>
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<tr>
<td>Sarah B.</td>
<td>Absolutely. This is a terrible disease, I would try anything to slow the progression of FA. This disease is chronic, if anything could possibly extend a higher quality of life, it’s worth it.</td>
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<td>Sarah B.</td>
<td>Growing up my sister was always put in some kind of summer camp. It was not because she was a bad kid, but she would often get bored because she was not mentally challenged enough when not in school. My sister was diagnosed with FA well she was in college, the diagnosis at that stage in her life meant a large evaluation on what she was studying and how she might be able to have a career later on in her progression. Though she does not need an assisted walking device yet. Having the option to taking the drug/medication that has the potential to slow the progression of the disease. Would allow her more time in the work force to build up professional relationships and experiences that will open up more doors for her professionally and personally. As she progresses into the disease and is not as able bodied as she currently is, allowing her to be able to fill a more mentally full-filling life.</td>
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<td>Seth B.</td>
<td>Yes, anything to lead a more normal life. To have mobility and mechanical ability hampered at an age where her independent life is supposed to be beginning is an indescribable nightmare i wish on no one ever.</td>
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<tr>
<td>Shannon B.</td>
<td>Yes. Although our son is young, it will be there for him to slow progression. Thank you for considering the voices of patients, medical teams, parents and friends and family. We need a medicine that has promise to help those suffering with this terrible disease.</td>
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<tr>
<td>Shannon B.</td>
<td>My niece</td>
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<tr>
<td>Shawn B.</td>
<td>We need to help all people from pain and allow a normal life</td>
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<tr>
<td>Shawna B.</td>
<td>We have been dealing with the progression of FA for over 20 years now and my son is to the point of not even being able to do anything on his own. He has gone from walking to being permanently wheelchair bound and needing our help with all of his daily living needs. His only means of joy has been being able to stay in touch with his FA friends on social media and now he is to the point of not even being able to do that......He would do anything to be able to have some of his neurological functions back, even if it is a small amount. We have been waiting on drug development for decades and will try anything to get back even a little function. Please allow our kids to try Omav...</td>
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<tr>
<td>Shelly B.</td>
<td>Yes, we would want L. to have the option to try any drug that would stop any further deterioration.</td>
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<td>Shiree B.</td>
<td>My cousin improved greatly while in the study on the Rx</td>
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<td>Shirley B.</td>
<td>My cousins would prefer a longer life</td>
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<td>Spencer B.</td>
<td>Yes. He was already involved in trials at UCLA.</td>
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<td>Stephen B.</td>
<td>Yes because it could be a life or death situation without the medication.</td>
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<tr>
<td>Sue B.</td>
<td>Our family member would welcome any help combating this horrible illness. He struggles each day just to stay alive. To see a formerly active athlete resort to a wheelchair just to be mobile is hard to watch. He deserves to see his children grow up and to grow old with his beautiful wife.</td>
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<tr>
<td>Susan B.</td>
<td>My son is so newly diagnosed and doesn’t know yet.</td>
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<td>Suzanne B.</td>
<td>We have been waiting for a treatment for 26 years.</td>
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<td>Sydnee B.</td>
<td>Yes, my cousin wants to</td>
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<td>Tammy B.</td>
<td>Yes my sister in law has been battling this disease for over 20 years and she is getting worse and we would try anything at this point.</td>
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<td>Tanya B.</td>
<td>My son, J., age 25, was diagnosed at age 7 with FA. Over the years it has been hard to watch his disorder progress to the point that he is completely dependent on us for everything. Since hearing about omaveloxolone, he has been desperate to hear good news that it had been approved by the FDA. He was crushed (as were we) that it was not. Why? Why would he not want to participate in something finally seeming to have promise of any improvement—even if only a little? Every day is hard. For all of us. He struggles with everything, movement, sitting, his vision, even sleeping. It would absolutely be worth it to take this medicine, to participate in a trial, to have the opportunity to gain some strength and independence after being told for years that there is no treatment for FA and we just try to do the best we can. This medicine shows promise. J. needs this. Friedreich’s Ataxia patients need this.</td>
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<tr>
<td>Thomas B.</td>
<td>Yes Please! My son is doing well compared to many people with FA. He attained a masters degree and works for a professional sports team. However, his challenge is immense. Talking is more difficult, fine motor movements are gone, his daily fatigue is a challenge. We have all adapted to his use of the wheelchair, but losing all the little functions of life is cruel. Delaying progression would be a huge gift. His attitude and enthusiasm for life has been great. I’m just not sure how much longer he can keep his chin up. You all should know how hard FARA has worked to be open and professional with all research we support. It’s time - DO IT!</td>
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<tr>
<td>Thomas B.</td>
<td>Yes! There are no other options for treatment.</td>
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<td>Thomas B.</td>
<td>Yes. Absolutely. Our/her quality of life is changing daily. (losing her physical abilities) The sooner we can try something to hopefully slow down the progression the better. FA is a terrible genetic disorder and hopefully a cure will be available soon.</td>
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<tr>
<td>Thomas B.</td>
<td>Yes. I would want that option.</td>
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<tr>
<td>Tonia B.</td>
<td>Yes!!! We would like our son to keep the abilities and function he has now for as long as he can. If this medication will slow/delay the progression in any measure please let us have it now!!!</td>
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<tr>
<td>Tracey B.</td>
<td>Yes, our son would like to take omaveloxolone.</td>
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<tr>
<td>Tye B.</td>
<td>Yes, my wife was involved in the trial &amp; told me many times she felt better &amp; her body performed physical activities better.</td>
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COMMENTS FROM FA COMMUNITY
Parents & Family Members in the US

Valencia B. Approve Omav and help stop disease progression

Vikas B. My Son didn’t participate in this study but looking at the data from this trial and knowing about the experiences of some of the FA patients that participated in open label, I strongly feel that Omaveloxolone is the only hope for my his condition. Because of C19 lockdown his condition has worsened and it seems one year of lockdown has am impact of at least 3 years.

Vivian B. Yes. The parents are willing to try anything to help their 9 year old ochild.

William B. Both of our children would be willing to take the drug immediately. They are losing abilities daily and delaying this drug would be terrible for our family. Please allow us to help our children.

William B. Currently there are limited options for treatment. This drug has shown promise according to Dr testimony. Keeping all options available seems to be the best choice in my opinion.

William B. Yes, absolutely. After already losing one family member to FA prior to age 30, we would do anything to give any possible chance of quality of life extension to our second family member (already 30 years old now).

Alice C. Because my family and I are convinced that the results demonstrate meaningful benefit and low risk and would like our family member to have access to this medication. We believe that the studies completed to date provide sufficient evidence to support the approval of Omav

Amanda C. My 28 yr old is taking it and it works... Please Make it available

Amy C. My sister in law definitely wants to participate. She is progressing quickly and I feel like it’s her best shot and nothing to lose!

Anastacio C. Yes. I have seen my granddaughters health deteriorating with FA for several years she doesn’t have the time for another trial to take place.

Andy C. Absolutely! Anything that can pause the progression of FA, if not restore some functioning with limited side effects must be an arrow in our quiver. Please allow us the opportunity to try Omaveloxolone.

Angela C. yes - we would like to have the option

Annetta C. This is my cousin’s child. I did not participate.

Anthony C. Yes, my fiance is comfortable with the safety data that currently exists for the drug. We have no approved therapies to deal with symptom management so this medication would greatly improve her quality of life.

Antonietta C. I have two younger cousins who I believe would greatly benefit from taking this drug.

Barbara C. Of course she would. For quality of life.

Barbara C. Yes - anything helps

Bonnie C. Yes because it would improve his quality of life and slow the progression of the disease.

Braxton C. Yes, to find a possible cure

Brenda C. Yes We want the option of getting the drug/medicine.

Britni C. I believe the family member would like the option of taking this medication.

Bryce C. Yes! She deserves to have a chance at a normal life like she wants

Caelen C. Yes, the drug should be an option. With so few treatment options available, we owe it to the FA community to grant them access to anything that has shown this level of effectiveness.

Caroline C. Yes. Anything that might improve his quality of life, slow down the progression of the disease.

Carrie C. Yes, my son has FA. Please give us some hope! Please!!!!

Casey C. It’s my sister in law she is so strong and beautiful her smile lights up the room ....Would love to see her get more mobile again

Cassandra C. My cousin’s son was diagnosed with a severe case of early onset FA and this treatment would be life saving. He would definitely take the drug/medicine if offered.
### Comments from FA Community

**Parents & Family Members in the US**

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<th>Name</th>
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<tbody>
<tr>
<td>Chad C.</td>
<td>Yes, anything that could help my Mom we are absolutely willing to try.</td>
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<tr>
<td>Chanda C.</td>
<td>Yes. My niece would take this drug as soon as it would be released. Her sister was in the trial.</td>
</tr>
<tr>
<td>Chase C.</td>
<td>We would like the option as the right to try outweighs the inevitable fate of those diagnosed.</td>
</tr>
<tr>
<td>Cheryl C.</td>
<td>My daughter, J., is 41 years old. She’s been living with FA since she was 7 years old. We, her family and friends, have watched over the years as J. declines in health and physical abilities. We’ve watched her go from a happy, skipping, running little blond headed girl through scooting on her butt, walkers, scooters and wheelchairs. She no longer is able to assist in ANY activities of daily living and is blind and has bilateral auditory neuropathy, therefore, she can’t enjoy any of the beauty of life that we all take for granted. Not only can she no longer SEE television, she can’t even listen to it due to the hearing difficulties. Our communication is a major cause of frustration as she cannot speak as she once did. She suffers with mild hypertrophic cardiomyopathy, has diabetes type 1 and has very low pulmonary function. So much has been stripped from our beautiful girl by this dreadful disease. The one thing she has left is hope. Hope that the FDA will see that omaveloxolone can improve things for her, if not much, it may keep her from slipping away from us entirely. Please consider that our children and our FA community members do not have the luxury of time. We urge you to get this application made, approved and on the market.</td>
</tr>
<tr>
<td>Chessica C.</td>
<td>It is our last chance for hope!</td>
</tr>
<tr>
<td>Claudia C.</td>
<td>Yes! It’s the only hope we have!</td>
</tr>
<tr>
<td>Clover C.</td>
<td>This is a horrible progressive disease with no cure or treatment. Watching my 12 year old son loose his ability to walk this year shows us that time is the only thing we don’t have. Omav is the only hope we have currently. Please give my son a chance.</td>
</tr>
<tr>
<td>Connie C.</td>
<td>Yes, for better quality of life</td>
</tr>
<tr>
<td>Crystal C.</td>
<td>Yes. I have two cousins with the disease and they both deserve a better quality of life which could be obtained through this new drug.</td>
</tr>
<tr>
<td>Dan C.</td>
<td>Yes, we are desperate and the symptoms are worsening rapidly</td>
</tr>
<tr>
<td>Darrell C.</td>
<td>Yes, I want the option for my grandson to take the drug.</td>
</tr>
<tr>
<td>Deborah C.</td>
<td>Yes... it could save her life</td>
</tr>
<tr>
<td>Dom C.</td>
<td>I’m not sure.</td>
</tr>
<tr>
<td>Doreen C.</td>
<td>If she doesn’t receive the drug, her fine motor skills will deteriorate</td>
</tr>
<tr>
<td>Earl C.</td>
<td>As the father of a 41 year old daughter that has severe FA and having been able to talk and understand my daughter’s speech many years ago when she had the capabilities to do so, both she and I have always dreamed of some type of treatment or even a cure for FA. Now 41 years later, a treatment is at our door and our hopes and dreams, as well as hers, of keeping her alive longer could finally become a reality. My daughter is 100% dependent on my wife and I now, but she prays she can try the new treatment immediately as she has never had an opportunity for this type of hope before and there is no other option in her mind at this time of her life but to give the Omaveloxolone a chance for just one, just one, improvement that would outweigh every risk she has ever experienced.</td>
</tr>
<tr>
<td>Edward C.</td>
<td>Based on the statistics I see and the fact that my son-in-law’s Friedreich Ataxia has progressed significantly in the 6 years I have known him, please approve the Omaveloxolone for use. FA is only progressing and degrading the lives of those living with FA and the drug does appear to slow that progression. Additionally, there are no or mild side effects in using the drug and the alternative is dire. My son-in-law is a MS Biomedical Chemical Engineer and I asked him to look at Omaveloxolone from his professional perspective. Then I asked him from the data, would he take the drug. His answer was absolutely based on the data and his FA condition. He stated that it wasn’t even an issue in his mind, because there is no other alternative at this time.</td>
</tr>
<tr>
<td>Edward C.</td>
<td>Spouse and family members</td>
</tr>
<tr>
<td>Eleanor C.</td>
<td>My nephew is in a Stage 3 study. I would absolutely allow my child to take this drug. It could be the only hope.</td>
</tr>
<tr>
<td>Name</td>
<td>Comment</td>
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<tr>
<td>Elizabeth C.</td>
<td>We are requesting the option to take Omaveloxolone on behalf of our daughter. Since our daughter was four and a half, we have watched her decline, hitting milestones in reverse. Her gait widened, her falls increased, system after system was reported to be impacted as we went on the medical journey of, what is happening to our daughter? We have watched the tearful frustration when she cannot keep up with other children and adamantly says, I hate recess, no one plays with me. She is losing her vision with only 26% of her cones functioning in both eyes and no rods. She has lost peripheral vision, night vision and with fingers that struggle with neuropathy, she is attempting to learn Braille so when full darkness comes, she can still read. She struggles at times to hold a fork and spoon, she cannot walk without stumbling, she cannot ride a bike, she cannot play catch, she cannot navigate stairs without assistance, and we are left to watch, helpless. She is now 8 and her heart condition is that of advanced FA, meaning that she has a 20% chance of dying before she turns 18. While other parents are preparing their children for middle school, high school, musical endeavors or upcoming sports tournaments, we think about preparing her for the solitary confinement to which FA condemns its victims. Omavaloxolone’s top line data has shown statistically significant data that it slows disease progression. It is not a cure but it buys us time. We have read through the research, we understand the data, we understand the risks and we are willing to take them. We would choose to give our daughter this drug if it is made available. She is dying, we try to avoid this fact but it is happening before our eyes as more and more parts of her body begin to fail. Additional trials take time and time is not something we have as FA steals more and more every day. We have NO other options, we have NO other treatments and we can’t afford to wait. We have watched A’s decline over the years, and that decline pick up speed again in the last six months. All we are asking for is access to a drug that could give our daughter a fighting chance. Please consider moving forward with the approval of Omaveloxolone. A is an incredible person. Despite it all, she has tested off the charts as gifted in the area of creative thinking. She has so much to offer the world if she just gets a chance to live.</td>
</tr>
<tr>
<td>Ellen C.</td>
<td>My niece would be very interested in the option to take this medicine.</td>
</tr>
<tr>
<td>Emily C.</td>
<td>Yes - would try anything</td>
</tr>
<tr>
<td>Francesco C.</td>
<td>Yes ,to slow down the progression .</td>
</tr>
<tr>
<td>Giuseppina C.</td>
<td>Yes given the data I would ABSOLUTELY want the option of omaveloxolone for my children A. and L., and soon! This drug has demonstrated slowing the progression of this horrible disease along with significant improvement of symptoms. Our children/young adults lose their abilities regularly while their peers thrive. It is extremely heartbreaking to watch our kids physically deteriorate and emotionally fight to stay positive and hopeful. These kids are amazing for how they live and all they endure. Our children deserve to have omaveloxolone as an option, this is a step to living better. They deserve to live better, do things better and feel better! There is enough data and we’ve heard other FAers share their experiences and ask the FDA to approve this without another lengthy clinical trial. Time is of the essence here to have this drug available for our children, for all FAers; their time is preciously limited. Imagine if it were your child, your sibling, your grandchild or even you; wouldn’t you want the option now?! Thank you</td>
</tr>
<tr>
<td>Gwendolynn C.</td>
<td>Yes, everyone with this horrible condition deserves the chance to feel normal. To wake up and not think about this disease first thing.</td>
</tr>
<tr>
<td>Heather C.</td>
<td>To help feel better</td>
</tr>
<tr>
<td>Hilary C.</td>
<td>Yes they would</td>
</tr>
<tr>
<td>Jan C.</td>
<td>Yes, our children would like to take this medication.</td>
</tr>
<tr>
<td>Janet C.</td>
<td>Yes participated in MOXLe</td>
</tr>
<tr>
<td>Janie C.</td>
<td>Yes, hopefully it will help my great grandson be able to walk.</td>
</tr>
<tr>
<td>Jen C.</td>
<td>My son would want the option of taking the drug. We have waited for years for a treatment that will improve his mobility and functionality and are encouraged by the results from the clinical trial of omaveloxolone in people with FA.</td>
</tr>
<tr>
<td>Jennifer C.</td>
<td>Yes. It benefited my niece</td>
</tr>
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**COMMENTS FROM FA COMMUNITY**

**Parents & Family Members in the US**

<table>
<thead>
<tr>
<th>Name</th>
<th>Comment</th>
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<tbody>
<tr>
<td>Jessica C.</td>
<td>Yes. I want to be able to give my bright and loving daughter every opportunity to live her life to the fullest!</td>
</tr>
<tr>
<td>Jessica C.</td>
<td>Yes. The current data shows statistical significance, safety &amp; efficacy.... these patients have no treatment no cure. Any unknown risk is meaningful to this population. Time is not on our side. Knowing that there is a treatment that is just out of their reach is devastating..... please hear our cry. help us.</td>
</tr>
<tr>
<td>Jillian C.</td>
<td>Yes. The FDA is suggesting another clinical trial be performed before approval is considered. This could take years, even longer given the current global situation. Living with a degenerative condition means my nephew may not have the luxury of being able to wait years.</td>
</tr>
<tr>
<td>Joann C.</td>
<td>Yes. We need new trials to find a cure.</td>
</tr>
<tr>
<td>John C.</td>
<td>My brother would love to be in any fa trial or program available.</td>
</tr>
<tr>
<td>John C.</td>
<td>We would like to get the medicine</td>
</tr>
<tr>
<td>John C.</td>
<td>Yes for better quality of life</td>
</tr>
<tr>
<td>Justin C.</td>
<td>Yes. Based on proven results of the drug, my wife living with FA, would be interested in taking it. Thank you!</td>
</tr>
<tr>
<td>Karen C.</td>
<td>It has been made clear that Omaveloxolone is both safe and effective. It met the target criteria in the trials and did what was expected. It provided improvement in the condition of all participants. People living with Friedreich’s Ataxia have no alternative. This could dramatically change the lives of so many people that are currently without an effective treatment. Please approve Omaveloxolone for use. All those living with FA are progressing quickly. They don’t have time to wait for further trials especially given the size of the FA community and the difficulty of conducting trials during the current pandemic. Our son-in-law has FA and we have watched him struggle in his daily life. When you love someone with FA, you know the agonizing heartbreak of seeing their condition deteriorate. I plead with you to please approve this drug for use. Please consider the plight of those living with Friedreich’s Ataxia. Thank you for your time.</td>
</tr>
<tr>
<td>Katrina C.</td>
<td>Yes she needs this</td>
</tr>
<tr>
<td>Keith C.</td>
<td>Yes. My daughter had suffered with FA since she was a child. She is currently in a wheelchair and I would welcome the opportunity for an improved quality of life for her.</td>
</tr>
<tr>
<td>Kelly C.</td>
<td>Yes! My cousin E., who has FA, would do anything to help those with this disease and to get that much closer to a cure!</td>
</tr>
<tr>
<td>Kelly C.</td>
<td>Yes, I think it’s important for us to continue to support research on new drugs and activities that can help individuals with this disease</td>
</tr>
<tr>
<td>Lauren C.</td>
<td>I believe that my aunt, uncle and mom would take it. They have nothing to lose and if any or all of them could get any of their mobility back, whether large or small, they would be so greatfull. I would love for my son to be able to see his grandma be able to take a couple of steps.</td>
</tr>
<tr>
<td>Lena C.</td>
<td>Yes, she need</td>
</tr>
<tr>
<td>Leonardo C.</td>
<td>Yes...its taking away your normal everyday quality of life very slowly and the outcome is slowly devastating that no person needs to live life that way. Think about your life if you lost control or arms, walking as a teenager, slurring and you have the same strong mind so physically you know your deteriorating!! We need to take some risk like all medicines to help...otherwise the risk of life itself will take it away ! Thank you</td>
</tr>
</tbody>
</table>
Linda C.  
I am the parent of two children with FA. Our oldest son was diagnosed at 14, at that time, his sister (also having FA) was only 5 years old. She was not aware of her diagnosis and lived quite an active life until she started to experience symptoms at the age of 14. Even though she saw her older brother (ten years her senior) lose many of his motor skills and suffer heart conditions, diabetes and several hospital stays to combat his illness, it didn’t occur to her she too would have FA. Hearing the words, you have FA too, was a deep blow. Can you imagine having a footprint in front of you, her older brother, and know what challenges you will face ahead? Unfortunately, she progressed faster and lost her mobility skills sooner than her brother. We now have two wheelchair bound adult children in the home. We spent savings and took loans to modify our home and vehicle to be able to combat the ever progressing difficulties our children face. Our son, now 29, needs assistance on a daily basis. What's more difficult to watch is that he worked so hard to obtain his masters degree, but his ever evolving medical issues has made it so difficult to hold employment. Our daughter, now a sophomore at college, aspires to be an attorney, but she sees her independence fading and wonders on a daily basis if she too will hold a degree that she cannot use. I know, as a parent, this drug will greatly improve the hope and condition of our children and would be a critical part of their self esteem to have this illness slow down or even regress. Any amount of time taken away from them is devastating to them and also as a parent to watch. I hope the FDA will allow Reata to move forward with this important medicine for our FA families.

Linda C.  
The colossal toll of Friedreich's ataxia on school systems, social service systems, families and communities, as well as the heart-breaking toll on those who are living with the disease, warrants the extraordinary action of approving an NDA for Omaveloxolone. Please, as soon as possible!

Lisa C.  
Because my family and I are convinced that the results demonstrate meaningful benefit and low risk and would like our family member to have access to this medication. We believe that the studies completed to date provide sufficient evidence to support the approval of Omav.

Lupe C.  
Yes, my son would take the drug if close to affordable

Makenzie C.  
Yes. My family member is still able to walk and do certain things, but who knows if that will still be the case a year from now. This drug could potentially be the reason from her being able to walk & her being put in a wheelchair. I think anything will be appreciated at this point.

Mari C.  
Yes. With 2 adult children who both have FA this gives hope.

Maria C.  
The availability of any type of therapeutic to lessen and improve the symptoms of FA would greatly benefit my husband who has been living with FA since 1998.

Marie C.  
My grandchild who is 16 would like the option of taking the drug. She desperately needs the drug to slow the progression of FA. Her symptoms are becoming more advanced. Every day, week, month, and year allows her FA to progress and we would love for her in the interest of her quality of life to have the drug. She has potential to do so much with her life that FA may compromise.

Marina C.  
I just want my cousin to be able to afford and have access to the medication she needs.

Marsha C.  
I would definitely want the drug to be available for my grandson and all the other FA patients. I would love to see my grandson able to live a more normal life instead of consistently going down hill. Any option is better than dying of this horrible disease.

Mary C.  
Yes, based on the safety data we would love the opportunity to try this medication. My family members have had FA for 25 years without any hope for any type of treatment. As this is one of the first promising medications, we are hopeful this will be offered to patients.

Maxine C.  
Yes. My granddaughter is eager to take this drug; she was diagnosed with FA when she was 12 years old; she has lived with FA for 17 years during which time she has graduated from high school and college. She is able to work and, with caregivers, to live independently. However, her disease is progressing (that seems like the wrong word, since progress is usually considered positive!)

Melissa C.  
Yes, one of my two step daughters participated and saw dramatic changes. This is the first sign of a chance of a reversal of the debilitating disease.

Meretta C.  
Yes, the drug was helping my nephew
<table>
<thead>
<tr>
<th>Name</th>
<th>Comment</th>
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<tbody>
<tr>
<td>Michael C.</td>
<td>Yes, She is 21 and needs intervention now.</td>
</tr>
<tr>
<td>Nancy C.</td>
<td>I absolutely want my niece be given the option of taking MOXie immediately. She has the intellect to fully understand the implications and any risks involved as do I.</td>
</tr>
<tr>
<td>Nicole C.</td>
<td>Absolutely. To have the ability to walk again would just be amazing to my Mother. Give her some Hope that there is something out there to help improve her life.</td>
</tr>
<tr>
<td>Nicolina C.</td>
<td>To have a better life</td>
</tr>
<tr>
<td>Patricia C.</td>
<td>This is a terrible disease which results in increasing loss of function, mobility and strength. Life expectancy for children with FA is decreased in proportion to the severity of the disease. Watching a lovely, energetic, bright grandson gradually lose the ability to do the things that he loves is heartbreaking and frustrating. In the years since his diagnosis, he went from throwing the opening pitch at Angels baseball game to relying on a powered wheelchair or electric scooter. Thousands of children and their parents face a disease with no cure and currently no medication which works to improve their health and quality of life. This is unacceptable. We are encouraged by the results from omaveloxolone and pray that it will soon be made available for those who so desperately need a treatment and a cure.</td>
</tr>
<tr>
<td>Patricia C.</td>
<td>Yes my niece wants to try it. Anything at all will help with her disease.</td>
</tr>
<tr>
<td>Paul C.</td>
<td>Yes, as I have experienced how important drug trials help.</td>
</tr>
<tr>
<td>Rachel C.</td>
<td>Yes. It is heartbreaking to watch our son slowly lose his ability to function independently knowing that there is something that could slow this disease. Please help our families.</td>
</tr>
<tr>
<td>Robert C.</td>
<td>My daughter was diagnosed with FA at 13 and is now 29. Watching her lose function has been excruciating, but I’m sure nothing compared to her suffering as it happens. My daughter has said she will take Omav as soon as it becomes available. Omav has met a high statistical bar in not just halting the progression of FA, but in demonstrating partial reversal of some neurological function loss. My family and I strongly urge Reata and the FDA to proceed with authorization and production of Omav as a treatment for FA based on the existing trial results and to do so quickly, so that FA sufferers have the ability to preserve function before they lose more. Requiring a second phase 3 study will delay statistically demonstrated relief for not less than another two years. Given the requirements for a phase 3 study in FA patients, including recruiting a statistically significant sample size and meeting a requirement for ambulatory function (most patients are already in wheelchairs) among a small population makes assembling another cohort difficult and expensive. Please approve Omav for immediate use by FA patients.</td>
</tr>
<tr>
<td>Rocco C.</td>
<td>Yes, I think taking this new drug would help my niece and nephew with the fight stop the symptoms of FA.</td>
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</table>
Sixteen years ago, my big sister was diagnosed with Friedreich’s ataxia (FA). After reviewing the research findings and discussing the data with her, she would absolutely want the option of taking Omaveloxolone. I have not lived with FA, so I cannot speak to the experience of having it. But I have stood by my big sister’s side, supported her, and witnessed her grapple with the significant ability loss accompanied by FA over the years. When I was little, I used to cheer my sister on at soccer games with my parents as she ran down center field with her teammates. I applauded with excitement as my big sister joined in the progression of FA. As a family, we have become accustomed to jolting out of bed and running down the hall when we hear a crash or fall in the dead of the night: all too often finding my sister on the floor, injured, and whimpering from the pain and fear of falling while trying to preform a basic task without help. I have watched my big sister go through an astonishing amount of ability loss in our short lifetimes as well as endure complicated surgeries and other diagnosis connected to FA such as diabetes. For those in the later stages of FA – like my sister – this drug offers the chance to significantly improve quality of life and overall safety for the patient in their remaining time. For most of us, it takes a lifetime to experience such a dramatic loss of function – not 16 years as in the case of my sister. As a family and community, we understand Friedrich’s Ataxia is a rare genetic condition and that further trials would be extremely challenging even without the added hurdles created by the current pandemic for this community. Due to the severity of the disease progression and the shortening of life-expectancy, our concerns lie in increasing quality of life for those living with FA so that they can live more safely and comfortably in their day-to-day lives. I have read several peer reviewed studies that estimate the life expectancy for someone with FA to be anywhere between 35-50 years of age. My big sister will be celebrating her 30th birthday this year. My big sister is eager to try any treatment that offers improvement in her ability, regardless of how minimal the results are or severe the side effects maybe. We never actually expected that a treatment would be found, let alone a treatment that has shown this much success with limited side effects. We support her decision – and others living with FA – to take Omaveloxolone if given the chance by the FDA.

Yes if there was a drug that would help with there every day living or slow down the progression of FA I would want them to take it.

My brother-in-law has FA, diagnosed in his mid to late twenties. Friends, coworkers, and his children’s teachers, noticing the beginnings of his declining speech, eye movement, and coordination, at first were alarmed that he was intoxicated and an alcoholic. Over the years we’ve seen him lose his balance and fall multiple times, and each time he’s embarrassed, and sometimes he’s cut his head and had to seek urgent care. I’ve seen how he’s affected him and his family, from the ache of not being able to teach his daughter how to ride a bike, or being determined to put away the kids’ laundry and taking the stairs at a crawling pace one at a time sitting down backward to haul it up, to being powerless when his teenage son lost his temper at a family reunion and was in danger of hurting someone. In his professional career, he had advanced quickly as an engineer and manager in a factory. The environment became dangerous and he changed career tracts to take a position at the company’s headquarters, which was a huge blessing, but also painful to give up leadership and income. Over the last several years he’s declined physically and gone from a cane, to a walker, to a motorized scooter. One of the hardest things for him was losing the freedom to drive. He didn’t want to admit how dangerous driving had become (I wouldn’t let him drive my kids—it scared them and me, and it was awkward to explain without injuring feelings). A police officer pulled him over and in talking to him about seeing him swerve and hearing the causes, the officer let him know how many times his license plate had been called in (often mistaken for a drunk driver). The officer kindly stated the reality my brother-in-law didn’t want to face, that he needed to stop driving. My husband drove him to and from work until Covid. I worry about him falling and getting injured, I worry he has the mental health support he needs, and I worry about him declining any further. All in all, FA has taken a toll on my brother-in-law physically and emotionally. He’s participated in fundraising as well as studies, hoping research can help. We support and hope progress to alleviate suffering from FA will be pushed forward by the combined forces of the best scientific minds, community support, and influential leaders.

Yes, I feel that his quality of life would improve as well as increasing his life expectancy.
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<tr>
<th>Name</th>
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<tr>
<td>Shannon C.</td>
<td>I would like to see my niece live a less strenuous life.</td>
</tr>
<tr>
<td>Sheila C.</td>
<td>Family member needs the medication</td>
</tr>
<tr>
<td>Shelly C.</td>
<td>Our family member has FA. She is 21 and would like to have the opportunity for this drug. FA has her wheelchair bound, And we would like to have access to any options to better and prolong her life,</td>
</tr>
<tr>
<td>Shelly C.</td>
<td>Yes. Based on the research, I believe my daughter would benefit greatly. Slowing her progression and improving her mobility is something we hope for everyday.</td>
</tr>
<tr>
<td>Sheryl C.</td>
<td>Yes, my dear niece wants to try anything that can possibly improve her life.</td>
</tr>
<tr>
<td>Stephanie C.</td>
<td>Yes! Give the willing the option for treatment!</td>
</tr>
<tr>
<td>Trisha C.</td>
<td>Yes, I want my grandson (living with FA) to have the option to take omaveloxolone. Since he was diagnosed about 8-9 years ago, I have watched as his progression has dis-enabled him from being a talented, promising, multi-sport participant to requiring a wheel chair and assistance with some of his daily living tasks. It is heartbreaking. Based on the clinical trials, access to this drug with the potential to delay the progression of this devastating disease should not be held up for those living with FA. Time is of an essence with this disease. Please act fast to approve this drug.</td>
</tr>
<tr>
<td>Valerian (Larry) C.</td>
<td>I would like for my son to be able to try MOXIe to see if it helps his condition.</td>
</tr>
<tr>
<td>Walker C.</td>
<td>My grandson has FA. It has been devastating to watch a once promising athlete become wheel chair bound. He has inspired me with his tenacity to try and carry on as best he can. He has recently volunteered in a drug trial. Yes, I would want him to have the option to take the medicine. I would support anything that would help this young man and others who are living with this disease.</td>
</tr>
<tr>
<td>Whitney Noel C.</td>
<td>YES, she wants to take the drug!</td>
</tr>
<tr>
<td>William C.</td>
<td>Yes, she has lost so much any hope would be great.</td>
</tr>
<tr>
<td>Alley D.</td>
<td>Yes! Hopefully it will help my mother living with FA</td>
</tr>
<tr>
<td>Amy D.</td>
<td>My brother in law was diagnosed with FA at 17, he is now 32 and doing fairly well despite the daily obstacles he faces. J. is a beautiful soul and the only human I have ever met that always wears a smile and never complains. He has been wheelchair bound for the past 10 years and I have seen a big decline over the past two years. He is falling more often when transferring from his bed to chair and it’s becoming more difficult getting him in and out of our home. He still lives alone in a garage apartment right behind our house. He has visitors all day long and our children love to go see Uncle J. Eating is a challenge and all of his meals have to be puréed. If there is a drug that would help our dear Uncle J. we would love for him to have the opportunity to try it. I know he would take it in hopes for a better tomorrow! CURE FA</td>
</tr>
<tr>
<td>Angelo D.</td>
<td>Yes. I know someone who participated in the open label extension study and has had no adverse affects and shown mild improvement.</td>
</tr>
<tr>
<td>Ashton D.</td>
<td>Absolutely! I have watched my mom struggle with this my whole life as well as my Aunt!</td>
</tr>
<tr>
<td>Bill D.</td>
<td>My nephew B. has been living with FA since being diagnosed at 13 years old. B. loved playing soccer and lacrosse but found he could not keep up as the devastation of this disease began to rob him of his mobility. By college this bright energetic young man was wheelchair bound. His speech, flexibility and mobility decrease with every month. His family moved to a warmer climate to help with the stiffness he was experiencing. He tries to stay active and has adapted a car to help get himself around but the deterioration is evident. Another clinical trial would mean less mobility, stress on organs and further deterioration. Please get this drug to market. Let’s give those afflicted with this cruel disease a fighting chance. Let’s get this out on the market now. Thank you.</td>
</tr>
<tr>
<td>Bill D.</td>
<td>would like my wife to get access to the drug.</td>
</tr>
<tr>
<td>Camille D.</td>
<td>They would absolutely take it. I have twin cousins suffering from it and want to take it for the opportunity to save their lives.</td>
</tr>
<tr>
<td>Name</td>
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<tr>
<td>Carrie D.</td>
<td>Yes, my nephew would like the option to take omaveloxolone as a potential treatment for FA. Fortunately, my 16 year old nephew has a slowly progressing form of FA, however, he is slowly losing more and more functioning skills each day, even with intensive therapy. If this medication could slow or stop the progression of FA, then the quality of life for many young people, including my nephew, could be maintained. Please consider approving this medication immediately since the progression of FA is in fact a time sensitive matter.</td>
</tr>
<tr>
<td>Cindy D.</td>
<td>Both my adult children would want to take it.</td>
</tr>
<tr>
<td>Cindy D.</td>
<td>Yes, I would like the option for my family member to take the drug. He knows the risk and is willing to take the risk because he knows the outcome if he does nothing. I support his decision to try this medicine.</td>
</tr>
<tr>
<td>David D.</td>
<td>Yes I would. It’s a terrible disease</td>
</tr>
<tr>
<td>Donna D.</td>
<td>Yes, would want the option based on data available.</td>
</tr>
<tr>
<td>Echo D.</td>
<td>yes, he is getting worse every day.</td>
</tr>
<tr>
<td>Elizabeth D.</td>
<td>Yes he is saying if the studies are showing that it would help he 100% wants to take it.</td>
</tr>
<tr>
<td>Elizabeth D.</td>
<td>I cannot answer for my son but think at this point he would be willing to try anything</td>
</tr>
<tr>
<td>Name</td>
<td>Comment</td>
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<tr>
<td>Karen D.</td>
<td>If this drug should be given to my cousin. Stop all the red tape. He struggles everyday of his life. His life depends on this so get him better. He deserves a good life.</td>
</tr>
<tr>
<td>Karen D.</td>
<td>Yes. Trial and error is the only way to get to the next/best level of treatments. Those living with FA deserve the right to decide on what level of risk they are willing to take in an already devastating, pre-determined outcome. They need the right to choose what THEY are willing to sacrifice today - to help future generations afflicted with FA.</td>
</tr>
<tr>
<td>Karen D.</td>
<td>Yes, I have been waiting for 30 years for some form of treatment, help with this disease for my daughter. Losing all ability to do simple things over the years is heart wrenching to watch. 30 years is a very long time.</td>
</tr>
<tr>
<td>Kathleen D.</td>
<td>My niece has FA and has expressed that she wants to take the drug/medicine</td>
</tr>
<tr>
<td>Kimberly D.</td>
<td>Yes, he is progressing quickly and needs help now!</td>
</tr>
<tr>
<td>Krista D.</td>
<td>Yes, because it is needed to slow the progression of FA.</td>
</tr>
<tr>
<td>Lafretta D.</td>
<td>I would love to see my brother and his fiancè also her sister have the option of taking this med to help slow FA. Just having the chance of an amazing outcome I believe is important. Please give them the opportunity to slow or reverse symptoms they face from FA</td>
</tr>
<tr>
<td>Laura D.</td>
<td>My niece needs this medicine badly i worry about her health an want her to have a normal life</td>
</tr>
<tr>
<td>Lee D.</td>
<td>Yes, absolutely! Anything to delay, halt or reverse the progression would be very beneficial regarding quality of life. Considering omav’s excellent safety profile, it’s a very easy decision to want this drug administered to my son as soon as possible. I’ve even told him that if Reata doesn’t file an NDA, or if the FDA declines approval, I’ll synthesize and formulate omav myself, so he can benefit from the therapeutic effects.</td>
</tr>
<tr>
<td>Linda D.</td>
<td>Yes, my would like this for my son. My son has deteriorated alot with the inactivity during COVID. He is almost to the point where he can’t even transfer out of his wheelchair. It’s depressing for him to be home all the time and inactive!</td>
</tr>
<tr>
<td>Lisa D.</td>
<td>My son’s welcome anything that might make their lives easier.</td>
</tr>
<tr>
<td>Lourdes D.</td>
<td>Yes. He is willing to try something to slow the progression.</td>
</tr>
<tr>
<td>Luiz D.</td>
<td>Yes, if this new drug is going to help individuals with FA we are willing to try it.</td>
</tr>
<tr>
<td>Madison D.</td>
<td>Based on the data that has presented itself in the couple of years, I would feel 100% comfortable with my family members and myself taking this drug to manage the pain and symptoms of FA.</td>
</tr>
<tr>
<td>Marge D.</td>
<td>Yes. I believe MOXie would be very beneficial to all who are suffering from Friedreich’s Ataxia.</td>
</tr>
<tr>
<td>Marilyn D.</td>
<td>My daughter is anxious to take Omav, as she continues to lose functioning, interfering in her ability to socialize, work and take care of her needs without assistance. It has been many years (since she was 9) with treatment and no hope.</td>
</tr>
<tr>
<td>Mark D.</td>
<td>Yes she would try it</td>
</tr>
<tr>
<td>Michelle D.</td>
<td>My family member may be interested. I have not discussed it with her although I believe she should have the option available.</td>
</tr>
<tr>
<td>Molly D.</td>
<td>Yes! A crucial drug needed to slow the effects of fa.</td>
</tr>
<tr>
<td>Morgan D.</td>
<td>Yes they have faced many changes in their day to day life. Being able to participate in this would make them feel like a normal 9 year old again.</td>
</tr>
<tr>
<td>Nancy D.</td>
<td>I would want my daughter to have the option to take this medication. Time is running out. She has no other options. What is there to loose?</td>
</tr>
<tr>
<td>Nancy D.</td>
<td>I’m not sure at this advance age and disability if he would benefit.</td>
</tr>
<tr>
<td>Nancy D.</td>
<td>Yes. Please approve this drug to help my cousin</td>
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</table>
Nathan D. Absolutely I want my wife to have the option to take Omaveloxolone. The risk/reward ratio is off the chart from everything I have seen. I have known my wife for over 11 years now, and have watched as the treatments go through this long, arduous process. I know the disappointment when a trial doesn’t live up to its promise. I know the commitment my wife and other in the community have to show in order to make trials work. I know the amount of time it takes for those trials to take place. When the results were announced last October, it was like a beacon of light coming to a relentless and unforgiving disease, leaving an entire community crying with tears of joy and excitement. My wife is an amazingly strong person, and she will keep on going with or without this treatment, but I know she will be better for having the treatment in her life. It will make her life, her future better. It will make my life, and more importantly our children’s lives better in turn. I know so many people in the FA community, my Family, and I know they would all benefit greatly and have no time to spare. Please, please, please approve this drug and make the lives of so many so much better.

Olivia D. Yes. My loved one would absolutely want the option to take the drug. She has been living with FA for 16 years and needs assistance with all daily activities. This has also become increasingly difficult during the Covid pandemic. She would definitely want the opportunity to take this drug/medicine.

Patricia D. Yes, my children want the option to take this drug/medicine. They have taken part in many studies and if they can get any help to make their life easier they would at least like the chance. I see their condition failing almost daily, and they deserve the chance for a better life.

Peter D. My mother has FA and is extremely active in the research and development of drugs. I am supporting her.

Rachel D. Yes. I believe the study to be well controlled, the data sound, and there seem to be very few side effects. The possibility of reversing some of the effects of FA to provide a better quality of life for my husband is worth it.

Rebecca D. Yes in the interest of time

Ronald D. Yes, I would like my daughter to have the option to take this medication

Ryan D. No, however are very interested and would gladly participate.

Sallyann D. My son is late progression. Never be a candidate. I pray for all candidates

Sarah D. We WANT Omav!! Yes!

Steven D. Yes, anything that could improve quality of life

Susan D. My nephew, B., was diagnosed with FA at 13 years old. I have watched B. go from an active, athletic young man to being wheelchair bound. Although he stays active and does as much as he can with adaptive equipment, it is so important to push this new drug through. His decline is quite noticeable now and his speech, fine motor skills, and mobility are in jeopardy. Another clinical trial would impede the possibility of maintaining what mobility and speech he has left. Please get this through. There are so many young people losing their abilities. Let’s get this out on the market now. Thank you.

Tammy D. Yes. I would give anything for my son K. to have an opportunity to slow the progression of FA. He deserves to have the best quality of life as possible. It hurts terribly to see him going through this disease and his daily struggles are exhausting for him. Please help my son and many others who are in need of this great opportunity.

Terrence D. Absolutely want, need and have no reservations about getting access to omaveloxolone. Our daughter, B., has dealt with FA for 25 years. She has lost her ability to walk and is now having serious vision issues. We have been associated with FARA from its beginning, and have worked hard to get to this point of having a viable treatment. B. and other FA patients cannot afford to wait. We implore the FDA to reconsider its position and approve this drug for the sake of so very many. Thank you for your consideration.

Theresa D. My understanding is that Omavaloxolone will BENEFIT J. & others with Fredericks Ataxia. J. is a Beautiful,Vibrant child with a million dollar smile. To see him struggle with FARA is heart-wrenching. FARA is taking over his body and destroying his life. But he still smiles through it all and tries his hardest everyday. To think you the FDA has the POWER to APPROVE the drug Omavaloxolone that will GREATLY BENEFIT J. and others diagnosed with this dreadful disease. Omalvaloxolone has been proven to show improvement in many of the functions that FARA has destroyed for J. Omavaloxolone can reverse and stop the functions that J. is progressively losing control over. Please I BEG of you to think if God forbid if this was a Child or Grandchild of yours how fast you would want this drug approved. Thank You
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<tr>
<td>Wesley D.</td>
<td>Yes. Improved quality of life</td>
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<tr>
<td>William D.</td>
<td>Yes we want the option</td>
</tr>
<tr>
<td>Audrey E.</td>
<td>Yes! To be able to show improvement while waiting on a cure would be wonderful.</td>
</tr>
<tr>
<td>Bonnie E.</td>
<td>Yes. Have watched my granddaughter gradually become trapped in a body that no longer works. Her legs are now locking at night causing her enormous pain and anxiety.</td>
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<tr>
<td>Connie E.</td>
<td>Unsure.</td>
</tr>
<tr>
<td>Dan E.</td>
<td>Yes. Having this option could help my daughters!</td>
</tr>
<tr>
<td>Dawn E.</td>
<td>Yes my daughter and entire FA community sees the value of this drug however minimal it is better than nothing while they search for a cure.</td>
</tr>
<tr>
<td>Deirdre E.</td>
<td>Yes! My family member has no quality of life and nothing to look forward to without a cure. Only the progression of the disease. Give her some hope to see her children grow and one day her grandchildren.</td>
</tr>
<tr>
<td>Francis E.</td>
<td>May not help our daughter due to the advancement of her FA but can hopefully some diagnosed at an earlier age. Sure our daughter would have opted to take.</td>
</tr>
<tr>
<td>Jennifer E.</td>
<td>Cousin has FA &amp; YES, should could use this drug.</td>
</tr>
<tr>
<td>Jimy E.</td>
<td>Yes. Since omaveloxolone has proven to be effective, I want my brother to see me become a doctor before he passes away from FA. So by taking this drug, his chances of living longer should increase.</td>
</tr>
<tr>
<td>Judy E.</td>
<td>We want anything that can help</td>
</tr>
<tr>
<td>Lewis E.</td>
<td>Family member needy to try it</td>
</tr>
<tr>
<td>Lisa E.</td>
<td>Yes, my mother is interested in taking the drug.</td>
</tr>
<tr>
<td>Lori E.</td>
<td>My nephew G. has Friedrich’s Ataxia and was diagnosed at age 5 and is now 15. He is seeing many of the effects of this horrific disease and we as a family push for this drug and any drug that will help reverse and slow down the disease and hopefully a cure will be found in the very near future.</td>
</tr>
<tr>
<td>Marie E.</td>
<td>Yes, my daughter feels comfortable with the current safety data that exists to support this medication and would greatly benefit in life from the ability to use this medication. We have no approved therapies to help with symptom management so this medication would greatly improve her quality of life.</td>
</tr>
<tr>
<td>Marie-Jeanne E.</td>
<td>Yes if this drug has the possibility to help the patient with this devastating disease.</td>
</tr>
<tr>
<td>Mark E.</td>
<td>Yes my fiancé is living with FA this would be groundbreaking and a miracle for her. I hope this passes through. Thank you.</td>
</tr>
<tr>
<td>Shelby E.</td>
<td>Absolutely, yes. Time is of the essence, my brother needs more time! He is brilliant and has a bright future ahead of him, one that can be made possible by this drug.</td>
</tr>
<tr>
<td>Sierra E.</td>
<td>Yes, she feels her independence has been stolen from her and would love even to have a chance to try and lessen the hardships of FA.</td>
</tr>
<tr>
<td>Stephen E.</td>
<td>My grandson, who has been diagnosed with FA, has had positive results from being in a test study of the drug Omaveloxolone. Therefore, I am signing this petition to get the FDA to approve the NDA request.</td>
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<tr>
<td>Name</td>
<td>Comments</td>
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<tr>
<td>Tim E.</td>
<td>My daughter would want to take omaveloxolone. Every day is a struggle and having the opportunity to stop the progression would be a miracle. Thank you for considering the possibility of changing my daughter’s life and the life of many others.</td>
</tr>
<tr>
<td>Tom E.</td>
<td>Please! It’s our only hope! I’ve watched my step-daughter progressively get worse over the past 20 or so years!</td>
</tr>
<tr>
<td>Adam F.</td>
<td>With Omav being the only option available this should be available immediately. No need to wait any longer. The benefits are greater than any risks that have been documented.</td>
</tr>
<tr>
<td>Amy F.</td>
<td>Yes We need something ASAP</td>
</tr>
<tr>
<td>Angela Maria F.</td>
<td>To have a better quality of life</td>
</tr>
<tr>
<td>Anita F.</td>
<td>My cousin has FA and would love to try or have the opportunity to try this drug. She has had this forever it seems. If the drug even gave her the slightest improvement on mobility or speech...it would mean the world to her. She really wants to try the drug.</td>
</tr>
<tr>
<td>Aurora F.</td>
<td>Yes we need it to help me and my family</td>
</tr>
<tr>
<td>Brent F.</td>
<td>Yes, if proven to help in any way, my daughter would start taking MOXie.</td>
</tr>
<tr>
<td>Brooke F.</td>
<td>We are desperate for a treatment. I’ve watched my daughter slowly die for 8 years. Please help.</td>
</tr>
<tr>
<td>Bruce F.</td>
<td>Yes, Our family member would want the option to take the medication.</td>
</tr>
<tr>
<td>Cecil &amp; Elizabeth F.</td>
<td>Yes! He’s been living with this affliction all his life, diagnosed at age 12. He is now 33, married with a child. Any hope of a cure would be welcomed by him and others afflicted by this debilitating affliction.</td>
</tr>
<tr>
<td>Christina F.</td>
<td>Please give FA patients the opportunity to access this drug immediately.</td>
</tr>
<tr>
<td>Claudia F.</td>
<td>Yes. Our granddaughter is only 7 yrs old &amp; we want her to receive this drug to improve her health now &amp; in her future. Thank you.</td>
</tr>
<tr>
<td>Daniel F.</td>
<td>In recent months I have seen my girlfriend’s brother benefit from having access to omav. I know all people and their families affected by FA would benefit from having that same access. Whether the manifestation be internally or externally, I think they would all be better for having the option to do so.</td>
</tr>
<tr>
<td>Deforest F.</td>
<td>Yes. Children with FA don’t have years to wait for another trial. It is urgent that they get access to omaveloxolone ASAP!</td>
</tr>
<tr>
<td>Diana F.</td>
<td>Yes, as this is a life limiting disease any chance of a cure/treatment is welcomed.</td>
</tr>
<tr>
<td>Donjeta F.</td>
<td>I have three siblings who have been diagnosed with Friedrich Ataxia for over 15 years. Unfortunately, on December 13th, 2020, I lost my precious brother at the age of 30 due to Friedrich Ataxia. Our family is devastated because we felt so limited and so powerless to not be able to help him. If a drug like Omaveloxolone was available few years ago, my brother would have still been alive because that would stop the disease from progressing. He would get to do the things that he loved the most in his life such as playing soccer, get married, have kids. I grew up watching and witnessing my three siblings slowly deteriorating time by time. My biggest wish in life is that no other sibling or parent grows up watching their siblings/kids live with this terrible disease. The trauma of witnessing your siblings fall down all the time, start using the wheelchair, lose friends, lose the ability to speak normally, start having heart issues, not being able to breath properly is the most painful experience someone can live through. While I know that the FDA is looking out for people’s safety, please know how many lives you can save by approving Omaveloxolone to FA patients. Courage and hope is what keeps people alive. It is this drug that gives us hope that at least I won’t lose my sisters in the future as well.</td>
</tr>
<tr>
<td>Eric F.</td>
<td>Yes. We must try every available option.</td>
</tr>
<tr>
<td>Francis F.</td>
<td>Yes! I have seen the results with my grandson taking this medication.</td>
</tr>
<tr>
<td>Grady F.</td>
<td>Yes my cousin by marriage is 32 years old and would love the opportunity to try this drug. Anything she could do to help her mobility or speech or any of the side effects she has associated with FA would be wonderful.</td>
</tr>
<tr>
<td>Granjon F.</td>
<td>Sorry I don’t understand</td>
</tr>
<tr>
<td>Hannelore F.</td>
<td>Yes. We feel this drug will help with the ability to perform dexterity involved activities once again.</td>
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<tr>
<td>Hayden F.</td>
<td>I would like my brother to receive this medication so he can maintain the strength he still has, I want him to live a very good life.</td>
</tr>
<tr>
<td>Irma F.</td>
<td>Yes, because it is an option.</td>
</tr>
<tr>
<td>James F.</td>
<td>Yes my wife T. has FA for 40 years now and would love to do anything to improve her symptoms.</td>
</tr>
<tr>
<td>Jenn F.</td>
<td>Yes, this would be an excellent option.</td>
</tr>
<tr>
<td>Joanne F.</td>
<td>It is my niece that had FA. If the drug is safe and works, my brother would want to do anything to save his daughter.</td>
</tr>
<tr>
<td>John F.</td>
<td>Yes. The benefit of omav is clear and the drug is safe. Also, there are no approved treatments for FA.</td>
</tr>
<tr>
<td>Joseph F.</td>
<td>Yes. My brother has been taking omaveloxone as part of a trial and we believe it is safe and effective.</td>
</tr>
<tr>
<td>Katlyn F.</td>
<td>My husband would love the option to take a medication that can improve his quality of life even if it’s a small amount. Small improvement are HUGE improvements when you have FA.</td>
</tr>
<tr>
<td>Keli F.</td>
<td>Yes. would let my child take drug.</td>
</tr>
<tr>
<td>Leslie F.</td>
<td>I would love for my family member to be able to take this medication to stop the progression of FA and allow him to live as normal of a life that he can and to be able to create memories with his grandchildren.</td>
</tr>
<tr>
<td>Lisa F.</td>
<td>As the sister of two FA patients who have been actively involved in the search for treatments for over 30 years, I am writing to support providing all FA patients with the option to use omaveloxolone. As a family, we have been profoundly affected by FA. There is not one facet of daily life that is not made more difficult for FA patients. The progressive nature of the disease means every day, week, month and year brings new challenges. The results of the MOXIe trial bring hope, especially for the next generation of FA patients-young people whose progression could be halted before FA steals their speech, mobility, and health. Our whole family encourages the FDA to approve the use of omaveloxolone, today, before precious time for our youngest patients is lost.</td>
</tr>
<tr>
<td>Marc F.</td>
<td>Yes would like to try the medicine</td>
</tr>
<tr>
<td>Marcy F.</td>
<td>&quot;Unequivocally. Yes. When you are a parent to a child with a degenerative disease, the grief never ends. You learn over time how to hold joy and grief at the same time -- but the grief never ends. You learn to adjust to a new normal again and again and again because you have no other option. Initially you grieve the diagnosis and the death of what you hoped for your child’s life. You grieve the life moments that will likely never come. You grieve each ability that is lost. You grieve the slow loss of what our culture views as freedom and dignity. And, even tho you feel selfish doing so, you grieve what this does to your life. Because being a caretaker for a person with FA is not the same as simply being a parent. You are now both and that has real, material implications. After we found out G. had FA, we went to visit my sister in Seattle and I took pictures of him as he ran on the beach, knowing that he would soon no longer be able to run barefoot in the sand as the tide chased him. On that same trip he was determined to find a sand dollar that was not yet broken. This was not going to be an easy task. There were many sand dollars in chards and some with chunks and chips out of them but we couldn’t find a whole one. G., however, was determined. He wouldn’t stop looking. He is and always has been determined. Sure enough, he found a perfectly whole sand dollar. I watched his determination as he refused to move to a wheelchair. He was determined to keep walking even as he had to hold onto walls and carts in order to do so. He told me he knew once he sat in that chair, he would never walk again. My son is a smart, wickedly funny, kind human being. Like so many of the individuals who I have met who have FA, he makes the world a better place. Unfortunately, the world hasn’t made a very good place for him. When our community was asked to share our perspectives on Omaveloxolone and FA, I was happy to do so. What I didn’t realize is that the process of thinking this through, the process of giving voice to the need for Omaveloxolone has proven to be a deeply painful one. I have had to confront what happens if we cannot get it. What if it takes too long? What if it never comes? I know the answers to those &quot;what if&quot; questions. It makes me think about each little loss we experience and how gut wrenchingly painful it is to be a witness to that loss. And, please do not think that &quot;small&quot; things are not significant. The ability to put tooth paste on a tooth brush and brush your teeth is a big deal. Being able to put your own socks and shoes on is a big deal. Being able to transfer to a bed or a chair without help is a big deal. Speaking and being understood is a big deal. Slowing progression is a big deal in the lives of people with FA and those caring for them. Without Omaveloxolone our future is already certain.&quot;</td>
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Dear Decision Makers of Reata and the FDA re Omaveloxolone. We realized this week that it has been 25 years since we started this odyssey with Friedreich’s Ataxia. Our eldest daughter S., then 9, had for a couple of years been showing signs of clumsiness and an inability to do many things her peers could do. Because there was not yet the discovery of the gene, she was subjected to some methods of diagnosis that a small child should not endure. Fast forward 25 years and she is no longer here. She died in 2012 at the age of 26. How clearly we remember naively asking her pediatric neurologist when there would be a cure. He responded that it would be years and potentially decades into the future. How sadly accurate he was. Today, we watch as S’s younger sister, L., awaits the same fate. She, at age 30, has entered congestive heart failure. L., a beautiful, bright, funny and talkative teen now is unintelligible as she whispers words that we try to decipher and then often are forced to spell out with her affirming head nod. We hold our breath as she chokes on food and drink; comfort her as she gasps to regain a steady breath. L. pushes through every day with the same passion to live fully as any other normal healthy adult. She engages you with a smile and a head thrown back in laughter. And then some days her head is down, her neck is weak, the fatigue is wearing. Is she resigned to this path; this end of journey? Some days we think so and other days she fights with her all. A drug like omaveloxolone could give her the chance to fight; could give us more time with our youngest. To lose a child in this way; with a rare disease that we never saw coming and didn’t know existed, is beyond expression. We read and listen to parents with younger FA children and our heart breaks for what they have yet to endure; to the sleepless nights ahead; the heartbreak of losses their child will suffer through and ultimately to the sacrifice they may one day make. Thinking of our own days ahead is almost too much to consider. Please, please act now, with urgency; 25 years is long enough.

Mary F.
Yes. Would like to give her every opportunity available to live a normal life.

Matthew F.
My wife is 49 and this has been a slow but sure progression. It seems that the last few years the symptoms have progressed faster. She now walks with a walker. And yes she would jump at the chance.

Melinda F.
Yes I would like the patient to be able to get it as she has declined tremendously and is a beautiful young lady with a beautiful soul. She has struggled so much relief would be a blessing from God!

Mike F.
Yes, urgently need a breakthrough.

Miriam F.
I have an older and younger brother who has FA. They both tried for a study about 15-20 years ago and it didn’t work

Nikole F.
My sister has been struggling through Friedreich’s Ataxia since she was 17, although she has done an amazing job at maintaining a semi-normal lifestyle, she is declining. She is nearly 37 years old with 5 children and an active duty Military husband. My sister is an amazing mother and is super headstrong, so she has held on to her ability to walk much longer than most have FA sufferers have been able to. Unfortunately, she has been on major decline over the past 2 years and has been spending more and more of her time confined to a wheel-chair, she is still able to use her cane for very short distances. She pushes herself through all struggles that she faces and would be an exceptional candidate to try Omaveloxolone on as I don’t feel she has much time left out of a wheelchair, she is definitely the strongest person I know. She has a huge family that is very supportive of her and we all feel very strongly feel that if Omaveloxolone were released to FA sufferers, she could potentially prevent some of the damage this disease causes and it might not force her future to be wheel-chair bound. The potential benefits far out weigh the negative side effects. She is willing to take on any potential side effects, often times, as with other medications, the benefits far out-weigh the side effects. Please help make Omaveloxolone available for FA patients and lets help slow the progression of this horrific and debilitating disease and help my sister lead a better life.

Owen F.
Yes, anything that helps my cousin joseph and the thousands of others who have FA is fine with me.

Peter And Margaret F.
Yes he is very anxious to try it’s breaking my heart seeing him trying to walk and falling all over, but is a real trouper hoping someday something will show up.

Rebecca F.
FA is so debilitating, access should be permitted to the sufferers to anything that may have the potential to help them.

Rhonda F.
My sister was an active healthy woman and i would like to see her that way again

Rob F.
Yes, because this disease advances so fast and attacks patients differently.
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<tr>
<td>Sandra F.</td>
<td>I absolutely would want my boys to take the drug as would they. We have seen such a decline in them over the years and it is heartbreaking. My 21 year old is now legally blind and wheelchair bound. Losing his vision is devastating since he is very limited physically needing help with all daily activities. My 26 year old also continues to decline. The drug provides hope to slow the progression and to give them more time.</td>
</tr>
<tr>
<td>Sarah F.</td>
<td>I would want my family member to have the option of taking the drug/medicine to give him a sign of hope. Hope for him, hope for the FA community, and hope for their families.</td>
</tr>
<tr>
<td>Sharon F.</td>
<td>Yes she would. Anything to help slow the progress.</td>
</tr>
<tr>
<td>Shawna F.</td>
<td>My cousin was diagnosed a few years ago. He has tried everything and participated in trials. This is one of his last hopes at preventing his symptoms from getting worse. He went from dancing and performing to not being able to bathe on his own. He deserves the opportunity to try.</td>
</tr>
<tr>
<td>Stacy F.</td>
<td>Hi, my son O. is 18, diagnosed with FA 2 years ago, he has lost so much functioning in the last 2 years, we would love the opportunity to halt this awful progressive disease. I feel like we are watching O. lose his functioning weekly. We would do anything and love the opportunity for O. to take Omav and be given the chance to slow his progression. Please give him that chance.</td>
</tr>
<tr>
<td>Steve F.</td>
<td>Yes please let him continue taking it.</td>
</tr>
<tr>
<td>Tim F.</td>
<td>I Think that they should try it on people who have this condition and who could die soon.</td>
</tr>
<tr>
<td>Tony F.</td>
<td>Yes we would have her take it. Not any other options for a terminal disease that eventually kills the person with the disease. What parent wants to lose a child. We won’t know if it works for her unless we try it. Nothing to lose and everything to gain. Please approve the drug. please.</td>
</tr>
<tr>
<td>Vanessa F.</td>
<td>Yes, we’ve seen my sister in law get worse. Anything to help stop the progression.</td>
</tr>
<tr>
<td>Alan G.</td>
<td>Yes. My grandson was part of the study.</td>
</tr>
<tr>
<td>Anne G.</td>
<td>Yes my family member deserves the right to try with the possibility at the very least to stop the progression of this disease. She has been a tireless advocate and role model for herself and the entire FA family. She takes excellent care of herself and is loved by so many people. She will never give up, she deserves the right to try.</td>
</tr>
<tr>
<td>Anthony G.</td>
<td>My niece would like to try it.</td>
</tr>
<tr>
<td>Austin G.</td>
<td>Yes, she deserves a chance to beat this disease. She is the kindest sweetest young women and she is effected by this disease tremendously. She just wants a chance to beat this and try anything that could help that mission.</td>
</tr>
<tr>
<td>Benito G.</td>
<td>I would like for my family member and the FA community to have the option to take it.</td>
</tr>
<tr>
<td>Bethany G.</td>
<td>Yes. Any opportunity for her to regain mobility and diminish symptoms would be wonderful!</td>
</tr>
<tr>
<td>Bizerta G.</td>
<td>YES SHE WOULD LIKE TO RECEIVE THE TREATMENT...SHE NEEDS IT...SHE WAS BORN WITH THAT CONDITION.</td>
</tr>
<tr>
<td>Branka G.</td>
<td>Yes. My cousin’s 16 year old daughter’s daily quality of life is diminishing.</td>
</tr>
<tr>
<td>Cale G.</td>
<td>Yes they want to take omav to help improve their daily living and functional abilities</td>
</tr>
<tr>
<td>Carol G.</td>
<td>Most definitely-a chance to speak more clear and regain motor skills</td>
</tr>
<tr>
<td>Carson G.</td>
<td>Yes my little brother needs anything and everything. As well as the other people with FA!</td>
</tr>
<tr>
<td>Chad G.</td>
<td>Yes, my mother in law has nothing to lose with this terrible disease. Taking this drug could only improve her quality of life.</td>
</tr>
<tr>
<td>Charli G.</td>
<td>It should be available for anyone who wants to take it.</td>
</tr>
<tr>
<td>Cheri G.</td>
<td>Yes she would like to take the drug</td>
</tr>
<tr>
<td>Cindy G.</td>
<td>My aunt had FA and therefore it is in the family. she died many many years ago and was debilitated by it. My cousin’s children have it and she is an active individual fighting for cures. I got this letter from her and trust that she knows what she is talking about in advocating this drug.</td>
</tr>
</tbody>
</table>
COMMENTS FROM FA COMMUNITY
Parents & Family Members in the US

Dana G.  Yes so it might stop the progression of it
Danica G. Yes she would absolutely take the medicine to try and slow the progression of the disease. She is already 33 years old and wanting to lengthen her life as long as possible to see her daughter grow up.
Daniel G. My sister would love the opportunity to try a medicine. She is showing serious signs and losing mobility. Anything helps
Danielle G. We are at the point where we are begging to have some kind of medicine to help my brother. My brother is begging. He works every day to exercise to maintain what little control he still has and the more time that ticks by, the less he’s ever going to be able to regain. If we can get this medicine sooner than later, I believe it will only help my brother. If we have to wait two more years. Who else knows what he’ll lose. Who else knows how much his spirit can take. It’s more of a risk waiting and letting this disease eat him up than letting this drug be available sooner than what would be considered normal. We are begging for this drug to be released and want it as soon as possible. Please consider the damage holding off will do to the people who need some kind of treatment. Please help my brother and let this drug pass through. Thank you.
Devon G. Yes! We are watching our son’s body deteriorate before our eyes. We don’t have the luxury of time to wait for another trial.
Earl G. Absolutely, time is critical
Eileen G. Yes. Anything safe that would help in any way. Thank you
Eva G. My family member would love to be able to take the drug. He has been living with FA for a few years, and he is soon going to be living on his own and this drug would help him live on his own and gain independence.
Gaby G. I would want her taking it. The progression of the disease seems to have slowed and she’s been less sick since taking it.
Garrison G. Yes my daughter would be willing to try it.
Greg G. Yes, my son of 22 years of age has participated in numerous new trial drug studies to see this disease either stop or slow it’s progression of FA. It is our hope as his parent(s) to see this medication come to fruition as soon as possible. Our son has been fighting this disease for 14 years and has worked out everyday to strengthen his body (over the last 3 years) to be ready when a drug like this is on the market. All we are asking for as his parents, is to move as quickly as you can to approve this medicine so we can see hope once again restored in our son. Every day counts, because every day we notice less mobility in his hands, feet, legs and arms. He resides now in a wheelchair but after seeing this medicine’s positive affect within the trials we now know it will slow his disease enough to find a cure in the near future. Please approve Omaveloxolone as soon as possible, we are counting on it.
Hannah G. Yes. My brother has FA & I think any type of drug or medicine would be helpful!
Hunter G. Yes. My wife has FA. She believes any help is better than her progressively getting worse.
Isabella G. Yes, he would be willing to try anything
Jarrod G. Yes, my son would want to take the drug and I would want him to. He is growing increasingly frustrated with his abilities and needs more and more help. He wants a chance at being more independent and wants to be able to spend time with his friends without feeling like he is a burden.
Jeff G. Absolutely. There is no other treatment available for FA, so even IF Omaveloxolone is not 100% effective, it’s still much better than the alternative. Even if a small benefit is the result, it’s still much better than the alternative. Even if NO benefit is the result, it’s still worth the effort. But given the results of the clinical studies performed thus far, the beneficial results seem to be inarguable, and thus worth the attempt to benefit those who have FA. Please carefully consider this decision. The impact will quite likely extend, or even save, lives.
Jeff G. Want the option of taking omaveloxolone
<table>
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<tr>
<th>Name</th>
<th>Comment</th>
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<tbody>
<tr>
<td>Jennifer G.</td>
<td>My daughter was a nice it in Phase 2 6 years ago! She can not take it in the open study because of heart enzymes were high by your labs but I had the same labs drawn on her when we came home and our labs she was way be normal! There has not been one person die! You passed a vaccine that has been in this country for 11 months but you can’t pass this for a disease that been around FOREVER! While our children are dieing of this! Do you know what’s it’s like to see your kids do one thing one day and a week later they can’t!!!?? I had seen my daughter take UN-ASSISTED STEPS FOR THE FIRST TIME IN YEARS on this medicine! STOP BEING MONEY HUNGRY AND THINK OF THE Family’s this affects!!</td>
</tr>
<tr>
<td>Jennifer G.</td>
<td>Yes. Anything is better than nothing and we need hope.</td>
</tr>
<tr>
<td>Jerry G.</td>
<td>Yes of course its for my sweet niece</td>
</tr>
<tr>
<td>Jessie G.</td>
<td>My grandson was diagnosed 12 years ago. Yes I would want the option of taking the drug/medicine.</td>
</tr>
<tr>
<td>Jesus G.</td>
<td>Yes would love for him to be a participant</td>
</tr>
<tr>
<td>Joan G.</td>
<td>Yes because at this point in our daughters life there is no hope a any quality of life!</td>
</tr>
<tr>
<td>Jocelyn G.</td>
<td>Yes because the risk is a higher hope for a normal life then continuing with no treatment at all .</td>
</tr>
<tr>
<td>Jon G.</td>
<td>yes. Anything that will give C. a better life style.</td>
</tr>
<tr>
<td>Jonathan G.</td>
<td>Yes. My daughter-in-law participated in the study &amp; wants to proceed with the official treatment.</td>
</tr>
<tr>
<td>Joshua G.</td>
<td>Yes, any advancement in research is helpful.</td>
</tr>
<tr>
<td>Julie G.</td>
<td>Yes. Any hope is better than none.</td>
</tr>
<tr>
<td>Karla G.</td>
<td>Yes! My husband has tried everything he can to stay independent but this past year he has had a hard time doing this. Even transferring from his wheelchair is becoming difficult and dangerous. He does volunteer physical therapy 3 times a week just to stay as independent as possible. Missing even one day sets him back. He has currently recovered from Covid which has set him back even further. But he is a fighter and is getting his strength back as much as possible.</td>
</tr>
<tr>
<td>Kathleen G.</td>
<td>My beautiful granddaughter should have a chance to have a great life. Without this she has no life❤️</td>
</tr>
<tr>
<td>Katie G.</td>
<td>Yes, my sister wants the option. She is living with FA, slowly becoming more and more reliant on others. My sister that I remember teaching to roller skate when we were young kids, now requires someone to transfer her out of her chair, all activities of daily living. My sister and everyone that suffers from FA, should have the option and availability to any therapies that could/would help them!</td>
</tr>
<tr>
<td>Kristin G.</td>
<td>The choice should be that of the family. If there’s a chance this can improve his life, they should have that right to take it.</td>
</tr>
<tr>
<td>Kyle G.</td>
<td>Yes, to see if the drug can help</td>
</tr>
<tr>
<td>Lance G.</td>
<td>When you are desperate, more options are always a good thing, not bad. You don’t know until you try. This could be a game changer for many loved ones suffering from FA. Thank you.</td>
</tr>
<tr>
<td>Lauren G.</td>
<td>My cousin has this and I believe she would benefit greatly from this medication</td>
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**COMMENTS FROM FA COMMUNITY**

**Parents & Family Members in the US**

<table>
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<tr>
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<tr>
<td>Leigh G.</td>
<td>Yes. After reviewing the data of the 103 people and knowing that there are no other drugs that have been shown effective my mother, D., would like to have the opportunity to take this medication. Currently, nothing helps her.</td>
</tr>
<tr>
<td>Mary G.</td>
<td>I believe everyone has the right to weigh the options and decide for themselves. FA has very little hope. You keep giving hope but never follow through with something to try. Let FA people decide for themselves.</td>
</tr>
<tr>
<td>Marybeth G.</td>
<td>yes. my children are being robbed of their adulthood.</td>
</tr>
<tr>
<td>Matthew G.</td>
<td>Yes. My wife is dx with this. I want her to have any opportunity that is available to make her life fulfill.</td>
</tr>
<tr>
<td>Matthias G.</td>
<td>Yes, have to try something. Things are getting worse for him every day.</td>
</tr>
<tr>
<td>Melissa G.</td>
<td>Yes! We will try anything. Watching my daughter suffer so much is heartbreaking. Please help us!!</td>
</tr>
<tr>
<td>Michelle G.</td>
<td>Yes, please!!</td>
</tr>
<tr>
<td>Monica G.</td>
<td>My son is fighting the debilitating effects of disease progression and would love the opportunity to be able to take the omaveloxolone to slow progression. My son was not able to participate in the clinical trials because he was not able to meet the travel guidelines. My son would definitely want the opportunity to take the drug/ medication Omaveloxolone. Please issue approval for this drug to administered for all individuals with FA.</td>
</tr>
<tr>
<td>Nancy G.</td>
<td>My daughter have been suffering from FA for many years and she needs this drug to be passed by the FDA. Thank you</td>
</tr>
<tr>
<td>Nathan G.</td>
<td>Yes, She has had for years it’s caused her alot of emotional pain along side physical and she would be willing to do anything to be able to have a normal life.</td>
</tr>
<tr>
<td>Pamela G.</td>
<td>Trying this is better than nothing.</td>
</tr>
<tr>
<td>Peter G.</td>
<td>As of now my wife has no future, FA is robbing her of the ability to do anything.</td>
</tr>
<tr>
<td>Peter G.</td>
<td>Yes, my mother it on her last chance and anything that could extend functional time would be a blessing.</td>
</tr>
<tr>
<td>Phil G.</td>
<td>My son B. is experiencing deterioration of his basic abilities to walk, eat, talk and participate in his world every day due to FA. At such a time when ‘a cure’ seems to be so close and yet so far away we need everything we can to slow this deadly disease so that when something does come along we have some chance at regaining that which was not lost forever. If this drug can help slow the progression at any level and is safe - we need this for B., all struggling FA children and their families ASAP.</td>
</tr>
<tr>
<td>Phyllis G.</td>
<td>Fix my niece</td>
</tr>
<tr>
<td>Rachel G.</td>
<td>Yes my sister in law would want to take it</td>
</tr>
<tr>
<td>Roger G.</td>
<td>Yes. Any hope is better than sitting around and waiting to die.</td>
</tr>
<tr>
<td>Scott G.</td>
<td>My cousin could extend her life.</td>
</tr>
<tr>
<td>Seth G.</td>
<td>Yes, if it helps slow down progression</td>
</tr>
<tr>
<td>Sharon Kay G.</td>
<td>My son D. was diagnosed at the age of 15 with Friedrich’s Ataxia and is wheelchair bound given the careful care of the Doctors at the University of Iowa Nero-Muscular and has a paramedic in the chest with an FA heart. He is a courageous soldier who would partake in any studies as they are administered through the U of I, Dr. M., attending physician.</td>
</tr>
<tr>
<td>Smith G.</td>
<td>My sister has been improving in her exercise and the disease appears to be slowing down</td>
</tr>
<tr>
<td>Susan G.</td>
<td>I’m sure to provide a cure for others.</td>
</tr>
<tr>
<td>Name</td>
<td>Comment</td>
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<tr>
<td>Tammy G.</td>
<td>Absolutely! FA robs its victim everyday and it is relentless! The physical and emotional toll is sometime unbearable and the only thing that keeps people going is the hope and prayers that one day there will be a treatment, something to put in our arsenal against this horrible monster. Imagine a life of loss and grieving that does not end. You cannot even fully grieve one loss before another ability if robbed from you. I cannot put into words the pain in watching your child struggle and slowly disappear and being able to do nothing to help them. It is so raw that even now, as I write this I can’t stop the tears from flowing. My son has waited 14 years for a drug that will give him a chance. . Please, I beg you to consider the benefit of omaveloxolone to people fighting this FA battle. It should not and must not be robbed from them as well!</td>
</tr>
<tr>
<td>Teresa G.</td>
<td>Most definitely.Anything to help her quality of life</td>
</tr>
<tr>
<td>Theodora G.</td>
<td>Absolutely, it should be available As soon as possible to all patients. The data provided by part one and part two of the study along with the open label extension shows significant statistical improvement when looking at the activities of daily life and measures on the FARS Scale. This is adequate and sound proof of the efficacy of MOXie.</td>
</tr>
<tr>
<td>Tim G.</td>
<td>Yes. Absolutely we want the option to take the drug.</td>
</tr>
<tr>
<td>Tina G.</td>
<td>Unequivocally yes! Imagine as a parent you see the disease progression in your child. Every. Day. Over the course of the time of the clinical trial/open label study for omaveloxolone, I have seen a decline in my son’s ability to walk. It’s devastating to see. Meanwhile, you hear from the FA’ers that are on the drug and how it has been life changing for them. How could I not want that for my child? This is the first treatment that has a chance to be approved to help slow the progression of FA. It seems like a no brainer to me but I get it. Why? Because anyone not automatically approving this after seeing the results of the clinical trial does not have a family member with FA. If you did, you would understand why we are so passionate about this cause. I beseech you to read these letters from those of us that are somehow affected by FA. Watch videos of FA’ers that have been on the drug explaining how it has improved their quality of life. Watch videos of FA’ers explaining their disease progression and how it affects them physically and emotionally. I guarantee that you will get it then.</td>
</tr>
<tr>
<td>Val G.</td>
<td>Yes, we’d love to have medicine that makes my cousin’s life better in every possible way.</td>
</tr>
<tr>
<td>William G.</td>
<td>Yes my daughter would be interested in taking Omaveloxolone.</td>
</tr>
<tr>
<td>William G.</td>
<td>Yes. I want my son to get better</td>
</tr>
<tr>
<td>Aimee H.</td>
<td>Yes, to function on a normal daily basis.</td>
</tr>
<tr>
<td>Alina H.</td>
<td>My brother was diagnosed when I was 9 years old. At just 14, he knew his life would change forever. Finding a cure would mean we could maybe grow old together, he could attend my future wedding and I could attend his. We could be aunt and uncle to each other’s children. It would let our family thrive for longer. This medicine would give us a chance.</td>
</tr>
<tr>
<td>Alisha H.</td>
<td>We definitely want the option to take medicine or trials</td>
</tr>
<tr>
<td>Amanda H.</td>
<td>Yes my cousin could really benefit from this!!!</td>
</tr>
<tr>
<td>Anton H.</td>
<td>Yes! We don’t often talk about how this disease is impacting our lives. She is an amazing &amp; determined fighter, but I see how she adapts her daily routine to deal with the progression. We don’t have the time for another round of trials, as the FDA is requesting. Every day counts.</td>
</tr>
<tr>
<td>Aundre’ H.</td>
<td>Yes and here’s why; My family member wrote this to his friends and family. Family and friends, as you probably know, I have a rare, progressive disease called Friedreich’s Ataxia. You know it’s taken away my ability to walk, and that it has altered my speech and hearing. But there’s even more beneath the surface I typically don’t let on. For instance, I have scoliosis, I have bladder issues, I have malformed feet, I have circulation issues (My toes are currently cold and my feet are purple to mid calf). Also, I have heart disease. Basically, I’m dying. But I’m still one of the more fortunate pupil’s with Friedreich’s Ataxia as I haven’t developed diabetes, chronic pain, or the feeling of extreme fatigue for no reason. Yet.</td>
</tr>
<tr>
<td>Benjamin H.</td>
<td>Yes!!! He is the most incredible person I know. We pray every night. Allowing this drug would answer our prayers.</td>
</tr>
</tbody>
</table>
Bill H. Yes because of no other remedy

Brayden H. Yes because I want my sister to live a long happy life. I love her and it’s horrible to see someone go through what she has.

Caety H. Yes her progress is starting to show and slowing it down would be a miracle!!!

Carissa H. Yes, absolutely. Any hope of slowing the disease is worth the risks, considering the alternative of certain, premature death.

Carol H. Yes, we want the option of taking the drug. It appears to be safe and effective, is recommended by our neurologist, and is needed now.

Caroline H. Yes my daughter and many living with FA would like the this drug available! The decision to take a drug that has shown great potential should be theirs and theirs alone and not held back by their government! My daughter would take it for the betterment of her life!

Casey H. Yes. Our daughter has symptoms that are getting worse and she’s only 10. The sooner she is on meds that slow or reverse symptoms the better.

Catherine H. Yes. My Daughter has lived with this disease for more than 13 years. She has started to go downhill physically pretty fast. Any help she could get to live longer and watch her daughter grow up would only enhance her life and mental health.

Catherine H. Yes. Two of our grandchildren (S. and M.) have FA. To see what FA is robbing them of affects the whole family. They are beautiful, bright adults struggling each and every day. Any help a drug or medicine that could possibly help would certainly be something to look forward to.

Cheryl H. Yes. We are needing something soon.

Chris H. I hope that the FDA and Reata Pharmaceuticals will move forward to make Omaveloxolone available as soon as possible. Friedreich’s Ataxia patients and their families cannot afford to wait 3 years for another clinical trial. Friedreich’s patients lose something every day, every week and every month. Time is a luxury we simply do not have. While most high school students were attending parties, playing sports and planning their futures, my son was being fitted for a wheelchair and learning to deal with decreasing mobility. Today, in his early 20’s, he needs help bathing and has difficulty transferring in and out of bed. His speech is beginning to slur and even I have difficulty sometimes understanding him. If we wait for another clinical trial his speech will have deteriorated to the point where no one can understand him. That is what we personally have to lose. We attend doctor’s visits annually terrified that the cardiomyopathy associated with Friedreich’s has started to get worse. In my opinion, the risk / reward relationship for Omaveloxolone strongly warrants approval based on the existing clinical trials. What is the risk? We don’t see as much benefit as we had hoped? That there prove to be detrimental effects down the road? For many Friedreich’s patients, without some treatment options very soon, there is no “down the road.” Based on the data to date, I think any Friedreich’s patient would accept these risks in order to get a more timely approval for Omaveloxolone. Thank you.

Christina H. My niece could benefit alot from this drug.

Cody H. Yes, he’s been taking it and using it for daily management and has had zero adverse effects.

Connor H. Yes, my brother has expressed that he wants to try a treatment. He’s wheel chair bound and not able to take care of himself.
COMMENTS FROM FA COMMUNITY
Parents & Family Members in the US

Crystal H.  
Yes, in hopes of having a better quality of life, even if it only helps a little.

D. Rolf H.  
FA is a unique illness. The Omav trial used the mFARS as a measuring stick of the efficacy of Omav. That measuring stick showed a distinctly positive impact on progression. However, there is another measuring stick that I hope you will consider - the direct and positive impact the Omav has had on the lives of the trial participants. Only they know what Omav has meant to them and their activities of daily living. Only they know the true potential that access to Omav will mean to many others living with FA. Two of those ‘others living with FA’ are my daughters S. and R. S. is graduating from high school this year and will be transitioning to a wheelchair as she also transitions to college. R. will be entering high school next year and to date her body is very minimally impacted by FA symptoms. Without Omav, this will not be the case in two years. Please give S. and R. the opportunity to take this safe and effective drug now, please give S. a chance to slow the progression of FA while she transitions to college and please give R. a chance to walk across the stage at her high school graduation in four years. The voice of those that have had the opportunity to participate in the MOXIe trials is loud and it is clear. I ask you to please consider it and the impact this safe drug will have on so many others.

Daniel H.  
Yes.

Danielle H.  
Have not had

Danielle H.  
We would be so grateful to have omaveloxolone for our child. He has declined so rapidly in the past year its devastating to see & his quality of life is diminishing as the minutes go by... we are willing to do and try anything that could help him at least reach his teenage years without being completely crippled by FA. The child is 9 years old and can barely walk anymore, falls so much he gets bloody noses & other injuries, has trouble making friends because he can’t keep up which effects his psychological health, and has no control over his own body whether it be periods of incontinence, cramps, spasms, choking on water because his hands are so shaky, etc. We desperately plead for the release of the drug Omav. Our child’s life means something, and this is a chance for him to lead a more normal life & be a part of society. Please consider. Thank you!

Dave H.  
Yes, they study results have convinced me my daughter can be helped by this and the sooner she gets it the better she will be.

Deborah H.  
Yes. She’s deteriorating rapidly.

Diana H.  
Yes, my 14 year old nephew has FA and he needs this drug to hopefully stop the progression of the disease.

Donald H.  
I’ll leave this to the discretion of their mother; I’d like to give her the option.

Donald H.  
Yes, we want the option of taking the drug. It seems to be safe and effective, and it is recommended now by the parents neurologist.

Donna H.  
Yes my child would to help her walk!

Elizabeth H.  
yes would try anything that might help

Fauna H.  
Yes, my cousin responded well to the trial! Thank you!

Gail H.  
My niece is in her 30s she has lived with fa since grade school. Mu nephew also had fa he died in his 30s due to a tragic accident in his whrl chair. This disease is tragic. The medicine is worth the risk. It has to do with quality of life not quantity. Let the fa families decide on this drug.

Gail H.  
Yes – this drug has a good chance of stopping the devastating effects of FA.

Gina H.  
Yes! This drug has shown to be beneficial for people with FA. I want my daughter to have the best life and this gives her a great chance.

Greg H.  
I’m sure my mom would try it

Heather H.  
I would love for my son to have the opportunity to take omaveloxolone. As of right now, we have no options to try an slow or stop the progression of this horrible disease. At least Omav gives us a chance to slow the progression and help improve some of the symptoms. Some hope is better than no hope at all. Please give us in the FA community the chance to take this drug that we believe is safe and effective.
<table>
<thead>
<tr>
<th>Name</th>
<th>Comments</th>
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<tbody>
<tr>
<td>Holly H.</td>
<td>Yes - we would be grateful for a therapy that slowed disease progression. The March of progression is relentless.</td>
</tr>
<tr>
<td>Isabelle H.</td>
<td>Yes because it slows down the progressing of the disease</td>
</tr>
<tr>
<td>James H.</td>
<td>Yes my son wants the option to take it</td>
</tr>
<tr>
<td>Jane H.</td>
<td>Yes. I think everyone needs to have the choice about taking potentially helpful drugs. As long as they are also aware of the side effects. The government should not make decisions about people’s health, they should give information. My body my choice..</td>
</tr>
<tr>
<td>Janet H.</td>
<td>Yes, my son would like the option to take this medication.</td>
</tr>
<tr>
<td>Jason H.</td>
<td>We have 2 children with FA, D., 18 and S., 14. D. uses a wheelchair full time, is struggling with his fine motor skills and speech. He has diabetes and hypertrophic cardiomyopathy. All of this is due to FA. S. currently has mild symptoms but is well aware of what her future holds. Based on the safety and efficacy data available about omaveloxolone, we would whole heartedly have our children take this drug. The potential benefits for a pause in their symptoms drastically outweighs any risks.</td>
</tr>
<tr>
<td>Jason H.</td>
<td>Yes if it offers a possible cure or to curve the symptoms</td>
</tr>
<tr>
<td>Jeannine H.</td>
<td>My 18 year old grandson was diagnosed at 2 and is in a wheelchair totally dependent on help. My granddaughter at 14 also has FA but not showing any effects. Both of them would greatly benefit by having a drug of this magnitude showing success that would provide hope and possibly improvement for them. Thank you.</td>
</tr>
<tr>
<td>Jenna H.</td>
<td>Yes, in hopes it could help increase quality of life.</td>
</tr>
<tr>
<td>Jennifer H.</td>
<td>We have two children with FA and definitely would love to have the option of giving them Omav. Our son, D., has significant progression. He has been a full time wheel chair user since he was 9 years old (dx age 5) and relies on others to push him. He lives with scoliosis, diabetes, and hypertrophic cardiomyopathy. Our daughter S., is 14 and a freshman in high school. At this point she only has very mild scoliosis. She is a cheerleader and loves playing volleyball. We would choose to pause FA (even if just for a couple of years) to give both of our children a chance at rolling around the park by themselves or cheering for one more game. The benefits out weighs the risk ten fold for us. Our children have not participated in the study. D. did not meet the requirements and S. was too young. Please approve this drug.</td>
</tr>
<tr>
<td>Jennifer H.</td>
<td>Yes, my brother was diagnosed with FA at the age of 8 and is now 22. Ever since he was diagnosed, he has been part of many trials and would want the option of taking this drug/medicine with the hope his health will not continue to decline.</td>
</tr>
<tr>
<td>Jennifer H.</td>
<td>Yes. If the opportunity is available to try and slow the disease, it’s worth a try.</td>
</tr>
<tr>
<td>Jenny H.</td>
<td>I definitely want my son to have access to omaveloxolone! He was diagnosed almost 2 years ago &amp; is still ambulatory, though his symptoms are progressing. This drug could help him remain ambulatory until research is able to provide a better treatment, or potentially a cure. Without access to the drug, given his current rate of progression, it is likely he will be mostly reliant on a walking aid within 1-3 years. Once that is necessary, there are no guarantees that any future treatment will be able to reverse that need. The ability to pause his progression where it is now would provide a wealth of hope for the future, not to mention a load of self-esteem for a teenager on the cusp of starting high school and shaping himself into an adult.</td>
</tr>
<tr>
<td>Jessica H.</td>
<td>Yes, absolutely.</td>
</tr>
<tr>
<td>Jimmy H.</td>
<td>He is 24 years old. His coordination and balance has gotten worse. He struggles to tie his shoes and buttons his shirts. He is always fatigue. This drug omaveloxolone needs to be approved as soon as possible to slow the progression. Thank you</td>
</tr>
<tr>
<td>John H.</td>
<td>I definitely would want my 18 year old grandson (diagnosed at 2, in wheelchair and totally dependent on help now) to have the opportunity to take this medicine. The hope that this would provide to him is immeasureable. Thank you.</td>
</tr>
<tr>
<td>Joseph H.</td>
<td>Yes I would want my children to have the option of taking this drug. One of my children was on this trial and their progression slowed. Please approve this drug immediately.</td>
</tr>
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<td>Name</td>
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<tr>
<td>Josephine H.</td>
<td>I have seen my nephew deal with the consequences of FA for about ten years as it has placed more and stricter limits on what he can do. I don’t think he or anyone else with FA should have to wait, given the price of waiting, for this treatment which shows a good chance of abating some of his symptoms of FA.</td>
</tr>
<tr>
<td>Josh H.</td>
<td>Yes we would want the option to take the medication for both of my children.</td>
</tr>
<tr>
<td>Julie H.</td>
<td>Yes- This is a race against time. If there’s a drug that could be effective in slowing the disease, we do t have time to waste!</td>
</tr>
<tr>
<td>Karen H.</td>
<td>Yes I want my grandson to have every opportunity available to help improve his condition.</td>
</tr>
<tr>
<td>Karen H.</td>
<td>Yes. My nieces hope lies in the availability of MOXie. I don’t understand why the FDA would not approve the drug which had done well in trials. Those who suffer such pain, physical and emotional, from this wretched disease deserve this. If the COVID vaccine can be fast tracked then at least give patients MOXie. I beg of you on behalf of my niec, her parents, my family and all of the others whose lives have been destroyed by FA.</td>
</tr>
<tr>
<td>Kathleen H.</td>
<td>Yes, he has not participated yet</td>
</tr>
<tr>
<td>Kathryn H.</td>
<td>We would absolutely have our son take Omav. To think that there is a drug that has been proven to slow the progression of FA but we don’t have access to it is heartbreaking. Two years ago our son transitioned to a wheelchair full-time because walking had become unsafe. If he had had access to this drug he might still be walking. PLEASE, from the bottom of our hearts, approve this drug.</td>
</tr>
<tr>
<td>Kayleen H.</td>
<td>My Sister in law has been diagnosed with FA since she was 16. She is 50 yrs old now, I believe she qualifies for the medication trial it will help her be more independent if it works</td>
</tr>
<tr>
<td>Kim H.</td>
<td>Yes My niece would do anything to help the FA family</td>
</tr>
<tr>
<td>Kristin H.</td>
<td>Yes, I want my daughter to have access to omaveloxolone. When we saw the trial results, it was the first time my daughter had any sense of real hope since her diagnosis. I want to provide her every opportunity to hold off the effects of this disease. Omaveloxolone trials have proven a level of effectiveness that we are willing to sign onto.</td>
</tr>
<tr>
<td>Kyle H.</td>
<td>My step son has FA and I see him struggle daily with the simplest of task. Right now there is no medication to help those with FA. We believe Omav is the first step to start helping those with FA slow their progression. It is important this is made available sooner rather than later, as FA takes away abilities almost on a daily basis. Thank you for your consideration!</td>
</tr>
<tr>
<td>Lawrence H.</td>
<td>Yes, I have watched my nephew grow up with FA and has heroically risen to the challenges to become a spouse, father and a terrific lawyer. He is a proponent of this medicine and I hope that you will please consider this request. Thank You</td>
</tr>
<tr>
<td>Leia H.</td>
<td>Yes I think it should be allowed for these individuals they deserve a fair chance</td>
</tr>
<tr>
<td>Lisa H.</td>
<td>I would want my children to have the opportunity to take any medication that may help their symptoms or progression with this disease that currently has no cure! Any improvements us life changing.</td>
</tr>
<tr>
<td>Lisa H.</td>
<td>I’d have to read up on it since she has it yet.</td>
</tr>
<tr>
<td>Lynda H.</td>
<td>My daughter has been living with the effects of FA for more than thirty of he forty years. I feel that the availability of Omav to her and others with FA could improve and possibly enhance her quality of life. Thank you in advance for quickly making this drug available.</td>
</tr>
<tr>
<td>Maria H.</td>
<td>We want our daughter to take Omav. We have no other options.</td>
</tr>
<tr>
<td>Maria H.</td>
<td>We would like anything that will improve my Grandsons quality of life</td>
</tr>
<tr>
<td>Mark H.</td>
<td>Yes, my brother and sister would try anything to feel better and hopefully extend their lives</td>
</tr>
<tr>
<td>Mark H.</td>
<td>Yes. Desperately want to try it. Please.</td>
</tr>
<tr>
<td>Melissa H.</td>
<td>Yes, my sister would want the option to take the medicine.</td>
</tr>
<tr>
<td>Michael H.</td>
<td>My granddaughter would welcome the option. Because her parents believe in science.</td>
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115
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<tr>
<th>Name</th>
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<tbody>
<tr>
<td>Michael H.</td>
<td>One niece missed the trial by 1 person, both nieces want desperately to get the medicine</td>
</tr>
<tr>
<td>Michele H.</td>
<td>Yes. They don’t have years to wait.</td>
</tr>
<tr>
<td>Mike H.</td>
<td>Yes I believe a person should have the option of receiving even experimental medication if they sign off on the risk</td>
</tr>
<tr>
<td>Mike H.</td>
<td>Yes we want the option to take moxie as soon as possible!</td>
</tr>
<tr>
<td>Nairn H.</td>
<td>Yes! Please. Every day this is delayed, is another day lost for my amazing nephew. The clock is ticking. FA has dealt him a death sentence. There is just no reason to leave any stone unturned in this desperate search for help.</td>
</tr>
<tr>
<td>Nancy H.</td>
<td>Yes. I would like to slow down the progression of the disease until a cure is found.</td>
</tr>
<tr>
<td>Pam H.</td>
<td>My cousin was diagnosed at 8 years old he’s currently 24. His speech is slowing and his balance and coordination has gotten worse. He holds on to things and needs a cane in open spaces. S. has trouble tying shoes buttoning shirts. Suffers with fatigue and scoliosis and NEEDS OMAVELOXOLONE (meds)</td>
</tr>
<tr>
<td>Paula H.</td>
<td>I am the grandmother of two children with Friedreich Ataxia. I know that all children are special, but J. and C. are exceptional! From day one of finding out about this horrible, debilitating disease, J. and C. have, without hesitation, done all they could do to help the research on FA. J. and C. have willingly participated in clinical trial after clinical trial, with the belief that even if they don’t benefit from the research themselves, maybe, in the future someone with FA will. Omaveloxolone is a drug which has been shown to be effective in stopping or at least slowing down the FA deterioration, and gives the FA patients hope and improvement in their quality of life. If the FDA approves Omaveloxolone its use will improve the quality of life of the FA patients, and give a respite to the FA patients, while the cure for FA is discovered.</td>
</tr>
<tr>
<td>Richard H.</td>
<td>Yes, urgently</td>
</tr>
<tr>
<td>Richard H.</td>
<td>Yes. There needs to be options.</td>
</tr>
<tr>
<td>Rita H.</td>
<td>Yes I want my 14 year old grandson on omave ASAP. I see him failing everyday.</td>
</tr>
<tr>
<td>Robert H.</td>
<td>We would like the option especially since there are not other treatments at this time.</td>
</tr>
<tr>
<td>Robert H.</td>
<td>Yes, both my daughter and I would want the opportunity to benefit from taking Omav with the goal of enhancing and extending her life. She has struggled with the effects of FA for more than thirty of her forty years. Her husband and her two young sons also would appreciate the chance to see improvement in their wife/mom’s life. Thank you in advance for your help.</td>
</tr>
<tr>
<td>Robert H.</td>
<td>Yes. We would try almost anything to improve his quality of life.</td>
</tr>
<tr>
<td>Robert H.</td>
<td>Yes. Our son is willing to try anything at this point.</td>
</tr>
<tr>
<td>Robert L H.</td>
<td>I am the Maternal Grandfather of J. and C., both of whom are valiantly dealing with the progression of FA. I call upon the FDA and Reata to do whatever is necessarily to immediately get approval for the use of Omaveloxolone to attempt to stop the progression of the FA. Because there is seemingly no detrimental side effects, I see no reason why the drug should not be used.</td>
</tr>
<tr>
<td>Robyn H.</td>
<td>Please give my nephew the option to try omavelocollone. Everyday his symptoms worsen. Please give him this chance.</td>
</tr>
</tbody>
</table>
Ronald H.  Yes want the medicine

Ryan H.  Since our daughter was four and a half, we have watched her decline, hitting milestones in reverse. Her gait widened, her falls increased, system after system was reported to be impacted as we went on the medical journey of, what is happening to our daughter? We have watched the tearful frustration when she cannot keep up with other children and adamantly says, I hate recess, no one plays with me. She is losing her vision with only 26% of her cones functioning in both eyes and no rods. She has lost peripheral vision, night vision and with fingers that struggle with neuropathy, she is attempting to learn Braille so when full darkness comes, she can still read. She struggles at times to hold a fork and spoon, she cannot walk without stumbling, she cannot ride a bike, she cannot play catch, she cannot navigate stairs without assistance, and we are left to watch, helpless. She is now 8 and her heart condition is that of advanced FA, meaning that she has a 20% chance of dying before she turns 18. While other parents are preparing their children for middle school, high school, musical endeavors or upcoming sports tournaments, we think about preparing her for the solitary confinement to which FA condemns its victims. Omavaloxolone’s top line data has shown statistically significant data that it slows disease progression. It is not a cure but it buys us time. We have read through the research, we understand the data, and we would choose to give our daughter this drug if it is made available. She is dying, we try to avoid this fact but it is happening before our eyes as more and more part of her body begins to fail. Additional trials take time and time is not something we have as FA steals more and more every day. We have NO other options, we have NO other treatments and we can’t afford to wait. We have watched A’s decline over the years, and that decline pick up speed again in the last six months. All we are asking for is access to a drug that could give our daughter a fighting chance. Please consider moving forward with the approval of Omavaloxolone. A is an incredible child. Despite it all, she has tested off the charts as gifted in the area of creative thinking. She has so much to offer the world if she just gets a chance to live.

Ryan H.  Yes, if there is a medicine to help with FA, they need the option for it. It is very hard watch two of my brothers battle the disease.

Samantha H.  My sister passed two years ago, but she would have taken this drug 100%.

Sandra H.  My granddaughter R. was diagnosed with FA 8 years ago, at the age of 12. Please allow R. to take this drug.

Sara H.  Yes. I would.

Scott H.  They’d absolutely want the option!

Shannon H.  Yes. I believe my siblings would take any opportunity to improve the quality of life they experience because of FA. If there is at all a slight chance that their severe symptoms can be improved, or at least progression slowed, they would take the medicine. It would mean the world to our family for them to have an opportunity for treatment.

Shayla H.  Shes still young, I haven’t done alot of research regarding this drug specifically but she deserves the best and if this will help them she deserves a try.. she’s the one that told me about this and to please answer the questions. Thanks and I hope and pray this will help FA families around the world!! God bless

Sherrie H.  As a parent it is hard to watch your child ability to live a normal life deteriorate. If there is anything that can slow the progression of the disease and allow them to live an independence life they need it now.

Stacy H.  Yes, if there’s a chance it would help her.

Stephanie H.  Yes, we’d love for my dad to take it. He’s late onset, 62 years old so has never qualified

Susie H.  Yes I would because it has shown to be effective in has been shown to improve neurological function in people with FA in well-controlled clinical trials. Omav has the potential to prevent long-term consequences, slow progression of the disease and improve FA symptoms by addressing the underlying pathologic processes associated with inflammation, mitochondrial dysfunction, and oxidative stress.

Terence H.  Yes. FA is a sentence to a slow death. Imagine!. And remember Kingsley’s “Mrs Do-As-You-Would-Be-Done-By.”Let’s go! Covid vaccine sets an example for the bureaucrats.

Teresa H.  Yes, because we have heard of the positive results from the data collected.
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<tr>
<td>Teresa H.</td>
<td>We have 2 adult children diagnosed with the progressive Friedreich's Ataxia. They have not been able to have access to Moxie. Their symptoms are continuing to worsen. Please make this drug available. We attended the voice of the patient meeting in 2017 with the FDA, please collaborate with Reata, FARA and the fragile and amazing group of people with FA. As a parent, it is heart wrenching to watch our children lose everyday abilities. Please accept the positive data given with the clinical trial for the drug Moxie. Give our children hope. Give this mom hope.</td>
</tr>
<tr>
<td>Thomas H.</td>
<td>Yes. The data represent safety and some efficacy. I don’t see a downside.</td>
</tr>
<tr>
<td>Tom H.</td>
<td>Our family with two suffering from FA is a hard thing to live with. One was lucky enough to be in the study and the other did not. So hard to see the improvements in one child and the progression in the other. I need both children to have a fighting chance against this terrible disease.</td>
</tr>
<tr>
<td>Tonya H.</td>
<td>Yes my niece has FA and I would want her to take something that will help!</td>
</tr>
<tr>
<td>Tori H.</td>
<td>Yes my cousins both have FA and would choose to have the option to improve their quality of life if this drug may help.</td>
</tr>
<tr>
<td>Trisha H.</td>
<td>Yes I will allow my child to try anything that has been proven to help even if it was just a little bit!</td>
</tr>
<tr>
<td>Tyler H.</td>
<td>If it helps, I would want them to take it. As a family member, I know the importance of medicine and how it can help!</td>
</tr>
<tr>
<td>Valerie H.</td>
<td>Yes, I would love for my grandson to take omaveloxolone. I feel it is safe and we have nothing else to fight this heart breaking disease. I pray it will be approved.</td>
</tr>
<tr>
<td>Vera H.</td>
<td>Yes recommended by doctors</td>
</tr>
<tr>
<td>Vicki H.</td>
<td>Yes. We would want the option of taking any drug that has the potential to delay progression and/or increase the quality of life.</td>
</tr>
<tr>
<td>Virgil H.</td>
<td>This Is Ground breaking. Our Children All Need This Drug/Treatment, We/I Have Been Fighting For A Treatment For The Last 10 Years, Please Make This Drug Available For J. 25 F.a And All.</td>
</tr>
<tr>
<td>Wendy H.</td>
<td>Our niece has FA. This option should be available for her if she chooses to use it.</td>
</tr>
<tr>
<td>William H.</td>
<td>Yes. So far through part 1 and part 2, it has been safe and effective, therefore it is worth the risk to continue to advance the study.</td>
</tr>
<tr>
<td>Diana I.</td>
<td>yes, they need help soon. If they could come up with vaccinations for covid, now let’s get help for ataxia.</td>
</tr>
<tr>
<td>Dorris I.</td>
<td>Yes. I remember my grandson with so many basic human capabilities. I want to see that again!</td>
</tr>
<tr>
<td>Eileen I.</td>
<td>Yes she would take the medication</td>
</tr>
<tr>
<td>Elizabeth I.</td>
<td>Yes. Please allow this drug for individuals with advanced FA. She will die and should be able to try a drug that could help sustain her life for a bit longer. Thank you.</td>
</tr>
<tr>
<td>Mary I.</td>
<td>Yes they do want the option to start the medication. Delaying is not an option.</td>
</tr>
<tr>
<td>Michelle I.</td>
<td>Yes if found to be safe</td>
</tr>
<tr>
<td>Sherry I.</td>
<td>Yes, husband father of 5. and his sister a mother of 3 has FA.</td>
</tr>
</tbody>
</table>
Andria J.  
Sir / Ma’am, Good day. I hope this message finds you and yours well. My sister has been living with FA for approximately 20 years; diagnosed at 17 and now 38 years old. Since her diagnoses to present, she has been the epitome of positivity in the face of adversity. She exemplifies ability despite massive physical limitations imposed upon her by a debilitating condition. She inspires me daily. Supported by a phenomenal husband and model children, she has not allowed her condition to dictate any limitations in her life and those around her. Even with her positivity and determination to be abled in every facet of life, there have been multiple instances in which we were fearful for her; such as falling several times while pregnant and requiring medical monitoring. We are blessed that she has comprehensible speech and maintains upper body control. We pray her condition does not further degenerate. We cannot imagine and do not want to ever see her loose any more mobility or capability. It is frightening to consider. We feel that the risks associated with Omaveloxolone are worth taking, if it has any potential of halting the degeneration or return control in any degree. We know her to be very cautious and conservative with with taking any and all medications. So, if she is volunteering to take Omaveloxolone, it must be truly worthwhile prospect. We are all encouraged by it and feel strongly that our sister would be a great candidate. We are grateful for your consideration.

Arlyn J.  
Yes, I believe omaveloxolone can be a breakthrough facilitating lifestyles of those being or beginning to be affected by FA, thus bringing hope.

Bonnie J.  
Yes, there has been remarkable results in slowing down his progress. He has part of the study when they lived in LA.

Brian J.  
Yes they would want to take it.

Brian J.  
Yes, every time we visit we notice a deterioration and it breaks our hearts. These grandchildren are so smart and only want to be normal.

Caitlin J.  
My siblings, J. and C., have FA. If they got omaveloxolone, they could walk and play more with me. It would also be really nice to have them help more with doing dishes and cleaning the house. When I’m reading a book and about to find out a really good part, I wish I could stay there and read, but there are lots of times when I get interrupted because J. needs help getting something or doing something. I don’t mind helping him, but sometimes it would be nice if he could help himself. I really hope they can get omav!

Danielle J.  
We absolutely want the option of taking it as it is slowing the progression of my brother’s FA. It feels miraculous to have a treatment that works.

Dayle J.  
We want our grandchildren to have the Moxie drug. Please approve so they can benefit now. They cannot wait until another long trial. We know people who are taking the drug and it has improved their quality of life.

Diane J.  
Yes, any drug that can help with a fatal disease needs to be available to those wishing to try it.

Donald J.  
Yes, both of them would welcome the opportunity. They believe that their time is running out for a treatment.

Elaine J.  
We have 2 children with FA. As 19 year olds, they would like the option of taking this drug!

Eleanore J.  
My sister C. is really good at calligraphy and I want her to still be able to teach me how to write that neatly. Without this drug, she probably won’t be able to teach me for much longer. When her FA gets worse, she will only be able to tell me with words instead of showing me how. If she got this drug, she could help me through the hard parts. My brother J. is really fun to play with outside, but he can’t run around with us anymore. If he gets this drug, then he will be able to run and play games with me and the rest of my family again. I really hope that J. and C. get this drug.

Ernestina J.  
I have two children who have FA and access to omav is critically important to them. I have watched them suffer since they were kids as they have gradually lost many of their functions to the point of losing their independence, ability to work, pursue their dreams and enjoy life. They have been transformed by this brutal disease. I am 80 years old and have been taking care of the younger one of my children for over 20 years. It has been a full time job that keeps getting more onerous. The toll of this disease on them and my family has been extraordinary. Any opportunity to slow or even push back the effects of FA would be incredible. Please do not delay access to omav. We are willing to assume any risks that it may entail. Such risks cannot be worse than what my children are facing now and the prospects of more deterioration.

Haley J.  
Yes, he would want the option to take it.
COMMENTS FROM FA COMMUNITY
Parents & Family Members in the US

Haydee J.  
I have two siblings who have FA and access to omav is critically important to them. I have watched them suffer since their teenage years as they have gradually lost many of their functions to the point of losing their independence, ability to work, pursue their dreams and enjoy life. They have been transformed by this brutal disease. My 80 year old mother has been taking care of one of them and simply cannot continue anymore. The toll on them and the family has been extraordinary. Any opportunity to slow or even push back the effects of FA would be incredible. Please do not delay access to omav. We are willing to assume any risks that it may entail. Such risks cannot be worse than what my siblings are facing now and the prospects of more deterioration.

Jacquelyn J.  
Yes, my nieces are very advanced in the disease and need any treatment that would help their condition.

Jamie J.  
Yes please

Jay J.  
Yes, we think the option should be available for the individual to make the decision with their doctor.

Jeffrey J.  
Yes, absolutely. The current data shows the benefits greatly outweigh the risks

Jennifer J.  
I believe this will help, and shouldn’t take any longer to approve.

Jessica J.  
Yes to minimize the symptoms

Jessica J.  
Yes, watching this disease destroy my 10 year old cousin has being hurting all of us on the inside. These people need some kind of hope! We all do. And these drug will help alot of people. It been 2 years since my cousin was diagnosed and he is already in a walker and cant even shower alone. Please release this drug.

Juanita J.  
We know participants taking the MOXie drug and it has helped them. We want our grandchildren to have the opportunity to take the drug now before they get any worse. Please approve!

Judi J.  
YES, ANYTHING TO HELP WITH THE STEADY PROGRESSION OF FA AND THE ABILITY OF DOING ADL

Kenneth J.  
Yes. Both my niece and nephew have FA and both are losing more and more mobility and function as time goes on. Both are aware of the finality and projected course of this disease and both have participated in many research studies (which are not pleasant). They are doing their part of find a cure for FA. Studies to date of omaveloxolone indicate that it is safe and effective. I hope and pray that the FDA grants emergency approval of this drug to slow down the progression of this horrible disease. Imagine being 14 and experiencing the impact of this disease on your increasing frail body and knowing worse is to come. Imagine again being his 12 year old sister with the same disease, experiencing some of the same symptoms, and knowing that what her brother is going through now will be happening to her in a year or two. Please grant this approval.

Kristen J.  
Yes. FA is a terminal disease taking lives that are far too young. This drug could give those patients hope for a longer and better future.

Linda J.  
Yes Two girls in our family are both already wheelchair bound and face increasing challenges to their mobility. Any medicine that would halt or reverse degeneration would help maintain some level of independence and ability to function.

Lori J.  
Yes! Please

Lorna J.  
If it could help then yes.

Matt J.  
Yes, anything to help either reverse or stop progression of FA
FA is a devastatingly relentless disease. Tragically, my two oldest children have been diagnosed with FA, and we are watching this disease ravage them day after day. There is no ceasing. There is no relief. But there could be. And, it’s up to you to help them. You have the power to give J. and C. a pause from the devastation of FA. You have the power to move forward with an NDA for omaveloxolone. We have closely evaluated the data from Reata’s omaveloxolone studies. They are persuasive to our family! We understand what omav is…and what it isn’t. We know that it’s not a cure. But, it is a pause. It’s a safe pause. And a pause could be the difference between my kids becoming fully wheelchair dependent vs remaining ambulatory. Fundamentally, this is conversation about time. FA is moving faster than any of the treatments currently in the pipeline. We urgently need FA to slow down. We need it to stop stealing so much function from our kids, so that they can be strong enough to benefit from the other treatments that are on the horizon. Omaveloxolone would do just that. Omaveloxolone would help this disease slow down long enough for other breakthrough treatments to emerge. We all know the breakthroughs will take several more years. These are years that my children don’t have. For perspective, please consider the following: In 2015, when Reata enrolled its first patient in the Part 1 MOXie study, neither of my children were diagnosed. Our family had never even heard of FA. In 2017, when Reata announced positive results from the Part 1 study, my son was an active player on his school’s soccer, basketball, and lacrosse teams. In 2019, when Reata announced Part 2 of the MOXie Phase 2 met its primary endpoint (with observable clinical improvements), my son was ataxic, but still able to walk independently. In 2020, when Reata announced the positive results of the open-label extension study, my son had become dependent on his walker. We don’t have time for another clinical trial. J. and C. need intervention NOW. They have no other options. Their situation is urgent. Their future rests on your decision. Please hear us.

Yes, my family member wants the option to take the drug before the illness progresses to much

My son has paid the price of this disease. I can see the fear and worry in his eyes every time I dress him or help him go to bathroom or the countless other things that he needs help with on a daily basis. Not to mention the pain and sleepless nights. I made the mistake of getting his hopes up about this drug and been following it’s development for quite awhile thinking they were expediting it’s approval. I believe it’s time for FDA approval and give these kids a chance.

Yes, my daughter has FA (diagnosed in the last year, but shes had symptoms for approx 5 years…we just didnt know what was causing it until recently. F. would love the opportunity to take the medication and have it to hopefully stop the progression of her symtoms. She is just starting her adult life and shes so scared after being diagnosed and not knowing how quickly it will progress. F. is so smart…6th in her graduating class but FA is already beginning to rob her of her dreams (not only physically but emotionally) we would be forever grateful if she was able to take OMAV and have it hopefully stop her progression of fa. She is already losing some motor skills and shes almost ready to go to college, but of course its a huge concern to send her off on her own. This drug could truly give her the opportunity to live her dreams without the daily fear of her losing more independence.

I’m the grandparent of two grandchildren with FA diagnosed 4.5 years ago. Their decline has been horrific and swift. It’s torture to witness their loss of abilities every time we see them with the realization they will only continue to get worse as there is no treatment no cure. The hope that omaveloxolone had provided was dashed with the FDA’s recommendation of more clinical trials. We were with them the day of the FDA dictum; we as adults we’re trying to deal with the abrupt hopelessness we felt, but our oldest grandson (with FA) just sat on the couch and silently wept - I’m crying now as this memory replays. How can you take this hope away when the certain path of this disease is progressive loss of all abilities (except mental capabilities) and early death? Those with FA and their families know that two years in their lives means progressive loss of abilities and for some death. They are more than satisfied with the results of the current clinical trials of omaveloxolone and urge you to listen to their pleas to approve this medication to help provide hope and delay of this disease progression. Listen to them and take the right path toward this medication’s approval now!!
Misty J.

What would Omav mean to my family? Based upon the safety and efficacy of Omaveloxolone (Omav), my son and our family would definitely want the option to take the drug. Since 2011 when we first heard the diagnosis Friedreich’s Ataxia (FA), we have had to learn a new way of life. He was a ‘normal’ 9 years old boy who was enjoying the innocence of childhood. We have grieved many losses since that time, from dreams and ideas of what we thought our son’s life might look like, to his loss of function, friends, goals, etc., as a result of the havoc FA was causing. Since that time, we stopped living as though we were preparing for my son to die, and now focus on the “living”. The Omav results we saw in 2019 that are statistically significant, provided us hope. It has been said the improvement seen in the clinical trials are equivalent to gaining 2 years of function back. Wow! I am thinking of the difference we saw in a matter of 2 days back in Aug. 2017, when after a couple of falls at school, our son no longer had the confidence to walk without someone holding onto him. Change can happen rather fast in FA. They can be fine doing something one day and within days be unable to do it. We never know when something will be the “last”. The last time my son runs and plays, the last baseball game, the last bike ride, the last time he goes to Taekwondo (after earning his black belt) or Arnis (a handful of belts away from black) because he no longer feels he can stand up long enough, the last time he can participate in archery, the last time he gets behind the wheel of a car to learn to drive like his friends, the last time he stands on stage playing the viola or singing in the choir, the last time he walks by himself. It is heartbreaking! Omav is the only treatment option we have ever had. There is nothing else right now. We understand it is not a cure but would rather allow us to push the “PAUSE” button on my son’s life. If he were to be able to take this drug today, in 2 years he would be graduating with his degrees in Psychology and Neuroscience and be heading towards medical school. I see that happening with his current physical abilities. If he were to lose more physical function over the next 2 years, his dreams may become more of a challenge. Our son after 9 years is still walking with us. He is and has been fighting, because we believe that a treatment will come, and he needs to be in the best physical health to benefit from it when it happens. Well, it can happen with Omav. We pray that Reata and the FDA will show compassion on our small and rare population of mainly young people who are battling to live and be gracious and merciful to us. Reata, please submit the NDA for Omav on an urgent basis for us. And, FDA board, please exercise your flexibility that is granted by law and in your guidance in approving an NDA for Omav in FA based on the amazing evidence you can see from the clinical trials. We don’t have a huge number of FA patients to do repeat trials and we are running out of time. We are satisfied with the results of the single trial and are willing to take the chance. Please take a moment and consider, what if this were my child? What if you woke up tomorrow and heard FA is now your reality? What would you do for your child, grandchild or even yourself?

Natalie J.

Yes he would be interested!

Pat J.

We hope the omaveloxolone will be available as soon as possible.

Patricia J.

my granddaughter is 29yrs she has never been eligible for a clinical trial as she has vision loss and unable to walk at all.

Patrick J.

Yes, my mother needs omaveloxolone. We believe the positive benefits far outweigh the potential side effects

Peggy J.

Yes, my grandson is just about out of other options.
Randy J.

I am writing as a parent to five amazing children, two of whom have Friedreich’s Ataxia. They were not involved in the clinical trials and don’t currently have access to omaveloxolone. My request to you is simple and direct: Every person suffering from Friedreich Ataxia should have access to omaveloxolone right now. It is safe, it is effective, and we have nothing else. So, I am asking Reata and FDA to proceed with a new drug application, to quickly review it, and to approve omaveloxolone. This relentless disease is progressing so fast in J. and in C. that we do not have time to wait for another clinical trial. FA is a thief. Each and every day, I watch FA steal more and more from J. and C.. This is the nature of the disease; there is no pause and there is no rest. Things that were easy three months ago are now harder and things that were routine a year ago are now impossible. omaveloxolone - a drug we know from the data to be very safe and effective - offers us a pause button. The data are clear and persuasive: omav gives back points on the mFARS scale. And these points are a true gift - a meaningful and impactful respite from FA’s incessant theft. Omav is not a cure. We know this. But we also know that omav is all we have right now to stop or meaningfully slow what FA is stealing from J. and C. Over a year ago when the positive results of the omaveloxolone clinical trial were announced, we will never forget J.’s reaction. Tears of relief streamed down his face at the news that there was now something that could pause, and maybe even give back, some of the function that FA had stolen from him. Imagine if we had omav’s pause button even just a year ago. Back then, J. wasn’t dependent on his walker. Back then he wasn’t watching his fine motor control slip away. Just one year ago, J. wasn’t having bladder control issues. Imagine now, if we had omav two years ago, when J. was still playing basketball and lacrosse with his school teams, still hiking and camping with his Boy Scout Troop. That time has passed for J.; but FA continues to steal from him nonetheless. Without a pause, J. will lose even more. He will not dance at school dances, will not drive a car to hang out with his friends, and may even lose his greatest passion - creating digital virtual effects on his computer. But imagine if we could put a pause button on J.’s FA right now - to stop it or slow it down from stealing all of that from him. Omav offers us that. The battle is different for our daughter C.. She is just now beginning her fight with FA and it hasn’t stolen as much from her - yet. We know that without omav, J.’s losses will become C.’s losses. We’ve seen C. fall more often in these past few months. She knows – as we do - why she’s falling, but the reality of FA is too grim for her to acknowledge. So, she blames this fall on an untied shoe, and that other one on a loose rug. When she thinks we’re not looking, we see how she studies J. and his walker. We see her as she stares at that walker with a hollow sense of fear and dread and dark inevitability. We know her well enough to understand that she’s steeling herself for the inexorable; as best a young teenage girl can, she’s struggling to accept the reality that confinement to that same walker and that everything that follows will soon be hers as well. You have the power to pause this – to prevent this from becoming her reality. Right now, only omav offers us that; we have nothing else. Please understand this: my kids are running out of time. We can’t stand by and watch and wait for another full clinical trial to occur; by the time that finishes, FA will have stolen so much more from both of them. Omav can pause this. Omav can buy us time. We have studied the data, we know this disease, and say with confidence: Omav is safe. Omav is effective. Right now, omav is all we have in this fight. We want omav, we need omav, and without omaveloxolone, we will continue to watch these amazing kids, day by day, lose their fight against Friedreich’s Ataxia.

Roger J.

My son was a gifted athlete before he got this, became very depressed. Turned his life around and got a degree from college, got married, and now has a 7 year old daughter. I am so proud of what he has done with his life, but would love to be able to see him the way he was.

Sam J.

Yes! At this point, she just needs something. ANYTHING to start to slow or even stop this degenerative process! Please I’m begging. With COVID trials could take years and she is more than willing to take the vaccine without it being tested.
Sandra J.

S’s Story: The only child of my niece and her husband was playing football and sports in JR high to having difficulty ambulating across the stage at his high school graduation. He was diagnosed with FA at age 13. As his friends moved away to college he had to decline and perform online classes. As his driving privileges were taken away he became totally dependent on others to provide any transportation. His Mom had to resign from her job to care for him and his ADL. He is now 24 and his friends visit him as often as they can, but he has watched them start careers, get married and a couple start families, while he is home losing more of his functions daily. Any hope of a treatment to slow or reverse this debilitating disease much less a cure is what we have all been waiting and praying for over these 11 years. Time is of the essence. Please, please approve Omaveloxolone for use so these victims who are starting their lives or in the prime of their lives have some hope of normalization. At this point this drug is the only hope. My brother had a patient that he watched grow up with FA. He first came into his office walking advancing to stumbling to walker to wheelchair over the years. After his high school graduation and his friends went on with their lives, he was left to deal with this progressive debilitating disease. His parents came home from work one day to find he had committed suicide leaving a note that he couldn’t bear another day with this disease and he no longer wanted to be a burden on his parents. He was their only child. Without hope you have nothing. Again please approve use of this drug to give some hope for these FA patients.

Scott J.

Hi! I’m helping R. send this out. He is hoping that this drug will get approved before he gets worse.

Scott J.

Yes, we would like our son to take the medicine. We would love to have his FA paused or having him gain 2 years and possibly walk better again. We would love for him not to struggle as much getting around and be more comfortable at friends houses and school.

Tamika J.

My Daughters 12, still trying to get diagnosed, dad family has 6 generation of disease, some died, some still living aggressively with disease.

Thomas J.

Hi, my name is T., I am 8 years old, and I have a brother and sister named J. and C.. They both have FA. It would be really nice if J. didn’t need help with bringing his lunch over to him, with getting things like peanut butter for our lunches, and with turning off the lights in our room at bedtime. I really like playing football with J., and if you approve this drug, then maybe we can keep playing football. Right now, C. helps me with a lot of things, like making sure I put away my laundry and make my bed. If omav doesn’t get approved, then she won’t be able to help me with these things anymore. Please approve omav so my brother and sister can get better.

Thomas J.

After watching my child live with FA at such an early stage in her life is crushing to know she won’t ever play sports or run around with kids to play tag without hurting herself. Through all of her trails she hasn’t given up if there is the smallest of chance to stop progression or reverse effects. All deserve that chance

Abby K.

I would definitely want my family member to have this medicine. I would encourage her to take this drug, as I know she would definitely need/want to take this drug.

Alyson K.

Yes. My family member would absolutely want the option to take drug. She is in her 20’s and is looking for any option to prolong her health and stall the progression of this disease.

Amanda K.

Yes. This may be my cousin’s only option left.

Amol K.

Yes…would like my niece to avail of this experimental drug to attempt to improve quality of her life

Amy K.

Based on the data available from the trials for omaveloxolone, I would like people living with FA to have access to this drug. I think this drug would help improve the symptoms caused by FA. If another trial is needed to approve this drug, it will take multiple years to get approved. This is a problem for FA patients because a few years of progression means major life-changing losses in function. From seeing the successful data produced by the trials, I think omaveloxolone should be made available for the all FAers.

Amy K.

Yes my father whom is wheelchair bound would like the option to take this med as we seen a great benefit from it in others.

Amy K.

Yes, this would give my nephew and his family hope for more tomorrow’s.

Angela K.

Please pass this for the children who need it.

Ann K.

Yes my son wants to try this medication
COMMENTS FROM FA COMMUNITY
Parents & Family Members in the US

Annemarie K.  
I believe he would like to choice to take omaveloxolone or not

Art K.  
Yes she would!!--As J.’s Step -father, I have known her for over 20 years and she was already diagnosed with FA. I have seen the effects that FA has put upon her. When I first met her she was able to walk un-assisted and quite well with very minimum foot drop. She has progressed to today to not being able to walk un-assisted and is for the most part confined to a wheelchair. Despite all the difficulties FA has put upon her, she is the most optimistic person I know. She works tirelessly home schooling her 5 children and is an excellent home-maker. I admire her countless accomplishments. In addition she has recently completed an H&R Block tax school and is now working part-time doing taxes for H&R Block clients. I feel she is an ideal candidate for Omaveloxolone and so I encourage you to submit a new drug application with the FDA in an attempt to make it available to her and all FA patients.

Arthur K.  
I would want my family members (more than 1 are affected) to have the option to take omaveloxolone.

Ashley K.  
Yes we would absolutely want to take the drug. My son is only 9 and he started showing symptoms at age 4. The past year he’s lost so much of his ability to do things on his own. He’s not able to get dressed on his own, shower on his own, walk up and down stairs on his own, he no longer can write on his own and needs assistance in school. He no longer can participate in school sports or activities or even just trying to keep up with friends and family while playing is so hard. Every kid his age wants to run and play and just be a kid well my son J. who is the sweetest, caring, loving, funny boy is no longer able to do much of that. It’s heart breaking to watch your child progress each day and watch him fall more and more and get upset and frustrated that the things he was once able to do he no longer can. He asks me everyday is there a drug to make this stop or to help him and the fact I can’t say yes and to see his face when we have to say hopefully there will be a drug some day that will help you is heart breaking. Please approve Omavaloxolone

Ashley K.  
Yes. Whatever it takes

Brenda K.  
My cousin has been dealing with this her whole life and deserves a chance. This should be her decision.

Carol K.  
Yes, she would take this with the Hope of daily living improvements.

Charlotte K.  
My mom has FA. She would do anything for even just the slightest chance to stop the progression of her illness. As I have grown up, I have seen her illness progress, and the effects it has on her physical and mental health. Action needs to be taken not just for my mom, but for everyone experiencing FA. Please

Christopher K.  
My wife has it since we met in 1991.

Colten K.  
Yes, our cousin has seen experienced some vast improvements from being a part of this clinical trial. She is a young mother and wife. I believe having something as an option for her and so many others experiencing FA is crucial as it would be if we found something similar for all things as horrible as FA is.

Deborah K.  
Yes. With so little known about FA, if it helps at all, it’s worth a try.

Ehsan K.  
Yes, the current data safely suggests the efficacy of the drug. Please allow the drug to be used for the FA patients.

Frank K.  
Yes. It is heartbreaking to see my wife with little or no hope. This would provide much needed hope

Ilene K.  
This is surely remarkable. My niece would definitely welcome the new drug with open arms. My prayers were answered with this new development.

Isma K.  
Yes, the children would participate in taking the medicine because they need it !!! They require assistance in lots of daily activities.

Janice K.  
It would be wonderful if further deterioration could be alleviated.
COMMENTS FROM FA COMMUNITY
Parents & Family Members in the US

Jared K. Yes. My mother has had FA since she was in her early 20s, and for as long as my two younger siblings and I have been living, we've always known her to be in a wheelchair. There has been no development to improve her quality of life and it's gotten to the point to where I'm nervous to leave my parent's house - I too have become a primary caretaker for my 49 year old mother. My mom has been involved in a few studies over the years through U of M, but nothing has ever been proposed to improve or delay her deteriorating condition. She has been seeking assistance for years. Having diabetes and overcoming congestive heart failure, she's worked and continues to work hard to stay healthy through smart food choices and exercise with two pound hand weights. I'm certain my mother would be a good candidate for this drug, might it ever become available. She's as healthy as her condition will allow her to be and will do anything to improve her quality of living. Thank you.

Jason K. I believe that if this drug can slow down the progression of this horrible disease that we would be very willing to take this medication.

Jason K. Yes, because they just entered their early 20s, lost their career opportunity as a pilot with this diagnosis, and would take any chance to live past 35.

Jeremiah K. Yes I would want the option. There are no other treatments available and if something shows to be beneficial and safe in clinical trials it should not be held up by the FDA.

Jessica K. Yes, we would!! We have seen evidence that is truly promising, and any pause in this disease gives us precious time.

Joan K. I have 2 children with FA, please consider approval for Omaveloxolone!

Joanne K. I'm fearful as everyday passes that my niece will be more and more dependent. She faces this with courage and determination, but FA is inexorable. She needs this drug to continue to function in her high-level job and pursue her goal of starting a family. Please help by giving her your option to take this drug!

John K. Yes - would both want to take and would actually take based on current safety / efficacy information. Further testing unlikely given the structure of the FA community. Did not participate in study.

Kaitlyn K. Dear Reata and the F.D.A. My mother has been falling almost everyday when she is just getting up to use the bathroom and that is really hard for her. She has 5 kids and we have to help her watch C. (2 years) and the other 2 children (7 yrs and 9 yrs) it could make plenty of people lives happier and she would be able to support and be there for my siblings during there soccer games, school plays, and many more by just releasing Omav. to them and I would highly appreciate if you did this for our family and everyone else with Friedreich Ataxia.

Kasey K. Yes absolutely, we know of one that was in the trial that goes to therapy with my daughter who has FA and he showed great improvement and is still very mobile at 19.

Kathleen K. Yes! This drug would help my niece get through her teen years with a reduction in lost skills. We understand it is not a cure, but it buys us time while the research continues!

Kaylee K. Yes my sister would like be able to take this drug. She has friends that has participated in this trial and seen benefits from it.

Kendra K. yes - anything that will help cure FA

Kimberly K. Yes. It might dramatically increase their quality of life.
**Kori K.**  Yes, seeing my parent live the way he does as well as my aunt, this should be accessible to everyone with FA for hope.

**Larry K.**  This is for my nephew

**Latasha K.**  Yes. My sister wants to take this drug to slow and/or reverse her FA.

**Laurie K.**  Yes. Any little bit of help or hope is needed.

**Letitia K.**  My sister has FA and would absolutely want this drug as an option. We are talking about people who don’t have the luxury of time to wait on another trial.

**Linkoln K.**  My mother was diagnosed with FA when she was in her teens and has gotten worse and worse ever since. I’m the oldest of five children (same father) and have watched her as I’ve grown up become less and less independent. I remember as a kid not understanding because mom could go anywhere she just needed a cane but now she has to be in here wheelchair more and more. She tries to take care of us the best she can and give us a great childhood but it’s hard when we know what she goes through every day knowing how worried she is about getting to live long enough to see grandchildren and getting to live long enough so she can at least retain her ability to speak my mother wants this treatment out as soon as possible so she can live a long happy life she knows there’s a good chance she will be unable to walk without a cane or wheelchair for the rest of her life she just doesn’t want to lose any more.

**Macarena K.**  Yes. It would make it easier knowing there is a treatment and proof of improvement

**Marilyn K.**  Yes, if there is any chance of slowing down the progress at all, it is worth trying!

**Marley K.**  My grandfather developed FA when I was around 5 years old. He developed it late, he was in his 30s. He went from being able to do everything with me, to being completely in a wheelchair and needing assistance for everything. It would be absolutely amazing if this drug was offered in the US.

**Marsha K.**  Yes my grandchildren have been slowly deteriorating

**Mary K.**  Yes, my family member deserves the option of taking this medication. In the absence of any help or treatment for this progressive and unforgiving condition, and with full understanding of the limitations of this medication, it remains the only proven option at this time. Delaying approval is not a choice because this disease progresses in patients with no regard for extended studies. Progression in many patients, including my family member moves too quickly to wait and the losses are profound. Limitations of this medication are fully understood, and there are no notable negative effects. To this family, who knows the effects of FA and manages them daily, denial of this treatment feels negligent. In childhood, adolescence and now as a young adult, this disease leaves patients with little or no choices over so many aspects of their lives. The decision regarding whether or not to take it belongs to the individual and we urge the FDA and the manufacturer to take the steps necessary to give them a choice. Please approve this medication.

**Maya K.**  My sister in law L. lives with a severe and advanced form of FA, and my other sister in law S. passed away from FA 8 years ago. Patients like L. cannot wait any longer to take this potentially life saving medication! The studies that have been done show real evidence of efficacy and the opportunity to try this medication could literally mean life or death. Thank you for your compassion and consideration.

**Michael K.**  Yes, I would have my step Son take the drug. When watching a family member deteriorate like we do, the risks or concerns the fda may have , are far less than the issues that face freidreich ataxia patients.

**Michelle K.**  Yes, she deserves every option to make a better life for herself and her kids.
Mohammad K.  
Sir / Ma’am. Good day. I hope this message finds you and yours well. My sister-in-law has been living with FA for approximately 20 years; diagnosed at 17 and now 38 years old. I first met her in 2009. From our first meeting in 2009 to present, she has been the epitome of positivity in the face of adversity. She exemplifies ability despite massive physical limitations imposed upon her by a debilitating condition. She inspires me daily. Supported by a phenomenal husband and model children, she has not allowed her condition to dictate any limitations in her life and those around her. Even with her positivity and determination to be abled in every facet of life, there have been multiple instances in which we were fearful for her; such as falling several times while pregnant and requiring medical monitoring. We are blessed that she has comprehensible speech and maintains upper body control. We pray her condition does not further degenerate. We cannot imagine and do not want to ever see her lose any more mobility or capability. It is frightening to consider. We feel that the risks associated with Omaveloxolone are worth taking, if it has any potential of halting the degeneration or return control in any degree. We know her to be very cautious and conservative with with taking any and all medications. So, if she is volunteering to take Omaveloxolone, it must be truly worthwhile a prospect. We are all encouraged by it and feel strongly that our sister would be a great candidate.

Mukhlus K.  
YES. This medication will help my nephew with his balance and there’s no other drug and will stop the progression of this terrible disease.

Nathan K.  
Yes, my niece’s son has FA and she wants this for him.

Nikki K.  
Yes- our daughter is 17 and was diagnosed at 11. She progressively gets worse with each day. She has to have assistance with most activities of daily living. She has to use a walker or wheel chair for transportation if she does not she a family member to lean on. We would definitely allow her to be in this medicine if there was hope for improvement or a halted decline.

Norbert K.  
Yes, it should be available now! No more testing. The drug has been shown to help save lives.

Patricia K.  
Absolutely, it should be available As soon as possible to all patients. The data provided by part one and part two of the study along with the open label extension shows significant statistical improvement when looking at the activities of daily life and measures on the FARS Scale. This is adequate and sound proof of the efficacy of MOXie.

Patricia K.  
A new trial will take too long. Having this option could improve the quality of my grandson’s life. I urge you to consider the lives of the many people living with FA that could be improved.

Patricia K.  
Yes, they would want to take this medication.

Patricia K.  
Yes. A chance to reverse the deterioration would be worth the risk.

Patrick K.  
To whom it may concern, Yes, we would like to have the option to give the drug to my brother in law. We have watched his symptoms progress over the years. Not enough attention is payed to FA because it is so rare and taking away the opportunity to be able to take this drug would not help at all. There are not many companies working on drugs to help with FA and it should be the option of the patient and/ or family to be able to take this drug. The patients of FA deserve and should have the right to take a drug that can help with the disease and I don’t believe it is correct to take that right away from them. Please consider to bring this drug back on the market and help all FA patients and give them a chance to get better. My brother in law and all FA patients should have the right to choose whether or not they’d like to take the drug and they simply deserve the chance to do so.
COMMENTS FROM FA COMMUNITY
Parents & Family Members in the US

Paul K.
Dear FDA Decision-maker, a note about Omav: My 43 year old daughter will die soon of Friedreich’s Ataxia (FA). She has fought FA for 34 years but it has ground her down, gained the upper hand and she is now powerless against the onslaught of its effects. For me there are three progression groups of FA’ers; B. is in the 3rd group. 1) Still ambulatory, however tenuously. Omav can improve their ability to walk and coordinate. 2) Not ambulatory but relatively high functioning. For a minority Omav can return them to ambulatory and for the majority it will improve their speech, vision and ability to feed themselves. 3) Far advanced and close to death. Omav could literally stave off death, much as some experimental cancer drugs give those victims more months to live. But for FA’ers like my daughter B. Omav could be the bridge that would keep them alive for the next few years while the numerous other FA drugs make their way through your approval process. So, in a very real way you literally hold the power of life or death over my daughter and all those in group 3. You and other FDA decision-makers are making judgements on risk/benefit, side effects, and how robustly to adhere to the 2-trial rule right now on the Reata drug Omav. If you allow its use, with a needed phase IV requirement, my daughter may live. If you disallow this largely side-effect-free drug B. will die before the next drug in line can be approved. It is pretty much a given, and pretty much your decision. The 1)’s and 2)’s may survive until some later time of hope but the 3)’s will not. Born December 9, 1977 B. has always been a kind, caring and independent spirit. When she was 6 years old I called her my “colt” because of her ungainly running and by 11, after her diagnosis of the progressive incoordination disorder Friedreich’s Ataxia, I occasionally called her my “drunk” because of her by then drunken walk. She did well academically gaining a BA in Psychology in 2004, even though her rising disability prevented it from being used after graduation. In spite of her advancing ataxia B. moved into her own apartment and ran her own life with verve and independence. She rode a bike, drove a full size van, water and snow skied, sky-dived 32 times and spent 22 days touring Europe. She has loved, has been loved, and is loved. But now she is a high level quadriplegic unable to do the simplest thing for herself and largely unable to be understood. Some years ago I asked her what benefit she would want most from a FA drug? Her answer was not to walk or run, not to be married and have children, and not to have a satisfying career. Her answer was to speak clearly enough to be understood and heard, and to be able to read at an average speed again. Such a modest goal. Omav has demonstrated the ability on average to so-far stop progression for two years and to improve a host of ADL factors. This efficacy would minimally give B. the chance to live until the next more potent FA drug is approved and maximally might give some of her voice back to regain the ability to once again direct her life. You have the power of life or death for B. Omav will do no harm and may result in my daughter living for many more years rather than some few more months to a year. As her father and as one well educated in FA I fervently request your vote in favor of Omav’s approval! I believe to do otherwise would violate the “Do no Harm” of the Hippocratic Oath.

Rebekah K.
As a mother of my beautiful Daughter J., I have watched and experienced the progression and decline of my daughter’s abilities to be independent with activities of daily living. She was diagnosed with FA at 17 and decided to not let the disease define her. Today, married to an Air National Guardsman Officer for 18 years whom she met in middle school, she homeschools four of their five biological children with the fifth (the two year old) on her lap and all from her wheelchair. She also works from home as a cpa. She is an inspiration to all and the most kind, compassionate, gentle, loving person I have ever met. We all love her so much and she would love the chance to take omaveloxolone. She would volunteer to be first in line. After reading all of the available data we agree. Based on the existing evidence of progression arrest and possibly some reversal, please submit a new drug application request to the FDA in an attempt to make it available for my daughter J. and all other FA patients as immediately as possible. They do not have the luxury of time to wait. Their lives and quality of life may depend on it.

Rhonda K.
A cure and medicine is needed to help their functions

Ryan K.
Yes please I want to see my mom get better in any way possible.

Sabreena K.
Yes. My mother has fought this disease for 20 years and it takes a lot out of her. If there were a way to ease some of her symptoms, even in the slightest, it would be worth it. This treatment could change her life for the better.

Sami K.
Yes because if my mom were to take the drug she would, hopefully, be able to see me graduate

Sheri K.
Yes. Time is a factor. My children deserve hope and improved activities of daily living. They should be able to do things independently as they once did when they were little.
<table>
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<tr>
<th>Name</th>
<th>Comments</th>
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<tbody>
<tr>
<td>Stephanie K.</td>
<td>Yes we would love the opportunity for our daughter to look into all options that become available</td>
</tr>
<tr>
<td>Tory K.</td>
<td>Yes, a safe and effective therapeutic option to improve my child’s quality of life would be a very important breakthrough for him. I strongly support the FDA making omaveloxolone available for FA patients.</td>
</tr>
<tr>
<td>Travis K.</td>
<td>My wife has more character than anyone I know. She has taken this debilitating disease with strength, grace, and optimism. Over the last 20 years our 5 kids and I have watched how much has been and currently still is taken away from her. Her transition has stopped her from being able to bowl to a slow walk. From walking slow to a cane. In the last year she is becoming dependent on a wheelchair. The positive news about the treatment is that if treated soon; she may be able to walk again. We still have a 3 year old in the house and she may be able to chase him yet. She wants to go to the kids sporting events and other activities. Everywhere she goes she has a community of people that adore her and want to. Although everyone is ecstatic to help I can see frustration in her when she needs assistance and with her need of a wheelchair I know that she is fearing for the worst in any new progression. She has been cautiously optimistic in trying a treatment but says she will start this treatment tomorrow if possible. Please do right by her, it seems that the world’s most wonderfully kind people are the ones that get punished the most. She wants nothing more than to make the world a better place...her ability to walk can help her do that. We appreciate your consideration.</td>
</tr>
<tr>
<td>Tyler K.</td>
<td>Moxie</td>
</tr>
<tr>
<td>Wayne K.</td>
<td>My nieces case seems to be getting worse.</td>
</tr>
<tr>
<td>William K.</td>
<td>Our family has been living with FA for over 10 years. We would take the medicine if available. FA patients deserve the right to try their time on earth is short. Please push this forward.</td>
</tr>
<tr>
<td>William K.</td>
<td>Yes. The data and few experiences I’ve seen are very promising.</td>
</tr>
<tr>
<td>Addison L.</td>
<td>Yes. My step brother (26) wants the option of taking it.</td>
</tr>
<tr>
<td>Alison L.</td>
<td>We need a treatment or cure!</td>
</tr>
<tr>
<td>Allison L.</td>
<td>Yes. My brother, P., would love to have the opportunity to take this drug</td>
</tr>
<tr>
<td>Amy L.</td>
<td>Absolutely. My sister is 24 and has been living with symptoms since she was 10. She works full time as a social worker but requires a care giver to getting ready in the mornings and evenings. Any possibility of improving or maintaining her quality of living and independence would be highly taken advantage.</td>
</tr>
<tr>
<td>Andrew L.</td>
<td>YES. Our family member would DEFINITELY want to take the drug.</td>
</tr>
<tr>
<td>Brad L.</td>
<td>Yes. Relative indicated request to support effort.</td>
</tr>
<tr>
<td>Brenda L.</td>
<td>Yes take drug.</td>
</tr>
<tr>
<td>Brent L.</td>
<td>Yes let it be her option to take the medicine!</td>
</tr>
<tr>
<td>Carleesa L.</td>
<td>Would most definitely want to participate</td>
</tr>
<tr>
<td>Carmen L.</td>
<td>Yes, need to stop progression of FA in 18 yr old great niece.</td>
</tr>
<tr>
<td>Carol L.</td>
<td>I would support any drug that is safe and would help alleviate FA. I’ve seen first hand what a horrible disease it is. I love my grandchildren and want to see them live long healthy lives.</td>
</tr>
<tr>
<td>Carrie L.</td>
<td>My son, J. would absolutely take this drug if available. At age 33, he has nothing to lose and so much to gain.</td>
</tr>
<tr>
<td>Carrie L.</td>
<td>Yes, I would like Omaveloxolone to be available to my twin daughters. They are considered a more severe case and at 10 years old have already started to use a wheelchair. We are devastated by this disease already and I am frightened to imagine how much worse this will get for them as they get older without any treatment. This drug has proven to be safe and effective and I want my daughters to have access to it as soon as possible. Our family simply can not wait the years it will take for another trial to conclude before we can have access to this meaningful medication. Please consider the profound impact it will have on patient progression if this drug is not submitted and approved for use. Thank you for your time. I appreciate that the patient’s voice is being considered in these very important next steps.</td>
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<tr>
<th>Name</th>
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<tbody>
<tr>
<td>Carson L.</td>
<td>Yes they would like the option to take the drug. Given all the data now available regarding the possibility of treatment of FA, I’m sure anyone suffering from it would be more than willing to use the drug, even if at the very least it only slightly improved their symptoms.</td>
</tr>
<tr>
<td>Catherine L.</td>
<td>Yes, please make Omav available for all.</td>
</tr>
<tr>
<td>Cindy L.</td>
<td>Yes. Improvement in quality of life for my family with FA and for their families.</td>
</tr>
<tr>
<td>Craig L.</td>
<td>Yes we would. Results have been safe and promising. Have followed progress closely.</td>
</tr>
<tr>
<td>Dalton L.</td>
<td>Yes, my brother has showed a desire to do whatever it takes to beat this disease and we believe this is the next step!</td>
</tr>
<tr>
<td>Dana L.</td>
<td>Yes. It had a positive effect in the trial.</td>
</tr>
<tr>
<td>Danielle L.</td>
<td>My cousin has FA and would definitely take the drug.</td>
</tr>
<tr>
<td>David L.</td>
<td>Yes. I would always want the option available, and discuss it with our doctors.</td>
</tr>
<tr>
<td>Dawn L.</td>
<td>Yes, we would immediately choose to to take The drug!!! We see a decline in our son daily in his physical abilities, which is just heartbreaking. We would love to have an option for him to maybe even help slow down the progression. Currently, there are no other options, so to have something that could help, we are 100% willing!!! Our son, and all with FA, need this.</td>
</tr>
<tr>
<td>Dennis L.</td>
<td>Yes as it would improve quality of her life.</td>
</tr>
<tr>
<td>Diana L.</td>
<td>Yes! Please let my daughter take the drug. It’s the only thing she has to try before she is wheelchair bound.</td>
</tr>
<tr>
<td>Diane L.</td>
<td>Please approve this medication my nephew J. deserves to live his life.</td>
</tr>
<tr>
<td>Dorianne L.</td>
<td>Yes and Yes. It literally detained the progression of the symptoms and even lessen some of them.</td>
</tr>
<tr>
<td>Elizabeth L.</td>
<td>Yes, my son would like the option to take this drug. I would love to see him take this drug. I believe it can help with the progression of FA. I have been praying for something to help him and I believe this is a huge step forward.</td>
</tr>
<tr>
<td>Elizabeth L.</td>
<td>Yes, treatment is greatly needed.</td>
</tr>
<tr>
<td>Elizabeth L.</td>
<td>Yes. Anything that can potentially slow progress and keep my child more functional for longer is worth trying!</td>
</tr>
<tr>
<td>Elizabeth L.</td>
<td>Yes! We would use the drug omaveloxolone. This is a awful disease.</td>
</tr>
<tr>
<td>Ellen L.</td>
<td>My granddaughter is a fighter...and I know she would do anything to fight this disease!</td>
</tr>
<tr>
<td>Frederick L.</td>
<td>I have two children with FA. My son is 35 and my daughter is 31. They would both like the option of taking this medication.</td>
</tr>
<tr>
<td>Greg L.</td>
<td>Yes, anything that could potentially help.</td>
</tr>
<tr>
<td>H L.</td>
<td>Yes, right now there is no treatment, we can pass a vaccine in less than a yr, in the 8-10yrs it takes for a drug to be approved by the FDA many will have died and all will have lost the quality of life....right to try</td>
</tr>
<tr>
<td>Hayley L.</td>
<td>Yes I would want the option for my family member to take the drug.</td>
</tr>
<tr>
<td>Jacqueline L.</td>
<td>My siblings want to have the option this is huge for them. They deserve to have the option of getting this medicine/drug. Please help and support! Thank you!</td>
</tr>
<tr>
<td>Jasmine L.</td>
<td>Yes, he has been looking forward to trying this medicine. He sent our entire family and friends to this site &amp; is desperate to get this in his hands as soon as possible to hopefully enhance or elongate his lifespan!</td>
</tr>
<tr>
<td>Jeannie L.</td>
<td>This should become available to anyone living with the horrible disorder. My neice is only 20and was diagnosed only a few years ago. She can no longer walk and needs assistance with so many things.</td>
</tr>
<tr>
<td>Jeff L.</td>
<td>Please consider thank you.</td>
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**COMMENTS FROM FA COMMUNITY**

**Parents & Family Members in the US**

**Jeremy L.**  
This time of year is always challenging for me personally as I watch my daughters struggle with their battle with Friedreich's Ataxia. When S. and L. were toddlers, I started a Christmas tradition, I started recording them coming down the stairs Christmas morning. My expectation was that we would watch our daughters grow, change, and mature over the years as we looked back on these recordings. Little did I know, I was creating something that would be evidence of their battle against this terrible disease. In their early years, they progressed through development milestones like any other young child. Our girls transitioned from being carried down the stairs, to crawling, to walking on their own. Now as the years progress, we are seeing the effects of Friedreich's Ataxia, we are witnessing the regression from walking, to crawling, and eventually one day being reliant on a chair lift to get up and down our stairs. Our daughters are only ten and they can already no longer walk down the stairs and must resort to scooting on their butt as if they were 1 year old. This year was extremely difficult for me and I had considered not maintaining this tradition when I realized our documentation of this tradition had taken on a new meaning. The progression of FA is not easily observed day to day, week to week, or even month to month. However, when looking back year over year, the progression becomes obvious. We know this is a challenge for our community to prove effectiveness of any treatment or medication when change is difficult to prove over the course of 24, 36, or even 48 week trial. However, in Reata’s phase 2 trial, it did prove to show statistically significant evidence of making a positive change. It showed an average improvement in MFARS evaluation of 1-2pts, when patients score generally regress. When I consider that Reata’s Omavaloxolone can potentially pause the regression or even give back 1-2 pts on the MFARS scale, I think back to the past year. S. was able to walk with the aid of a walker. With this assistive device, she could keep up with her peers. In October of 2020, S. acquired her first wheelchair as Friedreich’s Ataxia continues to rob her of her abilities. A year ago, L. was able to walk independently without hand hold assist. As the year progressed, L. became more unstable and required hand assist. After seeing her sister acquire a wheelchair and gain a bit more independence and not have to resort to crawling on the floor when someone is not around to assist her, she has now requested a wheelchair of her own. S. has always taken these challenges in stride, maintaining a positive attitude about what she can and cannot do. For L. it has been more of a struggle as her progression has always lagged behind S’s. She watched her sister progress from walking to hand assist to walker to wheelchair knowing this was all in her future. L. is very observant and has seen the passing stares cast upon S., and has become subconscious about how others view her and what lies ahead. She faces her future with greater concern and worry of what lies ahead for her. Last week, our daughters had an assignment to write a personal essay. The title of S’s essay was “I Wish I Could Walk More” and the title of L’s essay was “We Have Too Much Therapy”. These are not thoughts a 10 year old child should be pondering. Our girls and all others living with FA, do not have the time or luxury to wait for another trial. Omavaloxolone has proven to be safe. Omavaloxolone has proven to provide a benefit that is statistically significant when compared to patients on placebo using the MFARS metric as a means of evaluation. We know this is not a cure. We know this does not stop the progression of Friedreich’s Ataxia in its steps. However, based on this data, we know that Omavaloxolone buys us time. We know that Omavaloxolone can help to bridge the gap until more advanced treatments or cures are explored and proven. We know that Omavaloxolone can buy our daughters some time to fight against the progression that Friedreich’s Ataxia brings. We also understand that even if Reata and the FDA decide to move forward with an NDA and approval, further testing would still be needed for patients under 16 years old. However, we would seek out opportunities to volunteer and help participate in those studies. We ask that Reata proceed forward with the submission of an NDA for Friedreich’s Ataxia. We ask that the FDA reconsider the recommendation that Reata would need to perform a phase 3 trial. We ask that Reata and the FDA work together to provide an approved treatment for our daughters to slow the progression of this terrible disease. I pray and hope that future recordings of my daughters coming down the stairs on Christmas morning, can someday be used to show how we changed their outlook, how we slowed their progression, how we provided them hope. I hope that one day we can look back and see that Omavaloxolone helped to buy us some time so that our daughters’ condition was not so far progressed that future therapies or treatments could not provide them the benefit of one day regaining what they have already lost. As a community, we ask for you to approve this safe and beneficial treatment to give our daughters and all patients living with Friedreich’s Ataxia hope for their future.

**Joan L.**  
My adult family member really wants the option of taking the medicine.

**Jodi L.**  
Yes. It can’t do any harm at this point.
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<tr>
<td>Joni L.</td>
<td>Yes, to give a future and a hope.</td>
</tr>
<tr>
<td>Joseph L.</td>
<td>Yes. Any support or improvement they can get to await the cure</td>
</tr>
<tr>
<td>Judith L.</td>
<td>Yes. Relative requested support for effort.</td>
</tr>
<tr>
<td>Julie L.</td>
<td>My brother-in-law battles FA everyday. He asked that I fill this out. He wants the option of taking this medication. I am willing to support him however possible.</td>
</tr>
<tr>
<td>Kim L.</td>
<td>Yes. We need access to every option out there to slow the progression of symptoms.</td>
</tr>
<tr>
<td>Krissa L.</td>
<td>Our son is a brilliant biologist whose opportunities are fading- he ABSOLUTELY wants any chance available to LIVE an improved life. Please make Omav available.</td>
</tr>
<tr>
<td>Lawrence L.</td>
<td>Yes, both my granddaughters have FA and it is heartbreaking to watch this disease ravish their bodies. Please approve the use to help them.</td>
</tr>
<tr>
<td>Lisa L.</td>
<td>Probably would take.</td>
</tr>
<tr>
<td>Lou L.</td>
<td>When you have a terminal illness and the quality of life decreases year after year faster and faster you keep hope but with the FDA process 10 to 12 years for any kind of help that hope starts fading if you can receive a treatment that does not cure you or make you better but just stopped you from getting worse would be tremendous for the lives of people with FA and their families we can come up with a vaccine and eight - nine months, why can’t we come out with help for people that have terminal illnesses, the FDA is failing American families</td>
</tr>
<tr>
<td>Lou Ann L.</td>
<td>Yes. She’s been in several trials.</td>
</tr>
<tr>
<td>Luz L.</td>
<td>Don’t know</td>
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<tr>
<td>Madison L.</td>
<td>Yes my immediate family member would want the option of taking the drug/medicine.</td>
</tr>
<tr>
<td>Malinda L.</td>
<td>My family members would want the option of taking the drug/medicine. One of them has participated in the trials.</td>
</tr>
<tr>
<td>Meaghan L.</td>
<td>Yes they would like to take the drug it has many studies showing how it helps people with FA</td>
</tr>
<tr>
<td>Michael L.</td>
<td>Yes, my brother wants to take Omav. He is having more and more difficulty with daily functions every day. Please let FA patients take this drug even if they were not I. The clinical trials.</td>
</tr>
<tr>
<td>Moriah L.</td>
<td>Yes this medicine is needed crucially.</td>
</tr>
<tr>
<td>Nicholas L.</td>
<td>Yes. My family member J. has been living with FA he is an amazing young man and truly reminds us what a real fighter is. Prior to him being diagnosed with FA he was able to do everything a normal child could do. Now he has to fight everyday, although his fight is a true inspiration to all, a child should not have to fight and enjoy the simple things in life to one day better this world for the good. Anything that may help this disease should be done and passed by the FDA immediately and faster then any vaccine!</td>
</tr>
<tr>
<td>Norman L.</td>
<td>Based on what I have read, there is nothing to loose by doing so</td>
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<tr>
<td>Parker L.</td>
<td>Yes, want the option</td>
</tr>
<tr>
<td>Patrick L.</td>
<td>I want my wife to have the option of taking this drug. It has been proven safe and there is nothing to lose and everything to gain, even if the gain is small. Today, there are cancer patients that take approved drugs with major side effects that extend life by mere months. Omaveloxolone has minimal side effects and has proved to increase quality of life for FA patients and could potentially extend life for years. This is a rare disease and does not get the national attention COVID-19, cancer, heart disease, and many others receive, but real people are suffering everyday with FA and if a treatment were available, even if the improvements were minimal, it’s worth it.</td>
</tr>
<tr>
<td>Patrick L.</td>
<td>Yes, any potential for a cure or a way to slow the debilitatings effects of FA are worth the risk. Time is short for those with FA, there is none to waste.</td>
</tr>
<tr>
<td>Paula L.</td>
<td>Yes! We need something and soon.</td>
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COMMENTS FROM FA COMMUNITY
Parents & Family Members in the US

Peggie L.  It is very important to my cousin’s daughter to have this available

Penelope L. Yes please. My son has been the most wonderful son while living with this disease and if the drug can help him in anyway, it would be wonderful. Seen many doctors who never mentioned this disease, until he went to the Cleveland Clinic this year.

Peter L. My daughter needs this, she can barely function without it!

Russell L. Please allow these kids and adults to receive this drug.

Ryann L. I’m not sure. I didn’t participate in the MOXIe study.

Sally L. I believe so.

Sam L. Yes, my family member says it helps her.

Shane L. Yes, I think at this point our daughter with FA would try a new drug to maybe be able to feel like there is some hope out there!

Sherry L. Yes....this treatment is so badly needed

Stephan L. Yes, absolutely.

Sue L. We need this made available to buy time for our grand daughters

Susan L. I have three first cousins who have FA, two of whom are parents. I would definitely want them to be able to choose to take Omaveloxolone. FA has severely impacted their lives due to loss of balance and deterioration of their ability to walk so that they now use wheel chairs and specially equipped homes and vans to continue life and work. FA now affects their speech. They all continue to bravely deal with the many ramifications of FA and I see what that requires of them. Any drug that would improve and give relief from their symptoms, while possibly also slowing the disease progression, would be a long-awaited gift that they and all FA patients should receive as soon as possible. Please give the letter from FARA your immediate attention and do your part to expedite approval of an NDA for Omaveloxolone without further requirements. Thank you.

Susan L. yes, it is my understanding this will slow the progression of FA

Taylot L. Yea my family member would want the option to take the drug because he would like the option to take a drug that can help prolong his life, reverse symptoms of FA, and live a somewhat normal life again.

Teresa L. I believe my daughter would want the option.

Thomas L. Yes anything that would improve her quality of life.

Todd L. As a father of two children affected by this horrible life threatening disease, OMAV is the first glimmer of hope we have to slow the progression of this monster. PLEASE allow those who need OMAV to have this medicine. The data is clear, it helps people w/FA little little to no side affects. Right now FA is incurable. I beg you to give our children, and all of our dear FAmily members who are losing their lives little by little everyday, the hope and help to slow their progression into pain, suffering and ultimately death. Thank you for your human kindness.
Trudy L. Yes, anything that would improve her quality of life.

Tyler L. Yes - my niece would take this medecine

Valerie L. I am married to someone that has FA. My husband and I have been together for 7 years and I have watched as he has steadily lost his ability to do things that he loves. One thing he wants in his life is children, but I know he worries all the time about how his health will affect how well he will be able to parent. Based on the data available on omaveloxolone, he would definitely want to option to take the drug.

Zenettra L. Yes. She has lost mobility and losing her within the next decade is NOT an option!

Abhinav M. Yes the situation is dire and access to a drug can improve the quality of life and willingness of patients to continue fighting.

Adrienne M. Yes I would want my nieces to be given the opportunity to take this drug...If there is any chance that it will help them I want them to have every opportunity to try it

Alexa M. Absolutely, it should be available As soon as possible to all patients. The data provided by part one and part two of the study along with the open label extension shows significant statistical improvement when looking at the activities of daily life and measures on the FARS Scale. This is adequate and sound proof of the efficacy of MOXie.

Alicia M. Yes, she is interested in taking it and we support that.

Alison M. Yes. My cousin has FA - she is young (23 years old) and just graduated from college and got her dream job. She has difficulty balancing and walking with FA, and now works as a nurse at a traumatic brain injury acute rehab facility. I want to see her live a normal life, continue her dream job without debilitating symptoms, keep doing fun activities with her friends and family, and find someone to spend her life with and potentially have a family.

Allan M. Yes, S. is my son-in-law & would benefit from an opportunity to maintain or improve his current life with FA.

Amber M. M., a cousin, has had FA for over 15 years and has suffered and missed so much out of her young life. Please consider releasing this drug before it's too late. We would love to see her quality of life improve and for her to be able to live out her dreams without this debilitating disease.

Amber M. Yes. They should have access to treatment.

Amber And Chad M. It's so hard to see our cousin in this shape and getting worse over time. Please clear this drug so she can have the opportunity to live a happier life. It would be amazing to see her be able to have her symptoms lessened or cured! Thank you

Amelia M. Yes I would want the option because there are no other treatments available.

Amie M. Yes possible cure

Amy M. My child would benefit greatly from Moxie! This time in her life this drug would be crucial for her social situation. If her progression could slow down enough to get her through middle and high school with lessened symptoms, it would have life-long impact on her!

Angela M. I know my family member would want the option.

Anton M. Yes, we would try it.

Aron M. The parents of the FA child (19 years old) are anxious to be involved in the study.

Ashley M. Yes. Anything that even slows the progression is better than this inevitable decline.

Barbara M. Yes, to hopefully slow progression, improve current physical state.

Ben M. Yes, my daughter A. would want the option of taking Omav. This is an easy answer for myself and her, as described in the letter and shared through many testimonies from the FA community on their positive experiences with this therapy. A. works hard on doing all the things that she can do to minimize the effects of FA on her life, but she and others with FA need help. And currently Omav is the only potential source of help, outside of her own will and hard work, which can only help so much to slow her progression. Thanks for your consideration and we appreciate your efforts to date.
<table>
<thead>
<tr>
<th>Name</th>
<th>Comments</th>
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<tbody>
<tr>
<td>Bernice M.</td>
<td>My nephew wants this medication to stop the progression. He is 19. He struggles to keep his balance. Stumbles often. The next stage will be a wheelchair.</td>
</tr>
<tr>
<td>Billy M.</td>
<td>We would all definitely want the option of being able to take the drug/medicine. There are hardly any options available for treating FA. Any type of drug/medicine that would safely and effectively help an individual with FA is an absolute necessity!</td>
</tr>
<tr>
<td>Bonnie M.</td>
<td>My daughter would like to try the drug to hopefully slow the progression of this disease</td>
</tr>
<tr>
<td>Bradan M.</td>
<td>Yes they would</td>
</tr>
<tr>
<td>Brenda M.</td>
<td>Yes! Anything to help with the symptoms associated with FA to help get us closer to a cure..we are all for!!</td>
</tr>
<tr>
<td>Brian M.</td>
<td>Yes, they would like the option of taking the medicine. After receiving her dream job of becoming a nurse, my cousin would like to continue to live her life as normally as possible and continue her work as a nurse.</td>
</tr>
<tr>
<td>Brian M.</td>
<td>At this stage, our family member is looking for a cure. But for individuals identified early enough for OMAV to help slow the progression of the disease, grant them access to OMAV.</td>
</tr>
<tr>
<td>Caitlynn M.</td>
<td>Yes! She is ready for her life back!!</td>
</tr>
<tr>
<td>Caroline M.</td>
<td>Yes anything to help my twins improve their quality of life and stop the progression of this life shortening disorder!</td>
</tr>
<tr>
<td>Caroline M.</td>
<td>Yes we would want the option of having my sister taking the drug.</td>
</tr>
<tr>
<td>Cassey M.</td>
<td>My sister has late onset FA. She has been waiting for this drug to become available while watching as her body shuts down, little by little. Recently, her heart has started showing signs of being affected by FA. She wants to see her children grow up. The youngest is just 4 years old. Her children need her. This drug will help to prolong her life and slow the effects of FA on her body. With this drug, her children will have more time with their mother. Please make this available as soon as possible. Please, before it is too late for her and for my nieces and nephews.</td>
</tr>
<tr>
<td>Cecundra M.</td>
<td>Yes they would want the option....they would try anything to have a better life</td>
</tr>
<tr>
<td>Chad M.</td>
<td>Yes, my cousin has been dealing with this disease for more than 15 years and other means of treatment have not helped. She has been dependent on the use of a wheelchair for at least 20 years of her life. The family is encouraged by the literature that is available on this medication and urges the action of the FDA to released the medication for use as soon as possible.</td>
</tr>
<tr>
<td>Chris M.</td>
<td>My niece and I want her to have the best chance she can for a good life</td>
</tr>
<tr>
<td>Christian M.</td>
<td>My sister-in-law-to-be has FA and I understand this drug could provide her the chance to live life in a way she hasn’t been able to for a very long time. She’s been in a wheelchair most of the time I’ve known her and she deserves the chance to feel independent again. She deserves the chance to have the option of walking down the aisle at their wedding, like most people dream of. This could potentially change her whole life, and she absolutely deserves that opportunity.</td>
</tr>
<tr>
<td>Christopher M.</td>
<td>My spouse would absolutely want the option to take a drug/medicine that slows or stops progression. Especially a drug that is proven safe. Having the option to try any safe drug is so important for patients suffering from FA. It may give them relief that they have not had until now. From what we’ve discussed with many other patients with FA, Moxie has had positive effects in their lives. Please, at least give these patients the option to choose this drug as a possible treatment.</td>
</tr>
<tr>
<td>Connie M.</td>
<td>Yes, we need immediate help before I lose another son.</td>
</tr>
<tr>
<td>Courtney M.</td>
<td>If you can by pass steps in covid vaccine in under a year you can get this drug out for people who have been suffering and dying. People can make their own choices of the risk and decide. For some like my Aunt who can hardly walk, falls, has had multiple surgeries she would rather die from trying this drug then continue to live in her current state.</td>
</tr>
<tr>
<td>Courtney M.</td>
<td>Yes. Immediate interest in any potential treatment.</td>
</tr>
<tr>
<td>Cynthia M.</td>
<td>Yes. With no treatments currently available, this would be a life changer for the FA community. My daughter is still walking with walker assistance at times and I’d love to see her maintain that ability even longer.</td>
</tr>
</tbody>
</table>
COMMENTS FROM FA COMMUNITY
Parents & Family Members in the US

Daniel/Rebecca M.  Yes would like the option for this drug or medication
David M.  S. would like any opportunity to extend her life.
David M.  Yes, I would definitely want my family member to participate.
David M.  Yes, willing do anything to help.
Denise  M.  Yes I absolutely would encourage her to take it.
Donna M.  yes we are open to anything that may improve quality of life.
Donna M.  Yes, please. It could prevent my son’s condition from progressing, possibly keeping him alive long enough for a treatment to reverse symptoms.
Eduardo M.  I would like my daughter to be able to take omaveloxolone. FA has taken a toll on our daughter and our family, right now she is unable to walk, or do any kind of activity with her hands without assistance. But she can still talk, stopping the progression is important for her and for those who are still independent.
Edward M.  Yes, he has been part of the clinical trial and has seen positive results.
Edward M.  Yes. Because it should be a choice to take it. Amd it works.
Eli M.  My family member absolutely wants the option to take omaveloxolone and would take it immediately when it becomes available. In their 16 years of being diagnosed with FA, there have been no viable treatments whatsoever. Even a drug with only the potential to slow progress of FA would be worth taking for them; the fact that data currently available on omaveloxolone show a halting or reversing of progress is beyond what they’ve hoped for. The news of these results has opened new doors to their potential futures that they thought were closed long ago. Over the years, they have had to re-learn how to do everything in their life, again and again. As soon as a new method is established (transferring, dressing, etc) the abilities involved change and they have to figure out yet another different way of doing it, which often involves re-teaching people in their life how to assist with it. This process is stressful, frustrating, and exhausting. Even a temporary period of stasis in just a few abilities/areas would be immensely relieving. For my family member, a meaningful benefit from a drug could be as small as everyday fine motor skills being less difficult (using a fork, typing) or general steadiness, posture, and fatigue not getting worse for a period of time. From the available data and accounts from those involved in the trials, it appears that omaveloxolone could confer those benefits to them. They absolutely want to have the option to see what the drug could do for them; any risks far, far outweigh even the possibility of the benefits. This is an urgent matter for my family member. As they quickly approach the average life expectancy of people with FA, waiting for a potential treatment becomes more and more painful. The time it would take for another trial to be completed (especially during a pandemic, and especially within an extremely small community) is time that my family member’s FA will be progressing in unknown and potentially fatal ways, time during which they will struggle to plan for their future. Instead, if omaveloxolone were approved immediately, that time could be spent enjoying as much independence as possible. I can scarcely imagine the pain for my family member, our loved ones, and me if this drug were to be approved mere years or months too late to change anything for my family member. We want access to this treatment and the possibilities it holds right now.
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<tr>
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<tr>
<td>Erin M.</td>
<td>Yes. The FA community doesn't have time to wait, as this disease is slowly killing them. They DESERVE a chance at trying this drug to improve their quality of life!!!!</td>
</tr>
<tr>
<td>Frances M.</td>
<td>Yes definitely take the medicine my family member heard it can help slow the progression</td>
</tr>
<tr>
<td>Frank M.</td>
<td>Yes, yes, yes!!!!!</td>
</tr>
<tr>
<td>Georgina M.</td>
<td>My daughter, I, was diagnosed on Sept. 25, 2019. I am still learning so much about FA, and all that comes with this terrible disease. She was not part of this trial, but what I know of and understand of it, I would definitely want her to be able to have access to Omav. FA has really affected her balance and walking. She has some heart thickening, but otherwise a happy healthy 12 year old girl. She has so many things that she wants to do when she gets older. She loves animals and wants to work with them in some capacity. If Omav, can help her with this, why would I not want her to have access to it? Please, please, please, give her that chance to fulfill her dreams.</td>
</tr>
<tr>
<td>Giovanna M.</td>
<td>Yes I would want to have them take the drug if it's going to help them improve there daily life</td>
</tr>
<tr>
<td>Girolama M.</td>
<td>Yes, I would want both of my family members to have the option of taking the medication-especially seeing how FA has effected them at a young age. This drug can give them the opportunity to slow down the symptoms, which in return can lead to more positive results in their mental and emotional health. I highly recommend that they take this drug.</td>
</tr>
<tr>
<td>Hailey M.</td>
<td>Yes we would like to try this new medication</td>
</tr>
<tr>
<td>Heidi M.</td>
<td>FA is a life shortening disease I have watched my son loose the ability to walk talk and carry out daily activities of life. He also has hypertrophic cardiomyopathy which will end his life to short,</td>
</tr>
<tr>
<td>Helen M.</td>
<td>Yes, I would love my daughter to take the drug/medicine. She wanted to be part of the clinical trial, but could not as she is not able to walk unassisted. As her Mother and full time caregiver, I can see the changes in my child on a daily basis. Our hearts ache when she cries, because she is not able to do the simplest things. We have supported research with fundraising, attending FARA/NAF events and most importantly praying for a treatment or cure.</td>
</tr>
<tr>
<td>Isabel M.</td>
<td>Yes it was working for him</td>
</tr>
</tbody>
</table>
| Isma M.     | I would Definitely want my child to take this remarkable drug. Anything that would truly help my child is an A+++.
<p>| Jacque M.   | Hopefully                                                                                   |
| James M.    | Need medication to help my family member's symptoms                                          |
| Jamie M.    | Yes! My son was diagnosed 6 years ago and is in a wheelchair. He now is overweight and has stage 4 cerosis at 20 years old and they think its from him not being able to get the exercise he needs. |
| Janah M.    | Yes, my sister absolutely would. She has been through so much and wants to feel better and live better |
| Janelle M.  | Yes. And she doesn’t have much time left before it’s too late.                              |
| Jean M.     | Yes it has showed promising results!                                                        |
| Jennifer M. | Yes. My cousin has FA, she is 57. To slow or stop the progression would mean a better quality of life. |
| Jesse M.    | Wants it for others                                                                         |
| Jessica M.  | She is a mother of two toddlers and it would help to be able to help care for them.         |
| Jim M.      | 19 yo nephew has this crippling disease. I support my family for his need of the drug       |
| Jodi M.     | This medicine would help my boyfriend be and to raise his children &amp; meet his grandkids!! If he could run &amp; play with those grandkids it would mean the world to him!!! |
| Jodie M.    | Yes- in my son’s case his disease has progressed so much that he has not qualified for any of the trials and really wants to make a difference somehow. If there is the chance his efforts can help him or someone in the future it would mean a great deal to him. |</p>
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<tr>
<td>John M.</td>
<td>My son is quite advanced in his progression. He is dependent on all ADLs, and does not expect that this is “his answer”. But what he does understand is that this is his last best hope of survival until his answer is available. He is nearly blind, flaccid lower extremities, spastic upper extremities, and his ability to verbally communicate is fading fast. His mind remains sharp, and he is painfully aware that airway management is his next big loss. Omaveloxolone may provide him the chance for a cure to be developed, tested, and approved before he loses his airway.</td>
</tr>
<tr>
<td>John M.</td>
<td>Would like the option to continue taking the medicine.</td>
</tr>
<tr>
<td>John M.</td>
<td>Yes, make the drug available. Too much of life has been inhibited by this disease. The quality of Life for the entire family would be beneficial to the community at large.</td>
</tr>
<tr>
<td>Jose M.</td>
<td>Family members are already planning to take it.</td>
</tr>
<tr>
<td>Kaci M.</td>
<td>Yes, this medicine would really help my mom’s boyfriend live a fuller, longer life!</td>
</tr>
<tr>
<td>Karisha M.</td>
<td>Yes! My sister has FA and is finding it more difficult to complete her daily activities. She works with children as an occupational therapist and is getting married this spring. We need a miracle! 😍</td>
</tr>
<tr>
<td>Kathee M.</td>
<td>I think this should be voluntary and available to those who are affected but know the risks. Our daughter in law was diagnosed prior to her coming into our lives, and at that time you never would have known about her issues. Over the past few years we’ve watched as her motor functions have declined to a point where walking is extremely difficult, using stairs is dangerous, she needs a scooter for anything taxing and her muscles and bones damage easily and heal slowly. She had done numerous medical drug trials and has just been approved for a service dog. It’s only getting worse, with the symptoms becoming more severe and prevalent in shorter periods of time. That being said, she has an older sister who suffers from this same disease and is wheelchair bound. She also has a younger sister who future ref this has not yet been determined. If this can save people who have this, or at least lessen their discomfort and progression, let it happen. Let them decide what risks to take so they can feel they’ve, at the very least, had some say in their condition and fate. This is the only logical, and yet most compassionate, way to handle this.</td>
</tr>
<tr>
<td>Kellie M.</td>
<td>Yes. Any drug that can help decrease the progression of FA would be beneficial to all who suffer from FA, and also those who are caregivers of those with FA. Seeing the progression overtime is heart breaking. I have watched FA continuously take and take and take from my family member with FA, and if there is a drug that can stop, or slow the progression, of just one more thing from being stolen from people with FA, I believe it is more than worth it. Omaveloxolone is more than a drug, it’s hope!</td>
</tr>
<tr>
<td>Kenneth M.</td>
<td>My nephew has FA and as a cardiologist I have treated several FA patients in my practice. Given the devastating neurologic consequences of FA on quality of life - speech, ambulation and independence especially and the absence of any FDA approved treatments as yet, Omaveloxolone provides a glimmer of hope. The encouraging results of the clinical trials to date including safety data are sufficient in the current environment for many such FA patients/families to desire Omaveloxolone as an option.</td>
</tr>
<tr>
<td>Kevin M.</td>
<td>Unfortunately nephew is too far along but wishes availability for others.</td>
</tr>
<tr>
<td>Kirsten M.</td>
<td>Yes! Our son has a severe case of FA and we would do anything to help him. And the chance to reverse some of the damage would be a dream come true. It would buy us time for a cure and improve the quality of life for all of us.</td>
</tr>
<tr>
<td>Kristal M.</td>
<td>Yes. Any hope or help to slow down the progression would be so welcome. It is so difficult to watch the deterioration of their mobility while they struggle with the psychological effects of this daily loss.</td>
</tr>
<tr>
<td>Lauri M.</td>
<td>Yes, she has pain so severe that at times she is suicidal.</td>
</tr>
<tr>
<td>Lawrence M.</td>
<td>My sister has lived with this disease and the situations it has presented her for a very long time. At first it was just falling. Now, it is a walker. It won’t be long before she will require a wheelchair. She is now older, single, and lives alone. Her independence is slowly being taken from her. She deserves the option of trying this drugs.</td>
</tr>
<tr>
<td>Lee M.</td>
<td>Yes yes yes... it will be her choice and we support the “right to try”.</td>
</tr>
<tr>
<td>Linda M.</td>
<td>Not participated</td>
</tr>
<tr>
<td>Name</td>
<td>Comment</td>
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<tr>
<td>Lisa M.</td>
<td>My 2 siblings have FA, they are aged 51 and 49.</td>
</tr>
<tr>
<td>Lisa M.</td>
<td>My niece and nephew both want this drug to allow them a better quality of life. Please! Do not deny them this chance!</td>
</tr>
<tr>
<td>Loretta M.</td>
<td>Yes! As of right now, there is nothing. S. is progressing and he would love the opportunity to try anything that could potentially make him even the slightest bit better. The disease has robbed him of so much, his ability to walk, eat/drink independently, his ability to hear and most recently his ability to see much of anything. S. requires assistance with every single thing he does, he should have the opportunity to try anything that has any possible change of improving his life.</td>
</tr>
<tr>
<td>Madge M.</td>
<td>My sister supports any therapeutic agent that would improve her symptoms.</td>
</tr>
<tr>
<td>Margaret M.</td>
<td>Family member would want the option of taking a drug to assist with slowing the progression of the disease for patients diagnosed with FA.</td>
</tr>
<tr>
<td>Marsha M.</td>
<td>Yes please we are desperate for a cure/treatment and have been waiting 20 years</td>
</tr>
<tr>
<td>Martha M.</td>
<td>She definitely wants the option to take this medication. I do not know if she participated in the study.</td>
</tr>
<tr>
<td>Mary M.</td>
<td>YES! My Daughter has been advocating for this to become available for some time. You see, my granddaughter would benefit greatly and hopefully stop or slow down the progression of this devastating diagnosis. EVERYONE......PLEASE, PLEASE VOTE YES!!</td>
</tr>
<tr>
<td>Mary Katherine M.</td>
<td>Absolutely, it should be available As soon as possible to all patients. The data provided by part one and part two of the study along with the open label extension shows significant statistical improvement when looking at the activities of daily life and measures on the FARS Scale. This is adequate and sound proof of the efficacy of MOXie.</td>
</tr>
<tr>
<td>Meghan M.</td>
<td>Yes, if it means adding years on to her life</td>
</tr>
<tr>
<td>Melissa M.</td>
<td>We have watched the progression of FA in our son for more than 20 years. Only recently has there been a real treatment in sight. Please give us the option of trying this drug and give our son a chance to hold on to the diminished quality of life that he is fighting so hard to maintain.</td>
</tr>
<tr>
<td>Michael M.</td>
<td>She wants the option</td>
</tr>
<tr>
<td>Midori M.</td>
<td>Any drug or treatment to stop or slow FA would be welcomed.</td>
</tr>
<tr>
<td>Muffie M.</td>
<td>I would want more than anything for omavaloxolone to be an option for my daughter. We have observed the positive effects this drug has had on her peers. My child is bright wonderful person and she deserves the opportunity to have hope and improvement.</td>
</tr>
<tr>
<td>Nancy M.</td>
<td>So important for the quality of life for my afflicted family member.</td>
</tr>
<tr>
<td>Natalie M.</td>
<td>Yes!! There is currently nothing on the pharma market to help with a disease that will likely kill both of my children in the next few years if no action is taken. This drug has been shown to slow progression. Even that is huge. Any drug that can help is certainly better than watching this horrible disease progress and claim each of my kids a little at a time. Please make this drug available now! Thank you.</td>
</tr>
<tr>
<td>Pamela M.</td>
<td>I have 3 siblings with FA, my mother also had FA, based away a year ago. all would be willing to take this drug for improvements. they have been living with FA for 20+ years.</td>
</tr>
<tr>
<td>Pamela M.</td>
<td>Yes. Their options are limited and things are getting worse.</td>
</tr>
<tr>
<td>Patrick M.</td>
<td>Condition is too advanced. if it is not insured that this is going to cure him he is unwilling to go through the process.</td>
</tr>
<tr>
<td>Rachel M.</td>
<td>My first cousin has FA and she has participated in the drug trial. It has helped slow the disease progression and ease her symptoms.</td>
</tr>
<tr>
<td>Ray M.</td>
<td>My sister n law believes it is needed, and will help.</td>
</tr>
<tr>
<td>Regina M.</td>
<td>Yes. As this disease progresses day by day, if there is something that can possibly stall the progression by all means approve it. This is a horrible disease that I knew nothing about until 2 of my cousins were diagnosed and they are brother and sister teenagers with so much potential to give this world. Please reconsider this decision.</td>
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<tr>
<td>Richard M.</td>
<td>Yes, she is expected to lose movement soon.</td>
</tr>
<tr>
<td>Robert M.</td>
<td>yes, my brother M. would want to participate.</td>
</tr>
<tr>
<td>Rosalie M.</td>
<td>Yes, slow nerve and muscle degeneration</td>
</tr>
<tr>
<td>Rustom M.</td>
<td>They would. They believe the benefits outweigh the costs.</td>
</tr>
<tr>
<td>Sally M.</td>
<td>Have 2 adult children with FA &amp; would probably take it</td>
</tr>
<tr>
<td>Sandra M.</td>
<td>Yes I will like my daughter to take omaveloxolone</td>
</tr>
<tr>
<td>Sandra M.</td>
<td>Yes, my daughter is 26 and wants the opportunity to take the drug. She has been in a wheelchair for 2 years now and is progressing daily. She would love the opportunity to try something that could help slow/stop her progression.</td>
</tr>
<tr>
<td>Sean M.</td>
<td>If it works, yes!</td>
</tr>
<tr>
<td>Sharon M.</td>
<td>I’ve watched my son deteriorate bit by bit over the last 29 years. His hopes &amp; dreams crushed by this horrible condition. His independence lost, pain &amp; discomfort daily, losing all hope and very progress toward relief. No mother should have to watch this. No child should have this suffering.</td>
</tr>
<tr>
<td>Sumit M.</td>
<td>Yes. We want the option take omaveloxolone. Any reasonably tested and FDA approved drug for FA child is a blessing from universe. Please work hard and let us know how we can help expedite. Children don’t have a lot of time at hand. Let’s cut the red-tape if such thing exists and is impeding the approval. Thanks!</td>
</tr>
<tr>
<td>Summer M.</td>
<td>yes. anything would help and be fantastic at this point.</td>
</tr>
<tr>
<td>Susan M.</td>
<td>I know that my nephew would want the option of taking omav. He has been Dr L’s patients for many years now. We all have hoped that a disease-specific treatment would be discovered- to bring the possibility of improvement to all who face this devastating disease.</td>
</tr>
<tr>
<td>Susan M.</td>
<td>She asked us to sign because she wants the chance of a better quality of life!</td>
</tr>
<tr>
<td>Tara M.</td>
<td>Yes I want the option of my child to take this drug. This could be a life altering drug that could slow the progression of FA.</td>
</tr>
<tr>
<td>Tommy M.</td>
<td>Please fast track this treatment so our daughter in law can have some quality of life, please...</td>
</tr>
<tr>
<td>Tyler M.</td>
<td>Yes, they would. I have been watching my mother be affected negatively by FAvmore and more throughout my entire lifetime and it is one of the most painful parts of my life. The knowledge that it is only going to get worse is one of the most terrifying facts I can conceptualize. Any and all medicines that may be able to improve upon the symptoms of FA NEED to be approved of- the longer it takes the more the symptoms will develop, and eventually it may go to far to be fixed.</td>
</tr>
<tr>
<td>Valerie M.</td>
<td>My niece and two of my 1st cousins both have FA. Of course I want them to to have any opportunity they can to live the best life they can.</td>
</tr>
<tr>
<td>Vicki M.</td>
<td>Yes, present meds are ineffective</td>
</tr>
<tr>
<td>Victoria M.</td>
<td>Not sure yet.</td>
</tr>
<tr>
<td>Virginia M.</td>
<td>child is already taking it</td>
</tr>
<tr>
<td>Yesica M.</td>
<td>Four of my siblings were diagnosed with FA a couple of years ago. The diagnosis was devastating because we also learned that there are no cures or treatments available for FA. Since then our family has been hopeful that researchers would come up with an option to help manage the disease. My siblings would want to take any medication available to them. After all the hard work from researchers and medical teams the possibility of having access to omaveloxolone for all FA patients would be ideal.</td>
</tr>
<tr>
<td>Zane M.</td>
<td>Yes; she has nothing to loose because of her diminishing ability to live a normal life. She would also agree with her being used as a trial patient of the medicine because she wants to help with a cure.</td>
</tr>
<tr>
<td>Bobby N.</td>
<td>Could be beneficial to our nephew</td>
</tr>
<tr>
<td>Name</td>
<td>Comment</td>
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<tr>
<td>Charles N.</td>
<td>Yes. My daughter has been a participant in the clinical trials at the USF in Tampa, and she believes that the drug is safe and that it would benefit her so I’m hopeful that the FDA will thoughtfully consider this letter and release the drug for patient use.</td>
</tr>
<tr>
<td>Colette N.</td>
<td>Yes, I believe it would give back a quality of live that she deserves</td>
</tr>
<tr>
<td>David N.</td>
<td>Yes. My daughter is bedridden, suffers horrific pain, has nerve and muscle spasms which cause her to scream frequently. Anything that might help her, and/or prevent others from suffering like this, would be a blessing. My other daughter died at age 25 from complications from Friedreich’s Ataxia.</td>
</tr>
<tr>
<td>Donna N.</td>
<td>Absolutely! N. deserves a right to try!</td>
</tr>
<tr>
<td>Fred N.</td>
<td>Omaveloxolone has been successful in slowing or stabilizing the progression of FA symptoms, therefore I believe it should be made available to those suffering with FA!</td>
</tr>
<tr>
<td>German N.</td>
<td>Not sure</td>
</tr>
<tr>
<td>Janet N.</td>
<td>Yes my Nephew would be a perfect candidate for clinical trials</td>
</tr>
<tr>
<td>John N.</td>
<td>Yes we need something to slow the progression now before it’s to late</td>
</tr>
<tr>
<td>Mona N.</td>
<td>Yes, I believe strongly that promising medications should be made available to patients with FA especially young patients have so much to give to studies in research of progression of such a debilitating, life stealing disease. Please please give our patients that choice and a chance at independence for life. God bless the researchers, doctors and all who devote their time and intelligence to bring hope to FA patients.</td>
</tr>
<tr>
<td>Naomi N.</td>
<td>Yes I do! Because my sister is progressing every single month and it’s hard for her to enjoy life on a daily basis. She would absolutely take this drug if there is even a slight chance it would work even if there was side effects, because soon she won’t be able to even eat on her own. She should be able to have the option of taking this drug because she might not be here next year and that is not fair to her or anyone else in her situation.</td>
</tr>
<tr>
<td>Nora N.</td>
<td>Yes we would want to try it for our son he needs help soon before he can no longer walk and or his spine continues to weaken or his heart condition gets worse this is a very hard disease for a young child and teen to deal with.</td>
</tr>
<tr>
<td>Raechal N.</td>
<td>Yes. My nephew has FA and is very eager to try some sort of treatment</td>
</tr>
<tr>
<td>Rich N.</td>
<td>Yes, my 2 children will take</td>
</tr>
<tr>
<td>Roberta N.</td>
<td>Yes..I watch her suffer..If this could improve her quality of life, Id feel blessed</td>
</tr>
<tr>
<td>Ruth N.</td>
<td>Yes. My daughter is end-stage, and requires total care. Any improvement in her symptoms would be a blessing. My other daughter died at age 25 from complications from FA.</td>
</tr>
<tr>
<td>Teri N.</td>
<td>This is for my granddaughter. We are just desperate to find something to help her.</td>
</tr>
<tr>
<td>Vanna N.</td>
<td>These patients should be allowed any relief possible no matter how small. It is insulting to make that decision for them.</td>
</tr>
<tr>
<td>Amyra O.</td>
<td>Absolutely, cousin can’t do things he could last time we saw him. He has trouble walking, playing, and speaking.</td>
</tr>
<tr>
<td>Angela O.</td>
<td>Absolutely, it should be available As soon as possible to all patients. The data provided by part one and part two of the study along with the open label extension shows significant statistical improvement when looking at the activities of daily life and measures on the FARS Scale. This is adequate and sound proof of the efficacy of MOXie.</td>
</tr>
<tr>
<td>Carl O.</td>
<td>J. needs this drug to function in life. He is progressively declining in his skills every time we see him.</td>
</tr>
<tr>
<td>Cesar O.</td>
<td>Yes he is aware and willing to receive this drug. Seeing my son of 26 yrs go from 14 years old running in the soccer field, having won wrestling matches, driving to school on his own car, a agriculture chapter participant, and proud JROTC member TO NOW restricted to a wheelchair. He has actively been participating all trials at CHOP and University of Florida.</td>
</tr>
</tbody>
</table>
Christi O.  Yes, my sister has participated in a clinical trial for another drug with good results and would try this one as well. She is 22 and wants every chance she can get at a normal life.

Christina O. Child is quickly losing ability to move anything that may improve would be life changing and should be done

Christina O. If this would help him at all then yes his mother would definitely want him to take this drug.

Cyndy O. Yes for the chance to slow or stop progression of this insidious disease

Daniela O. Yes, we want to take the medicine omaveloxone as soon as possible please. My brother is a very active person and can’t wait to be more independent and express himself better. If you can do anything to speed up this procedure please think about people like us who have wait enough for a miracle to happen because for us that is what omaveloxone means.

Debbie O. want help of any kind

Debra O. Yes!!! Any chance of was Easing the pain & trauma caused by this disease is worth taking!

Doug O. Yes, willing to try anything that’s safe.

Eduardo O. Yes, because it is an option.

Greg O. My family member deserves the opportunity to try it. She has been living with fa for 25 years and has gotten worse. This would be an opportunity to try to slow the progression and reverse some of the symptoms. Feel it is safe & effective.

Isaac O. Based on the safety and efficacy of omaveloxolone, my family member would like the option of taking the medicine.

Jane O. Yes she wants to take the medication

Jason O. Absolutely. My mother is 70 and has been living with FA for over 40 years. She is wheelchair bound and requires assistance with all aspects of her daily life. This is not the quality of life I would wish upon anyone and if there was even the smallest chance that this new treatment could provide some relief, we want that opportunity. We have been an active member of the community for many years and we continue to hear great strides are being made but when it comes to release these to the community, the FDA makes it difficult. To be honest, I don’t know if my mother will make it another 5 years to wait for another trial, nor do I know if she would qualify for this treatment at her age and profession of the disease, but there are many, many young children that have their whole life ahead of them. I would never wish for someone to live with this disease for a good portion of their life. If there is an opportunity to get this treatment released, you’d be giving these kids hope. Hope I wish I had for my mother 40 years ago. Please don’t let this drag out and please approve the use of this valuable treatment.

Jason O. Yes, we would want our family member to be able to take this drug.

Jennifer O. I am advocating for my FA community to have access to omaveloxolone. One of my brothers who has FA is deceased (B.), my brother A. is living with FA, and numerous family friends have children with FA. My mother M-L. (deceased) advocated tirelessly for people with FA, and I am sure would also support and agree with this call to action.

Judith O. My niece deserves the opportunity to try the drug since it has been deemed safe & effective especially if it would slow the progression and possibly reverse the symptoms.

Kathy O. Yea everyone deserves a better life then the path he is currently on

Kathy O. Yes, anything to slow down the progression of this disease

Kevin O. Yes, would love to see a drug therapy in her lifetime.

Kyle O. If his mom thinks it’s for the best then I agree

Leigh O. I want the option for my child to take the medicine.
### Comments from FA Community

**Parents & Family Members in the US**

<table>
<thead>
<tr>
<th>Name</th>
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</thead>
<tbody>
<tr>
<td>Maggie O.</td>
<td>Yes! Absolutely we are willing to try anything!</td>
</tr>
<tr>
<td>Michelle O.</td>
<td>Yes, J. has regressed every time we see him and needs this drug!</td>
</tr>
<tr>
<td>Mike O.</td>
<td>There is no other treatments available which might extend or improve conditions for FA'ers while we wait and hope for other options.</td>
</tr>
<tr>
<td>Richard O.</td>
<td>My child is losing the ability to move if there is a chance of ANY improvement she should be given the chance to get it.</td>
</tr>
<tr>
<td>Rochelle O.</td>
<td>My daughter would want the option to take this drug. She is extremely concerned about surviving as her symptoms progress &amp; become more severe.</td>
</tr>
<tr>
<td>Sandy O.</td>
<td>Yes they would like a chance of trying it</td>
</tr>
<tr>
<td>Teri O.</td>
<td>Yes, she would take anything that may help reduce the progression of the disease.</td>
</tr>
<tr>
<td>Tony O.</td>
<td>Yes we would absolutely want to try something that would help stop the progression of this horrid disease. Please help us.</td>
</tr>
<tr>
<td>Tyler O.</td>
<td>Anything that will help our B. live a longer and healthier life needs to be in place.</td>
</tr>
<tr>
<td>Wendy O.</td>
<td>We have been told the results of taking Omav are similar to about a 2 year improvement in the user's condition. My daughter is on the edge of not being able to transfer any longer. Once she loses that ability, her life will change drastically. She currently lives alone, but if she can no longer transfer, she may not be able to, any more. We desperately need something to stop or slow her progression until a better treatment can be found. She was diagnosed at age 15 and we have been told, every year, we were about 5 years away from a cure. We need treatment now!</td>
</tr>
<tr>
<td>Alexis P.</td>
<td>FA'ers live to their abilities and are courageous. Our desire is to have those abilities for as long as possible. The data shows that Omav can and does help with no detrimental side effects. We have a sense of urgency since abilities can and are lost with FA quickly. Allow us to our lives to the best of our abilities and slow the progression.</td>
</tr>
<tr>
<td>Allan P.</td>
<td>Yes, we would like the option. My daughter is in a wheelchair but was able to attend college/have some independence. However, she has lost a year of her &quot;normal&quot; life due to Covid lockdowns, and with the progression of the disease, she will soon not be able to do much more independently, and essentially be wheelchair/bed bound. So anything that can help slow the progression of the disease is a welcome advantage, and we would be willing to try the drug, given the known efficacy/safety.</td>
</tr>
<tr>
<td>Amber P.</td>
<td>Yes! His speech has slowed, his balance and coordination has gotten worse where he holds on to things and is needing a cane when in wide open spaces, he has trouble tying shoes, and buttoning his shirts, he suffers with fatigue and scoliosis also, and this drug called omaveloxalone needs to be approved soon as possible to assist with slowing the progression and to make his life easier.</td>
</tr>
<tr>
<td>Amy P.</td>
<td>My daughter would like the option to take this drug. She has lost the ability to walk and is full time in a wheelchair and is worried about the progression of symptoms. The clock is ticking for so many patients with FA and they’re losing abilities and willing to try this drug if it’s shown success.</td>
</tr>
<tr>
<td>Amy P.</td>
<td>My nephew has been diagnosed with FA and yes, I would want him to try this medication. He is willing to expose himself to available trials and treatments and he is educated about his disease. His parents and sister are very involved in understanding this rare and oft times confusing world of rare diseases and experimental treatments. There are so few options, there are so few doctors to consult with, this trial is all he has to hang on to with regard to treatments for himself and for helping future FA patients. I wholeheartedly want the FDA to approve this treatment on the fast-track.</td>
</tr>
<tr>
<td>Amy P.</td>
<td>On behave on my brother, M., I am answering these questions. His daughter, A. has this awful disease. She is going through depression. I wish she had a normal life and could get out of her house and be more mobile so she could have friends. It’s so hard seeing this family struggle. So, yes, if this drug could give her any type of normalcy.</td>
</tr>
<tr>
<td>Arthur P.</td>
<td>I had 3 sisters that died from this disease. My grandson is following in their footsteps. This is a much needed treatment, and is needed as soon as possible, while there is still hope.</td>
</tr>
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COMMENTS FROM FA COMMUNITY
Parents & Family Members in the US

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<thead>
<tr>
<th>Name</th>
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<tbody>
<tr>
<td>Ashley P.</td>
<td>Yes, she would.</td>
</tr>
<tr>
<td>Charlene P.</td>
<td>For a person who is going to pass due to FA they may want to be part of the cure.</td>
</tr>
<tr>
<td>Chérie P.</td>
<td>We want OMAV to be available for pediatric clinical for FA patients.</td>
</tr>
<tr>
<td>Christian P.</td>
<td>Yes. I've been told by doctors that the drug will help.</td>
</tr>
<tr>
<td>Cindy P.</td>
<td>Yes to help stop this terrible disease</td>
</tr>
<tr>
<td>Crystal P.</td>
<td>If there is a drug that could help it should be made available!</td>
</tr>
<tr>
<td>David P.</td>
<td>Yes I would want the option to take the drug.</td>
</tr>
<tr>
<td>Dean P.</td>
<td>Absolutely, it should be available as soon as possible to all patients. The data provided by part one and part two of the study along with the open label extension shows significant statistical improvement when looking at the activities of daily life and measures on the FARS Scale. This is adequate and sound proof of the efficacy of MOXie.</td>
</tr>
<tr>
<td>Dean P.</td>
<td>Yes she thinks it will help with her daily well being.</td>
</tr>
<tr>
<td>Deanna P.</td>
<td>Yes, we have been in many drug studies over the years and some of them have brought very little to no improvements. This is one of the first one that has brought back actual function. We have friend who were in the study and we were blown away by some of their reports on the drug. Each person with FA should have that opportunity.</td>
</tr>
<tr>
<td>Deirdre P.</td>
<td>Yes - patient options</td>
</tr>
<tr>
<td>Diane P.</td>
<td>Yes. She's tried other medications and at this stage in life she feels she has no other options and nothing to lose.</td>
</tr>
<tr>
<td>Doris P.</td>
<td>Yes, it would help her a lot</td>
</tr>
<tr>
<td>Elizabeth P.</td>
<td>Yes!!! My M.K. needs it so bad she is a nurse practitioner and taking this drug would allow her to continue working outside of the home!!!!</td>
</tr>
<tr>
<td>Emily P.</td>
<td>Yes. Because of proven treatments thus far and how it helps people with FA</td>
</tr>
<tr>
<td>George P.</td>
<td>My children didn’t qualify for the trial at the time. They would love to take Omav. Stopping progression for my son would mean he wouldn’t need a wheelchair and he could maintain his mobility independence. Our 20 year old sees Omav as a way to prolong their life and uplevel the quality of their life.</td>
</tr>
<tr>
<td>James P.</td>
<td>Yes because they are no good treatment options today for FA</td>
</tr>
<tr>
<td>James P.</td>
<td>Yes, we would absolutely want our son to take MOXie and he has expressed that he wants it, unequivocally!</td>
</tr>
<tr>
<td>Jarrod P.</td>
<td>My daughter is 15 years old and was diagnosed at age 12 with ataxia F</td>
</tr>
<tr>
<td>Jason P.</td>
<td>Yes, my cousin hasn’t walked in over 10 years of something exist to help him get back on his feet then let’s make it happen NOW!!</td>
</tr>
<tr>
<td>Jeff P.</td>
<td>Yes, both of my children would take it. My oldest daughter was a part of the trial and is currently taking it and has shown signs of improvement.</td>
</tr>
<tr>
<td>Jennifer P.</td>
<td>J. is an amazing 9 year old boy who is suffering terribly from FA. Once a normal, happy go lucky child who was able to play sports, ride his bike, and play with his siblings. Now needs help with his daily activities. We miss everything about this. J. would 100% take omaveloxolone. We hope one day in the near future he could get it. FA has already took too much from him &amp; his family.</td>
</tr>
<tr>
<td>Jennifer P.</td>
<td>Yes. Please allow us to have the option to take this drug</td>
</tr>
<tr>
<td>Jeremy P.</td>
<td>Yes, it seems like a great option to increase quality of life.</td>
</tr>
<tr>
<td>John P.</td>
<td>Yes. J. was a normal child who loved all kinds of sports but now due to his FA, he is unable to do the things that he loved so much.</td>
</tr>
</tbody>
</table>
Justice P. Yes they want the option of taking medicine. The trials showed great results even with the limited number of participants. This is his best chance at leading a normal life.

Kelly P. Option to take the drug. Her disease has advances significantly over the past 3 years. She just wants to be 21!

Kenneth P. Yes - because it has been shown to be helpful in slowing the progression of FA in our son.

Kris P. Yes we would like the option of taking the medicine

Kristi P. Yes, anything to try to minimize the symptoms and/or slow progression.

Laura P. All with FA should have the immediate opportunity to take a drug that can improve the quality of their lives. The data and testimonials about the drug suggest that it not only improves the physical symptoms of FA (lessening fatigue and helping with gait, speech and mobility), but taking it can also improve the mental health of those whose lives are so adversely affected by this terrible, progressive, degenerative and life-shortening disease. Please give those with FA, their families and their friends this hope!

Laura P. Yes for improved quality of life

Lina P. Yes, my cousin wanted to participate in the trial but was unable to due to the inclusion/exclusion criteria. Please open this up so that more FA patients can have the option of taking this drug.

Lynn P. Would like to be able to try new medicine

Marguerite P. I would like my family member to be able to take the drug.

Marilyn P. Of course as there are no other treatment options and this could change lives

Matt P. My daughter would take this drug without questions immediately

Melissa P. Yes. My son has been asking since he was diagnosed when there would be a treatment available. He has run out of hope. He can no longer see and has trouble with his hearing along with the inability to do anything for himself. We have been desperately waiting for something that may help.

Michael P. Yes. It has shown potential to treat this vicious disease. Reward far outweighs the risks for those whose quality or life/ability is severely limited.

Monica P. We urge the FDA to approve omaveloxolone for our daughter so that she has hope and a chance of slowing progression. We are heartbroken to see how she is dying a slow death as the disease progresses day by day. Anything that can be done to slow progression and give her some hope that in her lifetime a cure may be found, makes each day a little easier to bear. On behalf of not just the patients, but parents and families and friends, please approve omaveloxolone urgently. Every day we delay is another step closer to losing functions and quality of life. We ask for a fast response - our hearts hurt every single day we wait.

Morgan P. My sister who lives with these problems asked me to fill this out. Quality of life doesn’t even begin to explain how hard it is to live with these symptoms.

Muriel P. Yes, I would jump at the chance. For my daughter to have a chance of living more independently, and be able to walk without the assistance of a walker, would be the answer to prayer.
### Comments from FA Community

#### Parents & Family Members in the US

<table>
<thead>
<tr>
<th>Name</th>
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<tbody>
<tr>
<td>Nancy P.</td>
<td>We absolutely want access to omav and truly hope wise heads with prevail and we will have that opportunity soon. Watching my 15 year old son lose his ability to walk, type with less accuracy and isolate himself because he’s “different” is heartbreaking! Explaining to him that some adults (without FA) have decided he can’t have a medicine that has proven to slow progression is nothing a parent should have to do. Helplessness is built into a rare disease diagnosis with no treatments. Waiting for others to save you, hoping they understand the urgency, praying the red tape doesn’t delay approval past your death date is excruciating. Please understand that we are willing to risk side effects, willing to be guinea pigs, willing to endure or not endure many things, as long as these sacrifices mean the possibility of a better outcome than this disease currently offers. If we feel the trial data is enough to move forward and we are the ones ingesting it or, even more compelling, we are anxious to have our child ingest it, then your job is to find a way to let us. Thank you for your time and attention to this matter!</td>
</tr>
<tr>
<td>Natalie P.</td>
<td>Yes, my family members would definitely take the drug in order to regain some of their prior mobility back</td>
</tr>
<tr>
<td>Nicole P.</td>
<td>Yes - being that she is shut out of the majority of drug trials based on the stage of her disease this is one that she could greatly benefit from.</td>
</tr>
<tr>
<td>Olivia P.</td>
<td>Yes. My brother has lost a lot, it would mean a lot to us if the progression could be paused. He wouldn’t have to lose anything else, and he’d be closer to the finish line of getting stronger.</td>
</tr>
<tr>
<td>Pamela P.</td>
<td>Absolutely yes!! Mother to my 33 year old daughter diagnosed with FA 11 yrs ago.</td>
</tr>
<tr>
<td>Pat P.</td>
<td>They deserve the right to get the meds</td>
</tr>
<tr>
<td>Patrick P.</td>
<td>Yes. This is the first time in 16 years since my son was diagnosed with FA we seem to have some hope.</td>
</tr>
<tr>
<td>Renee P.</td>
<td>Yes, should have options!</td>
</tr>
<tr>
<td>Rhonda P.</td>
<td>I help some with my nieces’ care. Yes! She should be able to receive this drug NOW. Each year that passes we see FA progress and rob this beautiful young woman of the chance to walk and live her life independently. Please allow her to receive this drug now.</td>
</tr>
<tr>
<td>Richard P.</td>
<td>My nephew J., whose smile has never diminished during the progression of this devastating disease, deserves any and every possible opportunity to treat and or minimize the effects of this vicious disease. Please give him the option to HOPE and HELP himself.</td>
</tr>
<tr>
<td>Rick P.</td>
<td>Yes! My 26 year old niece wants the option of taking omaveloxolone. Each year that goes by sees a progression of the disease that increasingly robs her of her independence and the ability to perform daily activities. Please allow her the chance to stop the progression of this heinous disease.</td>
</tr>
<tr>
<td>Ricky P.</td>
<td>Both of my nieces children has FA</td>
</tr>
<tr>
<td>Samantha P.</td>
<td>Yes, E. needs this medication and cannot wait 2-4 more years through another trial to begin taking it.</td>
</tr>
<tr>
<td>Sharon P.</td>
<td>Yes! She is a young wife and mother with every desire to be well enough to care for her family.</td>
</tr>
<tr>
<td>Shellie P.</td>
<td>At this point we are desperate and will try whatever we can to improve daily life for D...he’s a precious talented individual but has been completely dependent on me and his dad got the last 5 years. This would be a miracle and a blessing!!</td>
</tr>
<tr>
<td>Sheri P.</td>
<td>Yes. If you know you’re going to die without treatment, what’s the worst that can happen if the treatment fails? You die. So there is no risk to take it. There is only a risk to not take it.</td>
</tr>
<tr>
<td>Stacy P.</td>
<td>Yes. I have two family members that have this horrible disease, they are both passed the normal age for surviving. Yes they will do anything to better or prolong their lives.</td>
</tr>
<tr>
<td>Suzanne P.</td>
<td>Anything to make my granddaughter a better life</td>
</tr>
<tr>
<td>Tobias P.</td>
<td>Yes - I would strongly want my brother to take the drug. He has been in the study and have seen his symptoms which had been progressing in a rapid fashion into maintaining his mobility and quality of life.</td>
</tr>
<tr>
<td>Tricia P.</td>
<td>I have an extended family member with FA. When she participated in one of the early trials it helped her tremendously. If she wants to take this medication and is familiar with it and any effects it may have and still wants to take it, then I am all for it.</td>
</tr>
</tbody>
</table>
Trudy P. My adult daughter has FA and is praying for the opportunity to take omaveloxolone as a treatment for her disease. I feel that this drug has been tested in clinical trials and is shown to be safe and effective in treating FA. My daughter has suffered for 25 years with the progressive effects of FA. She obtained her bachelors degree in Social Work in 2016 but has not been able to find work. Her faith and courage have kept her positive along with the hope that the drug Omav will be approved. Please help turn her tears of sadness to tears of joy by passing this drug for use by patients with FA.

Wendi P. Absolutely. My daughter was not able to participate in the trial, but we have followed the trial. We are desperate for a treatment for her as her health declines. It would not only help physically, but offer her hope that she has not felt for a long time.

Zoe P. Both my children have FA. They would both welcome the option to take omaveloxolone. One of my children is still walking and a treatment like Omav would be life changing for him and help to keep him from needing a wheelchair. Our daughter is already at an advanced stage and we believe a treatment will help her keep the ability to speak, her speech is getting more affected everyday.

Alexis Q. Yes my family member would want the option of taking the drug/medicine. Even if she decided not to take the drug it is still better to have that option than no choice at all.

Dave Q. Yes, if the drug is safe than she is eligible, then we as a family would support this trial. Time is of the essence.

Laura Q. Yes, I want the option for my daughter to take omaveloxolone. Currently, my daughter is able to perform all daily functions independently and does not require any assistive devices, but I can see her balance and coordination slowly deteriorating. At this point in time, there is no treatment options for FA. As this disease continues to progress, there is no getting lost functions back. If this drug is safe and effective as clinical trials indicate, she should have the right to decide for herself whether to take the drug.

Alex R. My husband would take the medication. He hasn’t been part of any studies, but prays for a cure everyday.

Alexander R. Yes, I would want the option to take the drug.

Alicia R. Yes FA patients do not have time to waste waiting for more trials when omav has shown many positive results with no significant side effects.

Amanda R. Yes, they would! They need this to extend the quality of her life!

Amber R. Through my brother I have seen the impact FA has on his every day life. Availability to omavelxolone and any other similar medication which may make every day tasks a little easier is always supported.

Armando R. Yes, simply because nothing else has worked.

Bailey R. Yes he would want this medicine to help him in the long run!!!

Becky R. Yes, it helps some people.

Besijana R. My family and I have discussed this and we would most definitely want the option for my sisters to take this drug. I am a pharmacist and in my professional opinion this drug should be made available for use. It is proven to be clinically significant and does not show to have severe adverse events.

Bobby R. Yes. He has dealt with enough pain and for a child, they deserve to live without pain.

Brady R. Yes, my family member is losing balance and motor skills very rapidly. He works out every day but his symptoms are slowly disabling him from doing his day to day job and lifestyle. Any drug or treatment that can give him a chance to live the rest of his life without this ataxia taking a further toll on his body would truly be a miracle. Our family and friends have been praying and hoping for this type treatment and understand that the long term studies have not been completed. But the clock is against my family member and many others. Thank you for your time.

Bric R. Yes. My cousin, S., has been living with FA for years. We’ve seen a decline in speech and various other motor skills, balance, being able to complete simple tasks such as tying his shoes and buttoning his own shirts have become more difficult. He is close to needing constant support so he needs medication now to at least prevent further decline.
COMMENTS FROM FA COMMUNITY
Parents & Family Members in the US

Chayson R. Yes would like the option of taking the medicine.
Dan R. Yes, of course. It is a travesty that the drug is not approved for those that need it. No different than the current vaccine for Covid. Ridiculous that this has not been approved and is delayed.
David R. Definitely yes!
Dawn R. Yes I would like for my family member to be able to try this drug
Donald R. Yes, seems like her only option
Donna R. Yes. Anything to give hope!
Drew R. Yes. It can help slow the progression of the disease.
Edward R. Yes; I would like my father, who lives with advanced FA, to have the option to take the drug/medicine. and i would like the option for myself, when symptoms eventually arise.
Emilio R. Yes it would be helpful to have that hope of being able to feel alot better.
Érica R. To have a better quality of life
Erin R. Yes! My mom has struggled with FA for YEARS! It would be nice to see some improvement in her lifetime!!
Fatime R. Yes, I want my daughters of having the option of taking the medicine. I am the mother of two daughters living with Friedrich’s Ataxia. There is no greater pain than watching your children slowly lose the ability to walk, to speak coherently and to miss out on special events. Although I was told that this disease was not my fault, I can’t stop feeling guilty for their disability. When I heard about Omaveloxolone, I was in disbelief; I could not believe there was actually a drug that could treat people with FA. I first thought of my older daughter who was the first to be diagnosed with FA. I remember running around hospitals, searching for a drug of any other kind of other treatment. Then, I thought of my youngest daughter who also has FA and how better her future can be because of Omaveloxolone. This drug is not a cure, but a treatment to better the quality of life for people with FA. Furthermore, let Omaveloxolone be the first treatment for my daughters and other people with FA.
Flora R. Not sure
Francine R. I would want the option, discuss with Dr L. and do what he suggests.
Gene R. Yes! She wants the medication and is ready to start it! PLEASE PASS THIS SO ALL FA’ers CAN IMPROVE AND LIVE LONGER
Ginny R. My daughter would take the medicine. She is degressing rapidly and soon will need a wheelchair full-time. She is a wonderful teacher and even got Teacher of the Year last year in her school. She will continue to work until she physically cannot due to weakness in legs and inability to speak.
Glenda R. She would like the opportunity to take the drug.
Hari R. Like start on Omav. something better than nothing
Heather R. Yes, my family member with FA wants a chance to benefit from this treatment.
<table>
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<tr>
<th>Name</th>
<th>Comment</th>
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<tbody>
<tr>
<td>Isabel R.</td>
<td>Yes! The FA’er should have the option and be able to decide taking or not the medicine! To them the positive outweighs the negative. They have nothing to lose and much to gain by taking it. Those are my sons thoughts and mine.</td>
</tr>
<tr>
<td>James R.</td>
<td>Any help to stop progression</td>
</tr>
<tr>
<td>Jamie R.</td>
<td>My cousin’s son has FA and would greatly benefit.</td>
</tr>
<tr>
<td>Jaymisyn R.</td>
<td>Yes. Anything would help at this point. Hope is really all we need.</td>
</tr>
<tr>
<td>Jennifer R.</td>
<td>Yes! Being able to have the option or ability to take drugs or medicine in order to benefit someone’s quality of life is LIFE CHANGING! Giving them a sense of hope and life in such a debilitating disease. The feeling of hopelessness is deep when you watch your loved one struggle or suffer and there’s nothing that can be done to stop the progression or the disease.</td>
</tr>
<tr>
<td>Jennifer R.</td>
<td>Yes, we want the option. We need the option</td>
</tr>
<tr>
<td>Joann R.</td>
<td>From everything I know about my cousin, I’m pretty sure she would take it since she’s participated in some trials.</td>
</tr>
<tr>
<td>Jordan R.</td>
<td>Yes because they are not many options</td>
</tr>
<tr>
<td>Joseph R.</td>
<td>Yes, family member is looking for treatment to help.</td>
</tr>
<tr>
<td>Josh R.</td>
<td>My family member has participated in studies/trials and would want the option to take the drug/medicine.</td>
</tr>
<tr>
<td>Judy R.</td>
<td>Yes, studies already conducted are sufficient for the FDA to approve the drug.</td>
</tr>
<tr>
<td>Karen R.</td>
<td>My daughter is open to any cure</td>
</tr>
<tr>
<td>Karen R.</td>
<td>Yes because this horrible disease needs to have a medication developed that gives hope!</td>
</tr>
<tr>
<td>Karen R.</td>
<td>Yes, want the option to take Omaveloxolone</td>
</tr>
<tr>
<td>Kathleen R.</td>
<td>We would take the medication. We have no treatment.</td>
</tr>
<tr>
<td>Kathy R.</td>
<td>I have a granddaughter, a niece and a nephew with this disease and they ALL desperately want to take this medicine!</td>
</tr>
<tr>
<td>Katrina R.</td>
<td>Yes, my 18 yr old cousin has FA &amp; taking this drug would improve her life.</td>
</tr>
<tr>
<td>Keli R.</td>
<td>Yes! She will take the drug/medicine!</td>
</tr>
<tr>
<td>Kelsi R.</td>
<td>My mother would love the option to take this medicine</td>
</tr>
<tr>
<td>Kyndall R.</td>
<td>Yes, I would want my sister to have the option for the drug. She deserves to live as normal a life as long as she can.</td>
</tr>
<tr>
<td>Leonard R.</td>
<td>yes please give this option asap. thank you</td>
</tr>
<tr>
<td>Lisa R.</td>
<td>Yes. He is young and could benefit from the drug and have a better quality of life.</td>
</tr>
<tr>
<td>Luis R.</td>
<td>Anything to help my mom or atleast give her hope for a better future for others who suffer from FA</td>
</tr>
<tr>
<td>Matthew R.</td>
<td>Yes my family member does.</td>
</tr>
<tr>
<td>Mckenzie R.</td>
<td>Yes! I would love to see my siblings finally get a medication geared towards helping the symptoms of FA! They were diagnosed at ages 7 and 5 and are both in their 30’s and wheelchair bound.</td>
</tr>
<tr>
<td>Melinda R.</td>
<td>Yes. My son has FA. There is currently no treatment options. Omaveloxolone has showed improvement for FA. It will slow down progression and will help give my son a longer life. As of now, FA is a death sentence. Please approve this treatment</td>
</tr>
<tr>
<td>Melissa R.</td>
<td>My nephew has it</td>
</tr>
</tbody>
</table>
Nora R.  Yes, absolutely. J. was once able to do things other children his age were able to and he can not anymore, and without omaveloxolone, he doesn’t have a chance of getting back there. This drug is hope for us, for him, and for any family or person with living with FA.

Paola Rego Santos R.  To have a better quality of life. Did not take MOXie.

Patricia R.  Yes. Results were promising and proven to be helpful. After endless research there is hope and this drug needs to be approved.

Rhonda R.  Definitely. Niece is a widowi with three children under 10 years old.

Rick R.  Yes, my niece definitely wants the opportunity to take omaveloxolone. She has been living bravely with FA for more than 21 years and this gives some real hope.

Rita R.  Yes any possible treatment is welcome.

Roycie R.  My son has been taking this medication with good results.

Rusty R.  Yes we want to be able to have family members try this drug.

Sarah R.  Yes! Anything to reverse this and keep my husband with me and our children getting their dad to watch them grow and hit milestones. My kids should be able to have their dad at graduations and weddings, play with grandkids, etc. If something is available to help that happen we absolutely would fight for it.

Shafford R.  Both my niece and nephew have FA time running out and they need all the help they can to slow the progression down they fight everyday to be able to do the little things in life. Please approve this.

Shannon R.  Yes, it would mean that ataxia effects would slow down and give quality of life back to Sean before he deteriorates more. Please!

Sharad R.  Absolutely yes to taking the drug. Other alternative is to do nothing and continue with the progression of the disease.

Sherri R.  Yes the only choice.

Srinivas R.  Yes... Will surely want this drug.

Teresa R.  My daughter-in-law would very much want to take this medicine.

Terry R.  Yes. Having lived with and witnessed my daughters decline and then for this drug to be available has been an amazing thing. As I listened to the webinar explain the findings from the studies I was, again, amazed. Then the news of how the FDA responded to said studies with requests for more studies just got me angry. With all the variables with this disease to request more studies is beyond me. People with FA are living with less and less abilities to function. Time is not on their side. It is my hope the people at the FDA can see the urgency in passing this. Sooner rather than later. The people with the disease should have a huge roll in deciding whether or nor not to take the drug. For anyone else to be allowed to sit back and decide what is best is overreaching. Especially after hearing the results from the studies. Thank you to FARA for their continuing fight. I am so grateful for all you do.

Timothy R.  YES!!! My son,T., was officially diagnosed with FA at the age of 5, but showed the symptoms around the age of three. He is already in leg braces, is on an IEP, goes to physical therapy twice a week, and is in full remote learning due to the COVID pandemic. He also gets virtual OT twice a week through the school system. He has worsened over the past year, and his mother and are are distraught over his progression. I implore the FDA to allow this medication to be approved!!!! We see the effects of FA every. Single. Day. We see our smart, charismatic, inquisitive little boy struggle with the daily routines that we all take for granted. He never gives up. He’s stubborn. And for that I thank the lord that he will NOT go down without a fight. At age 6!!!! I realize that this medication will not cure, but if it gives us even one more day than what FA would give him without it, then PLEASE, let us have our son just that much longer. I am literally wiping tears off of my screen as I type this. We love our son, as all parents love their children. Please allow us to keep him as long as we possibly can!!! Thank you for your consideration. Our family and friends are anxiously waiting for you to do the right thing.
<table>
<thead>
<tr>
<th>Name</th>
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<tbody>
<tr>
<td>Adam S.</td>
<td>They would definitely want the option. To see one trial be so successful but have to wait several years for the opportunity to try it themselves would be very difficult.</td>
</tr>
<tr>
<td>Alicia S.</td>
<td>Find a cure ASAP</td>
</tr>
<tr>
<td>Alicia S.</td>
<td>My nephew by marriage has two daughters with FA who are only 9 years old and both deteriorating quickly - this medication MUST be approved for their sake and every FA patient!!!</td>
</tr>
<tr>
<td>Alvin S.</td>
<td>Yes If there is any possibility of relief, comfort, improvement, stabilizing, or any other positive result of taking this medicine then it should be made available immediately to a person who wants it that has this unforgiving affliction</td>
</tr>
<tr>
<td>Amy S.</td>
<td>Yes, my son needs some kind of treatment urgently to help slow this down, but he doesn’t qualify for any trials because he is already wheelchair bound. I guess he’s useless to research scientists and it is heartbreaking to know he won’t get any kind of treatment in time.</td>
</tr>
<tr>
<td>Ana S.</td>
<td>My stepdad would definitely take it.</td>
</tr>
<tr>
<td>Anita S.</td>
<td>yes they would</td>
</tr>
<tr>
<td>Aubrey S.</td>
<td>I would take it in hopes that it would help change my life for the better.</td>
</tr>
<tr>
<td>Barbara S.</td>
<td>Yes, my grandson has been in trials and would take this medication to help with this rare disease</td>
</tr>
<tr>
<td>Bonni S.</td>
<td>Yes we want the option of taking the drug!</td>
</tr>
<tr>
<td>Bonnie S.</td>
<td>I would be happy to see my daughter M. to be able to have relief from this horrid disease.</td>
</tr>
<tr>
<td>Brad S.</td>
<td>Yes, we would take any opportunity/chance to slow down the progression.</td>
</tr>
<tr>
<td>Brian S.</td>
<td>I have watched my uncle suffer for 15 to 20 years with this disease and I was studying up on it and I have a lot of disk symptoms to it so as I may be a future patient I would like to have option and I would like for him to have options to</td>
</tr>
<tr>
<td>Brittany S.</td>
<td>Yes. No other options.</td>
</tr>
<tr>
<td>Brooklyn S.</td>
<td>Yes, we are optimistic for a medication that can aide in treatment of FA to prolong my sisters life and quality of life by reducing and preventing symptoms from developing.</td>
</tr>
<tr>
<td>Candience S.</td>
<td>When watching your children's abilities decline, a two year “pause” on disease progression would mean the world to us. You see, two years ago, my son (age 13) was still running around and playing with his friends. Today, he can no longer run. He falls frequently. Two years ago, my daughter (age 17) had the core strength to sit in a chair and to drive her scooter. Today, she must remain in her wheelchair. Two years ago, her speech wasn’t affected. Today, we must frequently ask her to repeat herself and she’s unintelligible on the phone. Please “pause” FA for them! Give them the gift of two years!</td>
</tr>
<tr>
<td>Carl S.</td>
<td>Absolutely, the options are all we have! Until there is a cure, there must be trials. Please make this happen!</td>
</tr>
<tr>
<td>Cassandra S.</td>
<td>I would love for my daughter to have the ability to take Omav. Knowing there is a drug out there that could slow her progression and not having the ability to give it to her is absolute torture. My daughter is losing her ability to walk more and more every day. She is already a part time wheelchair user and getting very close to becoming full time. Omav, I’d provided ASAP could keep her from being confined to that chair full time. I am willing to give Omav a chance with no other trials conducted. Omav has already proven itself safe and while it may not provide enough of a benefit for the FDA to consider it useful it is more than enough for the FA community. We have nothing right now. We need something. One more year of walking, talking, brushing her own teeth is absolutely better than nothing. I want one more year of my daughter.</td>
</tr>
<tr>
<td>Cassie S.</td>
<td>based on the safety and efficacy of omaveloxolone my family member would like the option of taking the medicine.</td>
</tr>
<tr>
<td>Catherine S.</td>
<td>Yes, she would like to add years to her already shortened life. She has nothing to lose by taking this medication.</td>
</tr>
</tbody>
</table>
Chase S. If the drug moxie was passed she would be taking it as soon as it is available. FA is not a condition that will get better. Patients condition will continue to get worse till death. Hearing of a drug that can potentially improve her health and standard of living is an answer to many prayers. People living with f.a should have the right to be able to try this drug.

Chris S. Yes I feel that persons with FA should have the chance to take any medication that might help with their FA.

Clarence S. The patient is my grandson. I feel that immediate treatment is necessary for his illness and well-being.

Claudia S. Yes, because it may help prevent further decline.

Claudia S. Yes we would love the option to have our son finally be able to get a medication that has the potential to help him with his daily FA symptoms and battle against this awful disease.

Clenia S. My daughter has not participated in any study, but if she had the possibility to participate, she would do it like taking the medicine, this would be a ray of light in the darkness.

Cliff S. Yes, please helpy son and others with Fa

Colleen S. Please allow this treatment to happen for the sake of people suffering with FA. J. needs this treatment which can reverse control loss and prevent further damage

Connie S. I would want my child to be able to have the option to use this medicine.

Cope S. YES! We would be willing to try anything

Cornelia S. yes, we can’t wait!

Cynthia S. Yes, definitely, my son, C., would take this drug. He was diagnosed with FA in 1997. We have watched this wicked disease steal the prime of his life. He has been in a wheelchair since 15 after scoliosis surgery to install rods in his back. Seeing his gradual decline has been heart-wrenching for both him and our family. His speech, eyesight, hearing, swallowing, sleeping, and almost every normal body function has deteriorated significantly. He is unable to scratch his nose. All this with no sign of a cure on the horizon. Omaveloxolone is the 1st viable treatment for this horrible disease. Although we are realistic about Omaveloxolone’s ability to impact C. in his late FA stages, we must try it to help him. Any side effects would be tiny compared to what he is suffering now. We also want to see the futures of other FA kids & families improve with this new breakthrough drug.

Cynthia S. Yes, I would want my niece to be able to take this medicine! To God be the glory!

Dan S. My family member is not eligible to take the drug, as his illness is too far advanced.

Danita S. I, D.S., am the mother of D., 17 and M., 14, both diagnosed at the age of 9 with FA. Stop. Before you read this, as I talk about my children, be thinking what if this was my child, my mother or YOU. I am asking, actually begging, that you make this personal and think about the lives that could change versus the numbers on paper. Grief: It is very hard to watch the health of your children decline daily. When I look at other children their age, I realize how much my children are missing out on life’s milestones: driving, dating, hanging out with friends, walking, all things we take for granted. Simply going to the kitchen for a glass of water is a challenge, how will I get a glass, fill it with water and then get it back to my room when I need my hands to wheel. Grief: I wonder, will D. and M. ever live independently? Is there ever a time when they will walk again? Everyone in the FA community knows what it supposed to happen to all FA’ers overtime. The FDA and Reata have a chance to slow and possibly reverse some of these awful losses of abilities by releasing Omaveloxolone. I urge you to look at our children and our families as if it were your own. The statistical data is proven to show positive results. I can’t imagine where my children will be without the drug in another couple years. The decline is very drastic, even though FA is supposed to be “slow progression”. Hope is real and Reata can help D., M. and the FA community by sending a new NDA urgently to the FDA. We would like you to express the need for this drug, the lack of time we have and to consider approving the drug to make my children’s lives better. Please think of us as you think of your family.

Danny S. yes my son would like the option of taking this medication to improve his quality of life.

Dawn S. Yes. Feel helpless watching my daughter deteriorate. Help!
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<tr>
<th>Name</th>
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<tbody>
<tr>
<td>Deanne S.</td>
<td>Based on the data available, I would absolutely want the option for my sons to take omaveloxolone. Any opportunity to slow their progression would be welcome. I can’t tell you how painful it is to watch this progression take place in your loved ones.</td>
</tr>
<tr>
<td>Debra S.</td>
<td>We would want the option because we have only seen continued progression to this point with no treatment for the condition!</td>
</tr>
<tr>
<td>Dermot S.</td>
<td>Yes, I think it is a human right to have access to a potential cure for Ataxia. The drug should be readily available for all who wish to take it.</td>
</tr>
<tr>
<td>Diane S.</td>
<td>Yes. P. is advanced in this disease and anything which would stop further problems or possibly reverse some awful side effects would be extremely helpful.</td>
</tr>
<tr>
<td>Dianna S.</td>
<td>My family member and nurse mother are waiting anxiously for the drug.</td>
</tr>
<tr>
<td>Edward S.</td>
<td>My grandson has a severe case and can’t afford to postpone or wait for treatments.</td>
</tr>
<tr>
<td>Edward L. S.</td>
<td>My grandson has FA. He is doing better after participating in the MOXie study.</td>
</tr>
<tr>
<td>Eileen S.</td>
<td>Yes, give them the option to take this.</td>
</tr>
<tr>
<td>Elizabeth S.</td>
<td>Simply put, my brother who has FA has been waiting for this moment for years! I admit that I have not done the research on omaveloxolone, but my brother has. I trust his judgement and know that if he is excited about this drug being released, I can be also!</td>
</tr>
<tr>
<td>Elizabeth S.</td>
<td>Yes I would give my family member the opportunity to take the drug/medicine. I work as a Physical Therapist Assistant and therefore am very familiar with helping people regain or maintain their ability to perform ADLs. I know the challenges my family member faces living with FA to perform the everyday tasks others perform without giving it a single thought. I support any therapeutic intervention including pharmaceutical that could improve their functional mobility.</td>
</tr>
<tr>
<td>Emily S.</td>
<td>Yes, this drug is our only hope.</td>
</tr>
<tr>
<td>Frances S.</td>
<td>YES! If it can help his quality of life, it’ll be worth it!</td>
</tr>
<tr>
<td>Fritz S.</td>
<td>It is a terrible, terrible decease and any drug showing promise should be use on any and everyone effected by FA.</td>
</tr>
<tr>
<td>Giuseppina S.</td>
<td>if anything out there can help them a little bit better daily its a huge plus as im sure there will be more good medicine that will come out of each trial test proven to be positive to all FA patience</td>
</tr>
<tr>
<td>Gustavo S.</td>
<td>My cousins both have FA, so they are not technically immediate family members.</td>
</tr>
<tr>
<td>Hannah S.</td>
<td>Yes as this gives the chance to live a better life</td>
</tr>
<tr>
<td>Harry S.</td>
<td>Yes, I hope this program will advance the research and cure for FA.</td>
</tr>
<tr>
<td>Hope S.</td>
<td>Definitely! M. can not wait for another trial. He is losing his abilities every day. FA has already taken so much from him. He has undergone scoliosis surgery and a heart ablation. He has already lost his ability to run, walk, and stand. He is totally dependent on others to help him eat, drink, bathe, brush his teeth. All he has left his playing on his phone and video games and he is losing these abilities as we speak. We do not have time to wait for another drug trial. If given the opportunity M. would take this drug to slow the progression of the horrible disease and improve function and quality of life.</td>
</tr>
<tr>
<td>Jan S.</td>
<td>Yes, most definitely. My daughter, so far, has a mild case of FA and it would be so beneficial for her to take this drug. FA is progressive, so this drug would greatly improve her quality of life. It’s hard to watch a perfectly healthy child struggle with daily activities.</td>
</tr>
<tr>
<td>Jan S.</td>
<td>Yes. If it helps, then they should be able to get it.</td>
</tr>
<tr>
<td>Jason S.</td>
<td>Yea I would absolutely have my children on Omav. This disease does ugly things and if there’s ANYTHING that will help it would be so meaningful to EVERY aspect of daily life!</td>
</tr>
<tr>
<td>Jenna S.</td>
<td>Yes! It will be a step in the right direction.</td>
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## Comments from FA Community

### Parents & Family Members in the US

<table>
<thead>
<tr>
<th>Name</th>
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<tbody>
<tr>
<td>Jennifer S.</td>
<td>Absolutely I would want my daughter to take it. We have nothing! Watching your child lose her abilities for the last 12 years is heart wrenching.</td>
</tr>
<tr>
<td>Jessica S.</td>
<td>Yes. It is a friend of mine. She is disintegrating. She is willing to try anything please help.</td>
</tr>
<tr>
<td>Jessica S.</td>
<td>Yes. My nephew has FA and can’t walk alone. He was adopted by my parents and I, his mom, would help them mentally and physically also!</td>
</tr>
<tr>
<td>Jim S.</td>
<td>Yes this or any medicine which shows a possibility of hope/cure is very badly needed for FA.</td>
</tr>
<tr>
<td>Joan S.</td>
<td>My friend needs this medication to help alleviate her FA symptoms,</td>
</tr>
<tr>
<td>Joanne S.</td>
<td>Yes, this is the only drug that offers hope.</td>
</tr>
<tr>
<td>John S.</td>
<td>Absolutely. Our family would like the option. Given the data to this point, we find the risk level to be acceptable. It’s imperative that we slow disease progression as research continues.</td>
</tr>
<tr>
<td>John S.</td>
<td>Yes. Daily living activities are challenging enough and any medication that demonstrates resistance to progression and offers symptomatic relief is critical to a fuller and longer life.</td>
</tr>
<tr>
<td>John S.</td>
<td>Yes. There are few options for treatment. Any medicine that can assist with treatment should be tried.</td>
</tr>
<tr>
<td>José Marcelo S.</td>
<td>To have a better quality of life. Did not take Moxie.</td>
</tr>
<tr>
<td>Joseph S.</td>
<td>I would like for my daughter to have the option for taking this medication in hopes that it will help provide for a less painful and healthier life style.</td>
</tr>
<tr>
<td>Joyce S.</td>
<td>Yes, all we have is hope—give this hope!</td>
</tr>
<tr>
<td>Julia S.</td>
<td>Would certainly take the drug</td>
</tr>
<tr>
<td>Julie S.</td>
<td>I’m sure she would.</td>
</tr>
<tr>
<td>Kaegan S.</td>
<td>Yes. I want to do anything that could help my little brother.</td>
</tr>
<tr>
<td>Kara S.</td>
<td>Yes absolutely. My cousin, C’s life has been so beautiful in so many ways, it has been humbling and difficult to watch FA slowly eat away at everything that his body could once do. Even though C. is far along in his disease progression and has outlived every expectation and timeline that was set for his life, knowing that so many other kiddos with this new diagnosis could have drastically altered disease progression gives me hope. I don’t think ANY parent should ever have to watch their child go through what C. has endured over the years.</td>
</tr>
<tr>
<td>Karen S.</td>
<td>Yes! I talked with my daughter M. about this drug, and while she recognizes that it is not the cure she is hoping for, she and I would love to see this approved. She would definitely take it because after nearly 20 years with the disease, she has experiences a decrease in her abilities every year. At 27, she needs help now with almost all of her daily living and her speech, eyesight and hearing are deteriorating at a frightening pace. For others earlier on in the disease progression, there is a huge benefit to maintaining their abilities (not getting worse) while a potential cure is developed. In the first 10 years after M’s diagnosis, this would have been a dream come true. Now, it provides hope that she may live longer and retain the abilities she still has. We urge you to approve this drug at this stage without requiring a phase 3 trial.</td>
</tr>
<tr>
<td>Katherine S.</td>
<td>My niece absolutely wants to take this medicine to help her. I believe she deserves the chance to see if this will help/improve her FA.</td>
</tr>
<tr>
<td>Kathy S.</td>
<td>We need omaveloxolone as the trials have worked for FA patients</td>
</tr>
<tr>
<td>Kathy S.</td>
<td>Yes, we need this ASAP</td>
</tr>
<tr>
<td>Katie S.</td>
<td>Yes, it’s about quality of life, and this gives that person hope.</td>
</tr>
<tr>
<td>Keith S.</td>
<td>Yes. Well researched and needed.</td>
</tr>
<tr>
<td>Kelly S.</td>
<td>Yes, I would like the option to take the omva drug. We actively participate in another drug trial but it is not as promising as the results of omva. My daughter has friends who participated in the MOXile trial and noticed drastic improvements on quality of life. We eagerly want to find a cure and omva gives us hope.</td>
</tr>
<tr>
<td>Name</td>
<td>Comment</td>
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<tr>
<td>Kenny S.</td>
<td>Yes. Studies to date show it is safe</td>
</tr>
<tr>
<td>Kevin S.</td>
<td>This is my nephew who has it..</td>
</tr>
<tr>
<td>Kevin S.</td>
<td>Yes, definitely, my son, C., would take this drug. He was diagnosed with FA in 1997. We have watched this wicked disease steal the prime of his life. He has been in a wheelchair since 15 after scoliosis surgery to install rods in his back. Seeing his gradual decline has been heart-wrenching for both him and our family. His speech, eyesight, hearing, swallowing, sleeping, and almost every normal body function has deteriorated significantly. He is unable to scratch his nose. All this with no sign of a cure on the horizon. Omaveloxolone is the 1st viable treatment for this horrible disease. Although we are realistic about Omaveloxolone's ability to impact C. in his late FA stages, we must try it to help him. Any side effects would be tiny compared to what he is suffering now. We also want to see the futures of other FA kids &amp; families improve with this new breakthrough drug.</td>
</tr>
<tr>
<td>Kristal S.</td>
<td>Absolutely! We have to try, we are desperate for a quality of life for those struggling with this illness. Please we need this quick since this is a progressive disease. It’s heartbreaking to watch your child regress &amp; there’s nothing you can do.</td>
</tr>
<tr>
<td>Krystal S.</td>
<td>Yes, I would love for my nephew you be able to feel more independent and be able to get out of his wheelchair more.</td>
</tr>
<tr>
<td>Kyle S.</td>
<td>Yes if they feel it’s helping</td>
</tr>
<tr>
<td>Larry S.</td>
<td>I’d like to have my son be able to decide if this medication was desirable for him.</td>
</tr>
<tr>
<td>Laurie S.</td>
<td>This could be a game changer for our beloved family member who has lived with FA and endured the steady debilitation for many years. Please please put the choice in the hands of families and each doctor.</td>
</tr>
<tr>
<td>Leopoldo S.</td>
<td>Yes. One more option to improve his life style.</td>
</tr>
<tr>
<td>Linda S.</td>
<td>Yes she would</td>
</tr>
<tr>
<td>Linda S.</td>
<td>Yes! Right to try!</td>
</tr>
<tr>
<td>Linda S.</td>
<td>Yes, I have, in the past, worked with people who had FA and all they ever wanted was a chance for their lives to be improved. Their attitude was always do something rather than do nothing.</td>
</tr>
<tr>
<td>Lisa S.</td>
<td>My grandson was diagnosed with FA at age 5. He is currently 18 years old. He has a severe case and needs assistance with all ADL’s. He does not have time to wait for another clinical trial. Please allow him to participate.</td>
</tr>
<tr>
<td>Lucy S.</td>
<td>As a mother of a FA I was waiting for Hope and feel like hope is coming❤️</td>
</tr>
<tr>
<td>Lynda S.</td>
<td>Yes, we would want the option as there is little that can be done to help people with this illness. Hopefully this would help improve their quality of life.</td>
</tr>
<tr>
<td>Lynn S.</td>
<td>Family member wants the option of taking omaveloxolone. Please approve!</td>
</tr>
<tr>
<td>Mac S.</td>
<td>My great niece and her parents I feel should be given the option of taking Omav. Time is of the essence and feel that the FDA act immediately in approving the use of Omav.</td>
</tr>
<tr>
<td>Margaret S.</td>
<td>Yes, In the hopes he will get better</td>
</tr>
<tr>
<td>Margaret S.</td>
<td>Don’t know</td>
</tr>
<tr>
<td>Mariana S.</td>
<td>To have a better life quality. Did not take MOXle.</td>
</tr>
<tr>
<td>Marty S.</td>
<td>Yes, most definitely!</td>
</tr>
<tr>
<td>Mary S.</td>
<td>Yes because it works and it’s the best option</td>
</tr>
<tr>
<td>Maureen S.</td>
<td>Yes anything to help with this life threatening disease</td>
</tr>
<tr>
<td>May S.</td>
<td>Yes. Because there is no other medication to stop FA from progressing and it would help with the balance.</td>
</tr>
</tbody>
</table>
Michael S.  
Yes, any potential treatment or cure should be available to all afflicted. The FDA’s role isn’t to restrict medications or make it easier on existing pharmaceutical companies to control medications. Any medication that has passed the testing protocols, or even in some cases those that haven’t should be made available to anyone suffering with this crippling disease.

Monica S.  
Our current hope is to stop progression of this disease. I want time for a cure to come about and Omaveloxolone will do this for us. This is the most difficult life long battle for my family. Its heart breaking. This will at the very least give is some hope. I would love to see my son get better and show some improvement. Theres no words to make people relate except please approve. We the FA community really need this.

Monika S.  
Time is of the essence here. My Daughter, M. is on the open label. Prior to her actually taking the drug, her progression was not only noticeable but swift. While on omaveloxolone, with some tasks there is marked improvement, but with all, progression has ceased. Buying time until there is a cure is the goal. I would like to see all patients with this odious disease have this chance. It makes a world of difference to them.

Nicholas S.  
Absolutely, it should be available As soon as possible to all patients. The data provided by part one and part two of the study along with the open label extension shows significant statistical improvement when looking at the activities of daily life and measures on the FARS Scale. This is adequate and sound proof of the efficacy of MOXie.

Pamela S.  
Yes. I see my sons symptoms worsening every day and Omav has been shown to halt the rapid progression of FA. If we have to wait for another clinical trial my son could be much further advanced. Let’s halt the progression now! Please don’t make him wait.

Paul S.  
I would love to see my brother have the opportunity to access something that may assist in improving his quality-of-life.

Paul S.  
Yes my sister would want to participate in taking it because if it has the chance to help her or others like her who have FA she would want to help find a solution to the cure.

Paula S.  
Not sure.

Phyllis S.  
My love one has been in other studies and feels we are so close to finding drugs that benefit those with fa. We need to get them to the families at a fast rate.

Phyllis S.  
Yes,our grandson needs this.

Ralph S.  
We feel that the efficacy that we have seen is better than not taking anything at all. Every moment is precious and if we can add a day or weeks or months to the life of our beautiful daughter and our time with her, we are full on. Please approve this drug for immediate use. We need it and deserve it.

Randy S.  
Nephew has FA. He can’t walk without assistance so this would benefit him.

Rebecca S.  
Yes - anything that might help - it’s a horrible disease.

Rebecca S.  
Yes. My sister was in a different trial years ago. Access to this new drug gives her hope. Not for some miracle, but just to hopefully not get worse or perhaps turn back the clock few years. She is completely wheelchair bound at this point and relies on my parents for all her basic needs.
COMMENTS FROM FA COMMUNITY
Parents & Family Members in the US

Reena S.  
Yes, I would want my son to have this drug accessible asap. With each passing day, his ability to walk and operate or even talk is declining at a fast rate. This drug will help slow down the progression and give him so much that only someone who has FA or someone who is living with FA can understand. Please pass this drug.

Richard S.  
Yes. At present there is no treatment. This could at least slow down progression of disease until gene therapy is available.

Rick S.  
Yes, K. would try anything that is safe to help with symptoms

Robert S.  
Our grandson needs this.

Ron S.  
My family member would take omaveloxolone. He has a niece and nephew that he adores and they adore him. They will move soon and be very close to him.

Rose S.  
This is terminal disease. My 3 children have no other choice but to suffer horribly and die. Let them try to get some relief from their suffering. This is a painful disease. Horrible!!

Russell S.  
Yes, we would like to have the option to take the medicine.

Sam S.  
Yes, open to any new treatment

Sarah S.  
Yes! Any chance at helping them get better is so important.

Sarah S.  
Yes, most definitely. V. and family are confident MOXle will treat and improve her health and overall well being significantly! Thank you so very much for making this happen quickly, timing makes all the difference!

Shaylee S.  
Yes, they would do anything do be able to live in a body to keep up with the life they wish to so badly live.

Shay S.  
Please pass use of this treatment for my dear niece, C.

Shelley S.  
My relative would want the option of taking the medication.

Sheri S.  
My niece is 17 yrs. Old. If she can take it to help slow the progression of FA then that will hopefully help her have an improved life.

Shyan S.  
Yes my family member wants the option. Any form of help/hope in her fight against FA is worth it to her.

Steve S.  
Yes, we absolutely want that option and would take the drug immediately. It is clear from both the data, but more importantly the drug recipients themselves, that the drug is effective. As a parent of two FA’rs we are thankful that there is finally a drug with effectiveness that is ready to go and just needs approval. In situations like this the bar for approval needs to be different than other drugs. The population is small, the number of companies developing is also small and when something shown to be effective is available it needs approval. As a parent to two children with FA we see the effects daily. It’s heartbreaking beyond description and we are powerless to do anything to stop the relentless destruction occurring in their bodies. You however are not. You can prolong lives and function, you can give hope for the for the first time since this horrific disease was named when there has been none. There is an entire community of caring loving people asking you to please move this drug forward to help us and our children. Please don’t make us wait any longer, please take action, remove the administrative hurdles and partner together to give us all a better future.

Steven S.  
Absolutely! We want this drug for our children. It could possibly stop or pause this thief of a disease. M. and D. have been showing more progression lately and we would love anything that could slow this process. Their lives are already shortened and we just don’t have many more years to wait, especially when something like Omav is available. Please help us get this for our children.

Susan S.  
My daughters would both want to take the drug omaveloxolone. They both suffer greatly from the symptoms of FA. My 13 year old has an extremely fast progression rate and loses various muscle and mobility functions each month. Any medication that could help slow or reverse the cruel progression of the disease would be taken with gratitude.
Tammy S.  
We NEED this drug. Watching our son progress, with no treatment is devastating. Please give our kids a chance to have a more normal childhood and be able to have dreams for a normal future. Time is not in our favor. This disease is relentless. We don’t have time to wait. If we don’t get a treatment, he will most likely never drive a car, may not graduate from high school, may never know what a first school dance feels like, what college life is like, have a job that turns into a successful lifetime career, having a family and his own children, being able to play with his children the way we were able to with him in his early years. Please, consider Omav for our son, and everyone else that if fighting this horrible disease.

Terry S.  
Yes. They have a right to try.

Tina S.  
Option to take the medicine

Tracy S.  
The option to take it should be available. Most FA'rs do not think they have a lot to lose.

Vivian S.  
Yes, my cousin would be open to the medication please

William S.  
Yes, one of the only options!!

Zachary S.  
Absolutely, it should be available as soon as possible to all patients. The data provided by part one and part two of the study along with the open label extension shows significant statistical improvement when looking at the activities of daily life and measures on the FARS Scale. This is adequate and sound proof of the efficacy of MOXie.

Abigail T.  
Yes. It should be the patient’s decision of whether or not it is worth taking considering all possible side effects, even if some are still unknown. This is a disease that offers no hope for improvement, so patients should be allowed to weigh their own desires against the risks.

Amanda T.  
Yes my aunt has been battling FA for 21 just want to feel better to enjoy her grand babies.

Andy T.  
Yes. My wife is 52 years old and was diagnosed with FA in her early 20’s. We would love to have the opportunity to slow down the progression of this disease.

Bobby T.  
My oldest sister is living with FA And would liked to take the drug. She has been struggling with it for the last 15 years and now is on the worst end of it. I’m hoping this drug can give her a better quality of life for whatever time she left.

Bruce T.  
My daughter would absolutely want Omaveloxolozone. I would also want access for her, as she is progressing in several different catagories. This drug will impact her quality of life and future. We pray that the entire FA community can benefit from this treatment. I can’t overstate the importance of how much we need FDA approval. We would want this treatment even if there were side effects, as the proven results could literally add years to my daughters life. The time is now, not three years of added progression.

Carole T.  
Yes, she has been a strong advocate for FA. She is progressing and certainly needs a pause pill.

Carrie T.  
Yes, my son would want the option to take Omaveloxolozone in hopes to improve his wellbeing. Living with FA for a teenage boy is a constant struggle! Thank you!

Casey T.  
Yes- any hope is better than none!
Cathryn T.  YES YES YES!!!! And the sooner, the better. This is a progressive disease that is relentless, and I want to slow it down, stop it, reverse it. For E...and for all who have FA. I cannot put in words what access to omaveloxolone would mean...but I will try. Our lives have been in two parts: before diagnosis and after. Before diagnosis now seems like a fairy tale...and after has been a horror story, the bad dream that you cannot wake up from. Omav has the potential to rewrite the plot; I desperately want that potential for E....please give it to her. As fast as you can. I had to do what seemed unthinkable: tell my 12 year old daughter that she had an incurable disease that would take away her abilities, one by one, and greatly limit her lifespan. I have watched my amazing daughter lose her ability to write, walk, stand, cut her food, bathe and toilet independently, dress herself, feed herself. Her body is misshapen with FA scoliosis....she lives in pain. She has the diabetes that FA causes, making her life even more difficult. She tires easily. She is weary of so many medical and PT appointments. At 29, she is approaching the average lifespan of 35 years. This gives her great pause. Stress. Anxiety. It seemed that the hope for a treatment or cure would not come in time for her. But it has. I...she...might grasp at hope alone, but this is so much more than hope. It is real...something with significant positive results and NO adverse events. I would not even hesitate to give omav to E. What is there to lose, when one has lost so much already? What is there to lose when your future is so bleak: loss of speech...perhaps vision and/or hearing as well, loss of bodily functions and basically unable to move at all...loss of friends and family because they just cannot deal with the emotional toll or the physical difficulty of care giver. It is heart wrenching to know that omav can change lives now and not have access to it. To delay approval/access to it for another multi-year phase three study seems cruel...imagine watching while you or your loved one's abilities disappear while knowing that there is something that could stall or prevent this, even cause improvement in abilities already lost. Well....that is the unimaginable we now face. I worked in the academic medicine field for almost thirty years, and I know how remarkable this outcome is. We also know that we may not be able to amass another group of participants for a second phase three study. This is rare disease...finding another 100 in the right age and ability group who can travel (never mind COVID)....perhaps impossible. Why not approve omav for Friedrich's Ataxia and let this be the second phase three study? I know that you have difficult choices to make. I hope that you decide for E.

Colleen T.  My niece will try anything. Her life has been stolen from her by this disease.

Cynthia T.  My niece would love to take the medication.

Dale T.  Yes, my sister would like access to this treatment.

Donald T.  Yes, I want the option for my son S. to take OMAV. I have read all the information from the trials and feel very good about what I have read. He wants to start taking the drug as soon as possible. It is the best drug to come out so far and we have waited so long. This will bring hope and sounds like it will buy us more time.

Emily T.  Yes. My family member deserves a chance to see how this drug will effect her disease

Eric T.  Yes. We are looking for any treatment possible. Time is short.

Erin T.  Yes. I am signing this for my nephew, B. My sister and her family are wanting to what they can to help this disease not progress more and to help him anyway that they can to get better.

Jamie T.  Yes, needing help.

Jeanne T.  Yes. We would want this option.

Jennifer T.  Everyday, I see more and more of my beautiful daughter slipping away. She has the whole world ahead of her and we need a treatment that can stop or slow this horrible disease! People with FA deserve the same chance as everyone else that has a helpful treatment! I urge you to let this drug become available for my N. that is slipping away from me.

Jenny T.  Any chance to pause this disease in 3 of our 5 young children, we will JUMP AT!

John T.  Yes I would. I have seen the results and have discussed this with both daughters and we concur. Make this available ASAP to all those who understand fully the the risks and wish to take the drug.

Karen T.  Yes, my daughter would love to try this medication.

Kelly T.  My sister in law would LOVE to try this medicine to help alleviate her FA symptoms.
<table>
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<tr>
<th>Name</th>
<th>Comment</th>
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<tbody>
<tr>
<td>Madie T.</td>
<td>I think it is worth trying</td>
</tr>
<tr>
<td>Maria T.</td>
<td>Yes I would like she take this medicine. So I don’t like to see how fast is her FA progress without do anything to slow down for a little bit.</td>
</tr>
<tr>
<td>Marina T.</td>
<td>Based on the safety and efficacy data, I would be extremely grateful for my sister to have the ability to continue taking the medicine. It has been significantly valuable to her not only in its direct effects of lessening her FA symptoms, but also in the many indirect benefits that that has on her everyday quality of life.</td>
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<tr>
<td>Marvin T.</td>
<td>Yes, he would like to take it</td>
</tr>
<tr>
<td>Melanie T.</td>
<td>We want the option</td>
</tr>
<tr>
<td>Melissa T.</td>
<td>I’m writing this letter on the behalf of my son S. He was diagnosed with Friedreich’s Ataxia at the age of 13 and he has just turned 24. (January 3rd). Over the past 10 1/2 years I have watched his body decline him, along with his hope for a cure. Hearing and seeing some of his fellow FA’er on the webinar regarding Omavaloxolone and the improvements they have noticed while taking the drug. I have seen a glimmer of hope in his eyes that there is something that could slow the progress down of this terrible disease while research continues for a cure. Our hopes and prayers are that you will approve the Omavaloxolone.</td>
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<tr>
<td>Melissa T.</td>
<td>Yes - any option is a worthy option</td>
</tr>
<tr>
<td>Milind T.</td>
<td>Best for the parents to answer this one, which I am sure they will do. I am a close relative.</td>
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<tr>
<td>Peggy T.</td>
<td>My brother and cousins are afflicted. My mother passed. I’m sure they would be very interested.</td>
</tr>
<tr>
<td>Rhonda T.</td>
<td>Yes. She has been traveling to Philadelphia annually for several years.</td>
</tr>
<tr>
<td>Robin T.</td>
<td>Yes. Any drug that can possibly give positive help, reversal, or stamina to my niece with FA is the greatest gift. She is getting worse and has not participated in any studies.</td>
</tr>
<tr>
<td>Ron T.</td>
<td>Any medication that can help extend the life of anyone who has this disease should be legal.</td>
</tr>
<tr>
<td>Rosalie T.</td>
<td>Yes, she should have the right to try to improve her life with this drug</td>
</tr>
<tr>
<td>Sally T.</td>
<td>I believe they would.</td>
</tr>
<tr>
<td>Sandra T.</td>
<td>Yes. We believe that this drug will benefit our granddaughter.</td>
</tr>
<tr>
<td>Teresa T.</td>
<td>Yes. It should be a choice given. If it works GREAT. If not no harm no foul.</td>
</tr>
<tr>
<td>Vincent T.</td>
<td>Yes! There are. I other real options.</td>
</tr>
<tr>
<td>Whitney T.</td>
<td>Yes. There is currently no treatment for this life shortening and debilitating disease. We need viable options.</td>
</tr>
<tr>
<td>Aspen U.</td>
<td>Yes, any medication that could help him would be given to him if we had the option.</td>
</tr>
<tr>
<td>Elissa U.</td>
<td>Yes, they would like the option.</td>
</tr>
<tr>
<td>Aroon V.</td>
<td>Yes, given the success of recent trials, we are keen that omaveloxolone be made available more broadly to people living with FA, including my family member.</td>
</tr>
<tr>
<td>Becky V.</td>
<td>Yes. We believe it could help him.</td>
</tr>
<tr>
<td>Bryan V.</td>
<td>Absolutely! In spite of any risks there may be, the benefits seem significant and the disease is slowly killing her without any type of treatment. It breaks our hearts and tears us apart every day!</td>
</tr>
<tr>
<td>Christine V.</td>
<td>Absolutely. There was a question of the tolerance of uncertainty in the FA community. When you have a family member, my case my grandson, there is nothing but uncertainty. Every day as you watch their progression so many questions come up. How much longer will he be able to walk? How will he function in the coming days when his fine motor skills are deteriorating so rapidly? And so many other questions too numerous to include. Any slowing of progression is desperately needed. There is no alternative.</td>
</tr>
<tr>
<td>Christopher V.</td>
<td>I would like to have my son to have the option to choose to take this medication. The disease is progressive and time is always going by. We need something to help to slow it’s progress and improve quality of life.</td>
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Costas V. Absolutely, it should be available as soon as possible to all patients. The data provided by part one and part two of the study along with the open label extension shows significant statistical improvement when looking at the activities of daily life and measures on the FARS Scale. This is adequate and sound proof of the efficacy of MOXie.

Darby V. Yes! My sister has FA. In the 16 years since her diagnosis, she is no longer able to walk, or even cruise while holding onto the counter. She has HCM, gets fatigued, slurred speech, difficulty swallowing. She is only 38. She has a wonderful husband and a beautiful four year old daughter. My sister has SO MUCH life to live for. If omav can slow the progression down and allow her to watch her daughter grow up, I know she would be willing to do anything.

Dorene V. I see him declining more every time you see him. It’s terrible to watch as he has poor quality of life & always gets hurt. He shows frustration when he can’t keep up with other children his own age and not can he participate in normal childhood activities. A treatment would give my grandson the chance to grow up like a more normal kid.

Gilbert V. Yea I would want her to have the option.

Graziella V. Two of my cousins (they’re siblings) have FA and Both diagnosed at 13 years old. Both are wheel chair bound. I would love for them to have the option of taking this drug immediately given the data showing this is a safe drug. we all know there isn’t much time to spare when it comes to FA. Within the 2 years of diagnoses they were both in wheelchairs. I would hate to wait any longer dreading what another year could possibly do to their health. Please allow parents to give this to their children immediately without waiting another trial.

James V. I want my grandson to have the option to take this medicine because it slows the process down and gives him a better quality of life. Right now there is no treatment and time is of the essence. Anything that will slow the process down is truly a blessing. They do not have the time for another trial to be conducted. We have seen tremendous results from the current trials and all the testimony and scientific data proves how beneficial this will be. There is no hope for an FA patient right now. This gives them hope. Thank you for the consideration.

Joanne V. Yes, my daughter would want to try this drug. There needs to be a chance for others to try this as well. What had already been studied has proven to benefit people with FA. We can’t keep something like this in testing stages forever. People’s quality of life depends on this. And it works. Let’s give others a chance to get better.

Kaleb V. This medication has the possibility of saving many lives including my cousin. If this is pushed off 2-3 more years a multitude of people could be faced with a life and death situation. Please pass this medication to save not only my cousins life but many others as well.

Kathy V. Yes, we want to try because progression to getting worst and we need drug therapy for both kids 16 and 13. Heartbreaking that they are falling apart. Things we doing to prolong life are not work so much anymore. Praying Omav can be helpful until gene therapy can kick in one day.

Katie V. I would support my mother’s choice whether she wants the medication or not, I’m signing so she and others with FA can at least have the choice.

Kimberly V. We are willing to try anything to help this disability. Anything that is close to helping my nephew is going to be appreciated and willing to try. He is clearly struggling and more and more everyday i see him declining and getting hurt and its terrible to watch as he has poor quality of life. I want a treatment to come out ASAP so he has a chance to live and grow up as a normal kid.
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<tr>
<td>Kirstin V.</td>
<td>Yes! My father has been living with this for years and has been deteriorating steadily. He is otherwise healthy and has not lost brain function.</td>
</tr>
<tr>
<td>Lisa V.</td>
<td>Yes, she would like the option to take the medicine. She has not participated in any of the MOXIe trials.</td>
</tr>
<tr>
<td>Mary V.</td>
<td>I want to see my grandchild not suffer anymore and have a new sense of confidence, instead of hopelessness</td>
</tr>
<tr>
<td>Michael V.</td>
<td>He has trouble tying his shoes, buttoning his shirt, needs a walking cane in open areas</td>
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<tr>
<td>Morgan V.</td>
<td>Yes, my sister is willing to try anything to make her FA more manageable</td>
</tr>
<tr>
<td>Nelda V.</td>
<td>Yes we would like the option. Our daughter is very compromised and any help would be welcomed. We have already lost one daughter to this devastating disease</td>
</tr>
<tr>
<td>Petar V.</td>
<td>Yes. To help improve her life and well being</td>
</tr>
<tr>
<td>Phillip V.</td>
<td>Yes, an option to take or not should lie with the one burdened with FA, anything that helps a patient with FA should have the choice.</td>
</tr>
<tr>
<td>Robert V.</td>
<td>I am advocating on behalf of parents with FA children. We have lost one daughter to FA and provide 24/7 care to our oldest FA daughter. While Moxie is unlikely to affect the health of a 40+ year old, it is desperately needed for younger FA children to lessen the impact of the disease.</td>
</tr>
<tr>
<td>Ron V.</td>
<td>Yes, any medication that can help with this disease is needed immediately.</td>
</tr>
<tr>
<td>Shawn V.</td>
<td>Yes, if it's safe and if it would help</td>
</tr>
<tr>
<td>Wendi V.</td>
<td>Yes. My niece has been fighting this for many years and she has done all the research. She wants anything the to slow or stop the progression as she is already wheelchair bound with 5 young children.</td>
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<tr>
<td>Wendy V.</td>
<td>I would want my adult son to have the option of taking the medication.</td>
</tr>
<tr>
<td>Amanda W.</td>
<td>My cousin is living with this disease and I have seen it take over his body with my own eyes. A child this young should not have to go through this. Anything to help him, I support.</td>
</tr>
<tr>
<td>Amber W.</td>
<td>Yes. She is brave and if it isn’t beneficial to her she will at least be helping other ppl in the future.</td>
</tr>
<tr>
<td>Anna W.</td>
<td>My niece that lives in Spain has this I’m sure she would try anything that would make her better. She is almost 16 years old. She already has a lot of problems from this horrible thing.</td>
</tr>
<tr>
<td>Anna W.</td>
<td>Yes, please make it available!</td>
</tr>
<tr>
<td>Arline W.</td>
<td>Yes my granddaughter was diagnosed at the age of 14. She is now 27 and has been on the drug for several years. She believes it helps her immensely.</td>
</tr>
<tr>
<td>Ashley W.</td>
<td>If there is anything that could/could have helped my oldest sister in her 23 years living a life effected by FA, I would want her to have the opportunities to try. At 39 yrs old, it may not help her, but it could benefit so many others. Her health has declined so rapidly over the past few years. I don’t like knowing that others have to endure watching their sibling/child struggle so hard to do basic things that we take for granted everyday.</td>
</tr>
<tr>
<td>Ashlynn W.</td>
<td>Yes I want my family member to have the option.</td>
</tr>
<tr>
<td>Barbara W.</td>
<td>He is my grandson I have no say in his healthcare decisions</td>
</tr>
<tr>
<td>Bessie W.</td>
<td>Yes, because it provides hope.</td>
</tr>
<tr>
<td>Bob W.</td>
<td>Yes, very very much! My niece desperately wants to take MOXIe.</td>
</tr>
<tr>
<td>Brandon W.</td>
<td>Yes, this drug would tremendously help my family member who has been living with FA for years. If this drug is not approved till years from now, it may be too late for my family member and many others.</td>
</tr>
<tr>
<td>Brittany W.</td>
<td>I would love people living with FA to have the option to try anything to facilitate their lives, prevent further progression of the disease, or to help their bodies recover from what FA has taken from them.... they need options to fight this rare and horrible disease</td>
</tr>
<tr>
<td>Byron W.</td>
<td>Yes, he has been asking for the opportunity to take it.</td>
</tr>
<tr>
<td>Name</td>
<td>Comment</td>
</tr>
<tr>
<td>--------------------</td>
<td>--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Camden W.</td>
<td>My twin brother J. has FA. It is hard watching him struggle everyday with simple things especially since we are twins and should be doing the same things. I hope you approve Omav to help my brother and others with FA.</td>
</tr>
<tr>
<td>Chris W.</td>
<td>For help.</td>
</tr>
<tr>
<td>Christine W.</td>
<td>Yes. The disease is progressing so much now. They will begin to loose abilities they will never get back.</td>
</tr>
<tr>
<td>Christopher W.</td>
<td>Yes. They are at a point of this progressive disease, that if they aren’t given the option to try a treatment, they will soon be lost to the disease.</td>
</tr>
<tr>
<td>Cynthia W.</td>
<td>Yes, absolutely. My son needs a chance at a better life. It should be his choice to make.</td>
</tr>
<tr>
<td>Dianne W.</td>
<td>Yes. This could really help my daughter</td>
</tr>
<tr>
<td>Donald (Don) W.</td>
<td>My family member would like to take the medicine.</td>
</tr>
<tr>
<td>Drew W.</td>
<td>My niece would be so grateful to have the opportunity to take the drug. She has told me so excitedly how it has helped friends of hers in the FA community with fatigue and balance, both of which are essential to more independent living with FA. Because FA is so relentlessly progressive, my niece feels that access to this drug as soon as possible could provide her (and the FA community as a whole) with some means to slow the progression and improve quality of life.</td>
</tr>
<tr>
<td>Elizabeth W.</td>
<td>My Granddaughter has been living with FA since she was diagnosed at age 12; she is 35. In the USA it is unbelievable that we waste trillions of dollars going to other countries, illegals, etc. and simply ignore the plight of our very own. Shame on the USA~</td>
</tr>
<tr>
<td>Emily W.</td>
<td>yes, small steps are better than getting worse.</td>
</tr>
<tr>
<td>Erik W.</td>
<td>Anything to find a cure</td>
</tr>
<tr>
<td>Evelyn W.</td>
<td>Yes my granddaughter would agree to this drug.</td>
</tr>
<tr>
<td>Francine W.</td>
<td>The wonderful individuals that make up FARA often call our FA Community to action in various ways to assist them in their goal to cure FA. Our family has full trust in FARA and we fully support their endeavors. As part of the FA Community, I now call on you to hear the “patient voice” and push forward the decision to approve a treatment that has been shown to improve neurological function, prevent long-term consequences, SLOW PROGRESSION of FA and improve FA symptoms. My son was diagnosed with FA when he was 12. He is now 29 and while he strives relentlessly to delay the progression of FA in every way he can, we do not have the luxury to remain “patient”. I therefore plead with you to take the steps necessary to move forward with this request. If nothing else, this can give those with FA more time to await even better treatments in conquering this disease. Thank you.</td>
</tr>
<tr>
<td>Geoffrey W.</td>
<td>I think the drug is safe and has helped enough people with FA to be potentially beneficial for my son.</td>
</tr>
<tr>
<td>Heather W.</td>
<td>My nephew needs assistance with all daily activities that he once could complete on his own. We would jump at the opportunity to give him a chance at a more normal life where he would once again be independent and do daily life activities on his own.</td>
</tr>
<tr>
<td>Hillary W.</td>
<td>Yes absolutely. Both my sister and brother have FA and we would be open to any opportunities for drug treatment.</td>
</tr>
<tr>
<td>Jackie W.</td>
<td>My family member DOES want the option to take the drug.</td>
</tr>
<tr>
<td>Jane W.</td>
<td>Yes, my family member would take the drug</td>
</tr>
<tr>
<td>Jason W.</td>
<td>Yes. The results of the Moxie study are significant. The FA community needs access to this drug. We cannot wait any longer. Every day that passes by, my daughter loses more and more abilities. I want her to experience a full and long life. Please give us access to this drug.</td>
</tr>
<tr>
<td>Joseph W.</td>
<td>Yes. With this disorder, time is very important. Sometimes, waiting is not an option.</td>
</tr>
<tr>
<td>Julie W.</td>
<td>Yes, anything that may help with this disease would be gladly taken.</td>
</tr>
<tr>
<td>Karlye W.</td>
<td>Yes my older brother would take the drug and he has been in several FA studies including MOXie.</td>
</tr>
</tbody>
</table>
Katherine W. Yes participate

Kimberly W. Yes. My my godchild’s mother thinks this would benefit him so I am fully on board and hope he gets a chance to try the drug before it’s too late.

Kristina W. This will enable M.K., My brother’s wife, to receive the medication which will change her quality of life. She is 29 and is a Nurse Practitioner that still is eager and willing to help her community despite her illness.

Lauri W. Yes I would want my daughter to take the drug, but only if there is a chance it could reverse some of the symptoms. I have a feeling it will not.

Lisa W. There aren’t many options to slow this disease. Need pharma intervention ASAP. Symptoms progress too fast (and impact daily living and mobility) to wait for the usual clinical trials.

Lisa W. Two of my sister in-laws are living with FA. It’s becoming a question of quality of life and this horrific disease needs to be addressed. If there is a chance they can have a better quality of life it should be their choice.

Lisa W. Yes. If this drug could possibly slow the progression of this disease it would be well worth it. It would allow more time for the FDA to potentially find a cure for FA and allow my nephew to possibly beat this disease and to live out his life long dreams! Thank you for allowing me to respond.

Margaret W. Yes, my nephew is D. and we are willing to try this to improve his life.

Marilyn W. Did not participate but my daughter in law needs this so badly

Megan W. Yes, she would be willing to try anything.

Michael W. Yes because it is the last option out there

Michael W. A. and A. both have FA. They were diagnosed in 2006 and are now at stages where they need assistance with almost all activities of daily living. Having this treatment would be amazing and make such a difference in our lives to be able to give them some sort of relief from this horrific disease.

Michelle W. My daughters have wanted to participate in clinical trials but have not been able to for a variety of reasons. They are very eager to try anything that is safe that could possibly slow down the progression of this disease as the list of things that they are unable to do because of it seems to keep growing.

Nikki W. Yes, we feel this option could benefit the progression of Friedreich’s Ataxia

Nikki W. Yes! My son is a straight A high school student and wants to be a doctor one day. He can if he can take MOXIe RIGHT NOW to give him a chance. MOXIe is our only opportunity to save our kids physically and mentally from Friedreichs Ataxia. Please don’t make us put our kids at risk for COVID with another trial and accept the data as is for approval. Thank you.

Patty W. Of course my grandson wants the option to take omaveloxolone. Based on current data, it could extend his life and restore some of his function. It would be an unbelievable blessing.

Peter W. Yes, we are confident in FARA’s guidance and so hopeful for something positive in treatment.

Raye W. My daughter has FA, and would absolutely want the option to take this drug. She has taken part in some studies with differing degrees of success, this one gives us the most hope.

Robin W. any progress in fighting neuromuscular disease, especially aggressive progressive disease like FA should be offered to parents and patients

Rose W. Yes, it’s better to have a voice in what the person living with FA desires for themselves. Trying a medication that has the potential to help or being trapped in a body with no voice at all.

Ryan W. Yes, as there is little that can be done currently to treat the symptoms of FA, any pharmaceuticals that can improve patients’ outlook needs to be urgently made available.

Sam W. Yes. My sister -in-law would like the opportunity to try any treatment that could possibly improve her quality of life.

Sarah W. One of my daughters was in the trial in November and another is going to participate (probably) in the upcoming January/February trial. The first one was impressed with changes she felt/saw others experience in the November trial.
<table>
<thead>
<tr>
<th>Name</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scott W.</td>
<td>Yes, i would want my 18 year old son to have the choice of taking this medicine that can keep him independent and walking as long as possible.</td>
</tr>
<tr>
<td>Sidra W.</td>
<td>Yes she absolutely would.</td>
</tr>
<tr>
<td>Sienna W.</td>
<td>Yes, I want my mom to have the option of taking the drug. I want to be able to have more time in life with my mother and for her to be with me through the rest of the milestones in my life. Anything that could help her or slow the progress of, she should have the option of taking.</td>
</tr>
<tr>
<td>Stephanie W.</td>
<td>My family member would. His sister also has FA.</td>
</tr>
<tr>
<td>Susan W.</td>
<td>Yes. Both son and daughter would be THRILLED to have the opportunity to improve their ability to physically function in a more normal manner.</td>
</tr>
<tr>
<td>Susan W.</td>
<td>Yes. My family member has been participating in drug trials.</td>
</tr>
<tr>
<td>Susie W.</td>
<td>Yes, it is initial treatment and an option to improve situation.</td>
</tr>
<tr>
<td>Tal W.</td>
<td>Yes, it could greatly benefit our daughter as well as so many others living with FA.</td>
</tr>
<tr>
<td>Tom W.</td>
<td>Want the option.</td>
</tr>
<tr>
<td>Tracy W.</td>
<td>Yes! This drug has shown to be safe and would be effective as a treatment for FA!</td>
</tr>
<tr>
<td>Travis W.</td>
<td>Yes. After several decades of living with FA, my wife is deteriorating and the drug might be helpful in slowing progression.</td>
</tr>
<tr>
<td>Valery W.</td>
<td>Yes, he is willing to try this drug. Prayers that it will work.</td>
</tr>
<tr>
<td>William W.</td>
<td>Please approve this medication. My son is dying from FA and this may save his life. For anyone that reads this, if you have children, please understand. Please hurry.</td>
</tr>
<tr>
<td>Andrew Y.</td>
<td>Yes. Please approve to prolong her life.</td>
</tr>
<tr>
<td>Brad Y.</td>
<td>FA is a death sentence. If omaveloxolone was effective in previous trials, why would the FDA withhold treatment from those facing a death sentence for years so that more testing can be done? Time is of the essence. FA patients need immediate assistance.</td>
</tr>
<tr>
<td>Lenette Y.</td>
<td>We would absolutely try omaveloxolone based on the research done so far.</td>
</tr>
<tr>
<td>Nael Y.</td>
<td>Asking for another phase of the clinical trial is asking for people to lose a lot. What the FA community people will lose: their ability to walk, transition to assistance devices of walkers/wheel chairs, glasses, scoliosis surgery or horrible spine that impacts the heart and lungs and posture, progression to diabetes or heart disease, inability to swallow, speech impairments, inability to perform daily activities independently, more falls and injuries. Another phase of a trial would do nothing but harm for these people. There aren’t enough people with this disease to get the power you want statistically. Many people can’t even join most studies because their disease progression limits them from joining. Help this community.</td>
</tr>
<tr>
<td>Nina Y.</td>
<td>My niece is 16 years old. If this drug will delay her symptoms or extend her life she should have the option of having it available to her.</td>
</tr>
<tr>
<td>Valencia Y.</td>
<td>Please help this community and approve Omav!</td>
</tr>
<tr>
<td>Amanda Z.</td>
<td>Yes. I want my cousin to live a long life.</td>
</tr>
<tr>
<td>Brad Z.</td>
<td>We would like to see our child receive any care that would help him through his life. FA has made my son have to adapt to his ever changing balance issues and if omaveloxolone can help, this needs approved ASAP so he can start taking it!</td>
</tr>
<tr>
<td>Elan Z.</td>
<td>I would want my brother to take the drug immediately. While my brother does not need assistance with a lot of things, the disease is slowly and surely progressing. If the medication will slow or even stop the disease, I want him to take it. I know the clinical trial results, and I am okay with the drug</td>
</tr>
</tbody>
</table>
Ellen Z. We definitely want the opportunity to take omaveloxolone. After 20 years we have seen our son lose so many hopes and dreams for the future...to be able to stop the progression and maintain limited abilities he has would be life changing for all of us. A promising mechanical engineer our son has never been able to work due to extreme fatigue. Yet he has a positive outlook and works out with trainer and PT 4 times per week to try to maintain what he has left. Z. has been wheelchair bound for 7 years, has afib and HCM, hearing loss, vision loss, poor fine motor skills, and increasing difficulty attending to bathroom needs even with help. We also know 2 teens in our town with FA for whom this could save their future. None of us can afford to wait... please pursue NDA (Reata) and rapid FDA approval.

Gilbert Z. Yes. My son continues to need more help but struggles each day to be as independent and positive as possible. Sometimes it gets him in trouble physically. If the progression can be slowed it would allow a very intelligent caring person to continue to add what he can to society. If there are indeed positives that come out of taking this drug the hope would be to help others that there symptoms are not as advanced as our son’s.

Gracia Z. My nephew, J. was diagnosed with FA 15 years ago. He deserves a long life with quality of life. He is so smart and funny. He has so many talents and gifts to give to this world. He tries his best to stay positive about his disease. He has a lot of hard days though. Please, please help him by allowing him to receive this medication.

James Z. Yes, we would certainly try Omaveloxolone based upon the data that is available. It is the only thing we have seen that works to slow the progression of this terrible disease. Time is ticking for our daughter.

Jennifer Z. Yes. Myself and my son would love to walk with limited or no assistance. He wants to be able to do a lot of the things his friends do.

Joseph Z. My nephew J. is rapidly deteriorating and is unable to do things without assistance he was once able to. Anything that could help slow or reverse the effects of FA of him could literally be life changing.

Kristi Z. Yes, my family member would absolutely want the option to take omaveloxolone.

Meghan Z. Yes, already participated in trial.

Meghan Z. Yes, my step daughter would like the option to take omaveloxolone.


Nael Z. February 22, 2018 I sat in the doctor’s office with my wife and the doctor just announced to us that my son has FA. I sat in shock as the doctor explained what that diagnosis meant, but all I thought about was how my world came crashing down within a split second. And the worst part of it is that there are currently no treatments available for FA. His mild clumsiness, unstable gait, and trembles would get progressively worse. Imagine having no treatment to stop this disease in order to save your son. Imagine watching month by month as he gets worse, loses abilities he once had, and not a therapeutic option in sight. At the time of the diagnosis, Reata was working on the MOXIE trial. We were hopeful and waited. During the time of the first trial, my son got worse, his motor function was slowly deteriorating, his scoliosis worsened, his vision changed and he quickly needed glasses, he was more socially aware of his condition and hung out with friends less. Then news of the second trial came out and we waited patiently, hoping for a successful trial. During the time, my son got even worse. Within a span of just 3 months his scoliosis progressed a whopping 30 degrees, which warranted emergency scoliosis surgery, his vision got worse and now has slight nystagmus, he can’t shower alone anymore, he can’t play with his friends anymore, him taking a mere flight of stairs frightens us all because of the risk of falling. His speech changed. My son changed. We don’t have time. This community of people with FA don’t have time. Every month that you go back and forth on this NDA decision with Reata we are losing time and they are losing more and more abilities. Help save this community. Save us time.
Natalia Z.  
February 22, 2018 was the worst day of my life. I was driving from LA to visit my family in San Diego on a Friday night after a long day in dental school. I called my mom to tell her I am on the way and I automatically knew my brother, L., was finally diagnosed. I pulled over, frozen from grief, and cried for hours. His life and our life will never be the same. A diagnosis didn’t come easy. It was years of watching him grow up and wondering what condition he was suffering from. This disease is so rare that the majority of physicians do not even know what it is. We took him from doctor to doctor for years trying to find answers and were unsuccessful. I am a practicing dentist in San Diego. I believe in science; I believe in research and I understand what the FDA has to do to ensure the safety of these medications. HOWEVER, rare diseases like this do not have the funding, the resources or the attention needed to develop drugs successfully. Reata is stating the FDA needs a larger population sample to ensure this drug is indeed producing positive results. If this is the case, I believe, we will NEVER approve a drug for FA. We are working with a limited population. Only 1 in 50,000 people have FA in the USA. Now consider all the patients who cannot participate in research due to finances or traveling. Consider all the patients who are unable to participate due to age or health restrictions. Consider all the patients who are misinformed and uneducated about the topic so they do not know of these opportunities. Consider all the patients who are already enrolled in a study and cannot co-enroll. You are working with an extremely limited population size. As a health professional, it is extremely difficult to believe in science and research and sit back and hear how the odds are working against the FA community. Omaveloxolone has helped these patients and right now we need to do what we can to slow progression. As I mentioned, I fully understand the process the FDA has to undergo to approve a drug, but I respectfully refuse to sit back and watch my brother progress when he should have the option of taking a drug that has shown the potential to help his condition. Our life is affected by this every single day. Every time he bumps into a wall, drops something or almost falls, we are reminded of his progression. This HORRIBLE disease affects every single organ in his body and something must be done. We, the FA community, are begging you to consider approving this drug. Behind every drug application are the faces of these amazing people affected by FA and the family and friends that love and support them. I come from a family who immigrated to the USA from Iraq many years ago. I am the eldest of four and a first generation college student who became a dentist. My sister, V., is a pharmacist and my brother, E., is in undergrad as a pre-med student. My parents are hard-working small business owners who dedicated their life to providing the best opportunities for their children. L., the youngest and probably the favorite, is the only one affected by FA. He dreams of also one day becoming a doctor. It kills me every single day knowing that he isn’t given a fair chance at life. His body is starting to fail him and what we all take for granted, is so difficult for him. Writing, speaking, walking are all difficult tasks for him and it will only get worse. Omaveloxolone will not only help him, but it will give him hope. Therefore, I am not asking, I am begging that you hear our voices and consider our stories when reviewing this drug. Thank you so much for your time.

Phyllis Z.  
Yes I would want my family to have the option to take the medication because it would alleviate the debilitating symptoms that are associated with FA.

Ricky Z.  
Yes, I would like the option for my child to take the medication.

Scott Z.  
From what I’ve seen. The drug has massive potential, and I truly think that this can help many people. Especially my brother.

Susan Z.  
I would like for my son to receive omav. He was diagnosed at age 7. I was told back in 2001- we will have a cure. Now it’s 19 years later and this is the closet drug to making a difference! My son went from running, playing sports to being a full time wheelchair user with medical problems. If he had this drug even 5 years ago, I feel he would not be needing the assistance he needs today! Let’s put a pause on the progression of this disease- until we can find a cure! My son is smart, recently graduated from a top business college in the country- and I fear his disease will prohibit him from living his dreams and goals! He does not want to live on a SSI disability payment- he wants to work and go do great things! This drug can help put a pause on this disease! If this was your child, your grandchild- I believe you too would want this drug for your loved one before it’s too late! Please use your hearts and minds and approve this safe drug for our family members who are losing abilities each year!
Valencia Z.  February 22, 2018 I sat in the doctor’s office with my mom and the doctor just announced to us that my brother has FA. And the worst part of it is that there are currently no treatments available for FA. His mild clumsiness, unstable gait, and trembles would get progressively worse. Imagine having no treatment to stop this disease in order to save your brother. Imagine watching month by month as he gets worse, loses abilities he once had, and not a therapeutic option in sight. At the time of the diagnosis, Reata was working on the MOXIE trial. We were hopeful and waited. During the time of the first trial, my brother got worse, his motor function was slowly deteriorating, his scoliosis worsened, his vision changed and he quickly needed glasses, he was more socially aware of his condition and hung out with friends less. Then news of the second trial came out and we waited patiently, hoping for a successful trial. During the time, my brother got even worse. Within a span of just 3 months his scoliosis progressed a whopping 30 degrees, which warranted emergency scoliosis surgery, his vision got worse and now has slight nystagmus, he can’t shower alone anymore, he can’t play with his friends anymore, him taking a mere flight of stairs frightens us all because of the risk of falling. His speech changed. My brother changed. We don’t have time. Every month that you go back and forth on this NDA decision with Reata we are losing time and they are losing more and more abilities. Help save this community. Save us time.

William Z. Yes, he is currently

Footnote 1- 599 signers commented- “Yea”, “Yes”, or “Absolutely”  Footnote 2- 31 signers commented- “No” or “NA”
<table>
<thead>
<tr>
<th>NAME</th>
<th>COMMENTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Albeiza A.</td>
<td>Yes, i would like him to take the medicine</td>
</tr>
<tr>
<td>Aina A.</td>
<td>Yes... its very god</td>
</tr>
<tr>
<td>Albulena A.</td>
<td>No we dont participated in Moxie part 1,part 2 .Here we dont have conditions for this kind of disease</td>
</tr>
<tr>
<td>Alejandro A.</td>
<td>At this point, any option is better than waiting for the FA to fully develop on my sister</td>
</tr>
<tr>
<td>Alexios A.</td>
<td>Yes. My nephew is 22 years old and crawling to get around the house. It breaks everyone’s heart, I think it’s time such treatment is made available!!!! We live in hope that it may help him.</td>
</tr>
<tr>
<td>André A.</td>
<td>Yes, I would like to take MOXIE</td>
</tr>
<tr>
<td>Andrea A.</td>
<td>She would like the opportunity of hope of taking back ownership of her life and having improved social conditions (ie the absence of bullying) in her life, which in turn end up affecting her self-confidence and emotional health.</td>
</tr>
<tr>
<td>Anna A.</td>
<td>All I want in my life is to help my little daughter having a good life. To slow down her progress.</td>
</tr>
<tr>
<td>Antenor A.</td>
<td>It would be a great help and hope for people suffering from this disease</td>
</tr>
<tr>
<td>Augusto A.</td>
<td>Part1</td>
</tr>
<tr>
<td>Belinda A.</td>
<td>Yes my cousin passed away from complications a few years ago and I know she would have preferred this drug as opposed to dying a slow death.</td>
</tr>
<tr>
<td>Cesar A.</td>
<td>Yes. She, my family member, wants to take that option.</td>
</tr>
<tr>
<td>Chamila A.</td>
<td>Because omaveloxolone is a safe drug and very efficient</td>
</tr>
<tr>
<td>Christian A.</td>
<td>My wife wants to be part of the study as her balance, speech and eyesight have deteriorated</td>
</tr>
<tr>
<td>Derya A.</td>
<td>my sister</td>
</tr>
<tr>
<td>Dimitra A.</td>
<td>Yes I would because I think it can help many patients and family members</td>
</tr>
<tr>
<td>Emiliano A.</td>
<td>Yes, it seems to be a good opportunity for patients</td>
</tr>
<tr>
<td>Emma A.</td>
<td>Yes absolutely!</td>
</tr>
<tr>
<td>Emma A.</td>
<td>Yes, desperately wants to take this as has already surpassed life expectancy and is trying best to maintain quality of life</td>
</tr>
<tr>
<td>Emmanuel A.</td>
<td>My sister lives with FA and she wants the option of taking Omaveloxolone, based on the data currently available on safety and efficacy.</td>
</tr>
<tr>
<td>Euridice A.</td>
<td>According to the information about the drug, I think it will be an efficient treatment</td>
</tr>
<tr>
<td>Fadime A.</td>
<td>Both of my brothers have FA and I definitely want them to use this drug. We have been waiting for a solution from science and medicine for years. It is a human matter that a tiny chance of recovery should not be spared from souls like this diamond, which has suffered a zero defeat in life and suffered physiological and psychological pain...</td>
</tr>
<tr>
<td>Fatima C.</td>
<td>Good</td>
</tr>
<tr>
<td>Fellippe A.</td>
<td>yes, i’m sure my cousin would like to volunteer for the medication. I very much hope that healing or stabilization is near.</td>
</tr>
<tr>
<td>Francesco A.</td>
<td>Yes, to slow down the progression of the disease</td>
</tr>
<tr>
<td>Gay A.</td>
<td>To get a chance to stop the disease progression</td>
</tr>
<tr>
<td>Geania A.</td>
<td>Yes, I want to take omaveloxolone</td>
</tr>
<tr>
<td>Gustavo A.</td>
<td>Yes, my cousin needs.</td>
</tr>
<tr>
<td>Hani A.</td>
<td>I would like my son to take Moxie as we follow the trials and see that the results are sufficient for an approval.</td>
</tr>
</tbody>
</table>
COMMENTS FROM FA COMMUNITY
Parents & Family Members Outside the US

Hannah A. We would definitely take omaveloxolone there is no current treatment for this devastating disease and everyday our daughter loses more and more of her independence even slowing down progression or keeping some aspect of independence will be so significant to her later life and ability to pursue her dreams.

Havin A. Yes I want tax

Helena A. Yes! Because we have no other options available

Ignacio A. Yes, would definitely participate. Some hope is better than no hope

Irini A. Yes because his health just gets worse. It’s worth the risk.

Iris A, Juliana B, Jens H, Christa K, Rosita S The debilitating effect of FA on my friends daughter and the emotional turmoil it causes his family leaves them wanting the option of taking the drug to provide their daughter with the best opportunities in life.

Janice A. Yes my family member wants the option to access omav as it will improve her quality of life and maintain her independence

Jason A. Since my daughters diagnosis at age 10 we have seen her go from walking, writing, having friends to wheelchair bound, loss of motor skills so can no longer write and almost no friends due to her low self esteem...we cannot wait much longer as this disease destroys us all on a daily basis...we urgently NEED to have this drug available.

Kacie A. Yes. Both the child & his mother are desperate to find any medication to help slow the deterioration of his condition. His mother made me aware of this as she has just signed it herself.

Karine A. After 33 years living with this disease I think my sister in law have the right to try medicine could help her. Thanks

Laura A. The most important thing is to improve quality of your life and give you the opportunity to live, not lead to certain death

Leonardo A. Yes, I want to take omaveloxolone

Lucas A. Yes. I want to have access to the medicine.

Lütfiye A. Would love to participate and take this medicine.

Lyn A. Yes Anything that might help

Marcelo A. Speed

Marcone A. Yes with that possibility, they will have a Glory life

Marcos Roberto A. Yes, I want to take omaveloxolone

Maria A. Yes it should be available As soon as possible to all patients! The data provided by part one and part two of the study along with the open label extension shows significant statistical improvement when looking at the activities of daily life and measures on the FARS Scale. And Currently there is no medication available to these poor souls dealing with this horrible disease.

Maria Aparecida A. Yes, I want to take omaveloxolone

Maria Nazare A. Yes, she wants to take this medicine

Mason A. Yes, we need something to slow the onset of symptoms. Our son was diagnosed at 3 years old and can no longer walk and look after himself with daily life. We need hope for T.
<table>
<thead>
<tr>
<th>Name</th>
<th>Comment</th>
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<tbody>
<tr>
<td>Michala A.</td>
<td>We desperately want this for my son, my friends son had it and I can’t believe the difference it has made to his health and life.</td>
</tr>
<tr>
<td>Nadia A.</td>
<td>Yes we would try anything as his condition is deteriorating</td>
</tr>
<tr>
<td>Natalie(Mum) A.</td>
<td>Yes, my son would take it immediately. A drug which might slow down the progression of his disease is critical.</td>
</tr>
<tr>
<td>Nelson A.</td>
<td>Yes, she wants to take the medicine to get a better life</td>
</tr>
<tr>
<td>Norma A.</td>
<td>Yes, I want that my boys get it</td>
</tr>
<tr>
<td>Nour A.</td>
<td>Yes, I want my son to have this medicine because it will help him reduce the severity of the disease and improve his health according to the results obtained with people who have used this medicine.</td>
</tr>
<tr>
<td>Oezlem A.</td>
<td>I don’t speak English</td>
</tr>
<tr>
<td>Pedro A.</td>
<td>yes, because he could have a better quality of life</td>
</tr>
<tr>
<td>Pierron A.</td>
<td>We are counting on you</td>
</tr>
<tr>
<td>Priscila A.</td>
<td>YES! We need something to stop the progression of FA.</td>
</tr>
<tr>
<td>Quentin A.</td>
<td>I strongly respect the regulatory process for approving the use of new drugs. Particularly the US FDA role and process. I am absolutely convinced the safety risks of using this drug are low to zero, but in any case, safety risk is hugely outweighed by the possibility of any result that slows the progression of FA. Today, at minimum, it is the only treatment that has shown evidence of the ability to do that. It seems probable that its effects in slowing or halting progression are significant. But again, for those living with FA, ANY effect that slows progression will be precious. The time needed to complete further trials is time ALL those living with FA don’t have. I would not hesitate in using the drug myself were it available. The FDA’s role and decisions are critically important to the outcomes of similar regulatory roles and processes in NZ. FDA recognising the desperate situation facing those living with FA and the known facts around its safety risks, and using their approved process to waive the need for further trial and authorise use of this drug immediately, will have huge and positive impacts for those living with and around FA here in NZ and many other countries beyond the US.</td>
</tr>
<tr>
<td>Rachida A.</td>
<td>Take the drug to have better quality of life</td>
</tr>
<tr>
<td>Raquel A.</td>
<td>I have one member in my family that want the drug/medicine</td>
</tr>
<tr>
<td>Renato A.</td>
<td>Because I want a better quality of life for all people with FA and achieve an improvement in their daily lives</td>
</tr>
<tr>
<td>Rute A.</td>
<td>I have a family member who has FA and want the option of taking the drug/medicine. Thank you</td>
</tr>
<tr>
<td>Salma A.</td>
<td>Yes. She will be better with omoveloxolone and its important for regrade her sintoms and no more bulling</td>
</tr>
<tr>
<td>Shakath A.</td>
<td>Loss of balance needs splints to walk...falls an trip due to balance</td>
</tr>
<tr>
<td>Shakira A.</td>
<td>Because I believe that the OMAVELOXOLONE it’s safe and will be effective for the treatment of the Ataxia , will minimize daily criticism, the consequences of bullying, will give more self-confidence and freedom of life</td>
</tr>
<tr>
<td>Shatha A.</td>
<td>Yes he dose</td>
</tr>
<tr>
<td>Shehina A.</td>
<td>I have two family members who have FA, yes, we would the option of them taking the medicine</td>
</tr>
<tr>
<td>Soledad A.</td>
<td>I think my sister’s fiance would want to have an opportunity to have a better quality of life because he is a young man full of proyects for make this society more inclusive and friendly for dissabled people (he’s even working in the government for this purpose)</td>
</tr>
<tr>
<td>Sonia A.</td>
<td>M. feels that he is a perfect candidate to participate in this study and is ready to try.</td>
</tr>
<tr>
<td>Suheima Salim A.</td>
<td>A friend was diagnostico with FA and we believe that she can try, since in Mozambique there is no other option. Please help her.</td>
</tr>
<tr>
<td>Tarciana A.</td>
<td>Yes.Because i hope he gets a better quality of life</td>
</tr>
<tr>
<td>Thanasi A.</td>
<td>Absolutely, it should be available As soon as possible to all patients. The data provided by part one and part two of the study along with the open label extension shows significant statistical improvement when looking at the activities of daily life and measures on the FARS Scale. This is adequate and sound proof of the efficacy of MOXie.</td>
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COMMENTS FROM FA COMMUNITY
Parents & Family Members Outside the US

Theo A. Absolutely, it should be available as soon as possible to all patients. The data provided by part one and part two of the study along with the open label extension shows significant statistical improvement when looking at the activities of daily life and measures on the FARS Scale. This is adequate and sound proof of the efficacy of MOXie.

Thomas A. I would like to have the opportunity to try the medicine.

Valeria A. Yes I would

Vanessa A. To stop or slow further progression of FA in my son, now not 10 years time this is time we need.

Vesile A. Yes, we want the option of taking the medicine.

Vinicius A. That improves

Virginia A. Based on the data and efficacy of omaveloxolone and if indicated by his doctor, I would like that my son receives the treatment with that medication. He did not participate in the clinical trial.

Yagmur A. I have not tried this drug yet. I wish it comes to Germany

Yara A. My family member wants the option of taking the medicine.

Yüksel A. My little sister have Fa and she needs the medicine.

Yussra A. Yes, my family member wants the option of taking the drug/medicine. She has been doing the research about omaveloxolone, and shared it with us, and she believes it might be safe. So, with that in mind I'm singing this petition.

Zuhal A. None of my familie has this disease this have just my children.

Zuhal A. Yes I want to buy it please.

Adriana B. Because I am sure that this medicament help my familiar.

Alain B. Omaveloxolone is so far the only chance we have. So it is urgent to get this product!

Alain B. Yes, for help the research and maybe help my son.

Alfredo B. Yes we would like to use the medicine.

Aliye B. My daughter is suffering from FA for more over 16 years. We have not received a real treatment yet. This is the first drug for real diagnosis. We need to take this drug as soon as possible.

Amélia Beatriz B. Yes. Anything to help her get better.

Andrew B. Yes 100% - we need to take any step to slow the progression and to give the many treatments that are in the pipeline a chance of retaining as much of my girls independence.

Angel B. I accept for our family member to try the drug.

Annet B. 2 children from my sister have fa.

Augusto B. My sister with FA world take it.

Benjamin B. The data currently available (as presented by Dr Lynch last year), as well as practical experiences shared by those who took part in MOXie part2 + open label extension, prove that at the moment omaveloxolone is the best hope to slow down (or even stop) the disease progression while waiting for a definitive cure (GT or a polytherapy). We’d start right away if it were available.

Bert B. 2 children from my sister have fa.

Betania B. yes because it would be a great opportunity.

Blain B. Based on the data available and the fact there are no approved alternatives in the market, people with FA should have access to this drug and the option to decide for themselves.

Carlos Alberto B, Natasha Jazmine B, Noelia B, Jane C, Tessa C, Maria L, Niki L, Amadeo P, Maximo Roberto P, Monica P, Alexander S, Fernanda S, One S, Paolo T. Because my family and I are convinced that the results demonstrate meaningful benefit and low risk and would like our family member to have access to this medication. We believe that the studies completed to date provide sufficient evidence to support the approval of Omav.
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<thead>
<tr>
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<tbody>
<tr>
<td>Carolina B.</td>
<td>Yes, since the effects have proven very positive, with no significant side effects. And it is a terrible disease, which needs help.</td>
</tr>
<tr>
<td>Catalina B.</td>
<td>I think it is necessary for people to have hope and here is their only option</td>
</tr>
<tr>
<td>Cauley B.</td>
<td>Yes - the research shows a clear benefit</td>
</tr>
<tr>
<td>Caydn B.</td>
<td>I have watched my older Sister and younger Brother suffer through for almost as long as I can remember in my life. One of the worst parts, I'm told by these very special, brave, resilient, inspiring individuals with FA, is the lack of hope they are given regarding any genuine treatment. Let alone something like this which can potentially actually help many sufferers' lives quite quickly. In my siblings' case, time is beyond being of the essence. It's a killer. Any and all attempts to give just a glint of hope for FA sufferers is something we desperately need. FA sufferers need hope and also deserve the opportunity urgently to decide whether or not to take a possible life-saving drug.</td>
</tr>
<tr>
<td>Christian B.</td>
<td>I think they can answer themselves, I have forwarded this letter. But I think yes, they are waiting for a treatment for so long time ...</td>
</tr>
<tr>
<td>Corey B.</td>
<td>Yes I want my dad to get this treatment it's effected him and all our lives greatly and are looking for anything we can get</td>
</tr>
<tr>
<td>Cristiana B.</td>
<td>Yes, we should try everything in order to save the ones who we love</td>
</tr>
<tr>
<td>Cristina B.</td>
<td>Yes, me and my family have interest on take this medicine, because we want to be cured.</td>
</tr>
<tr>
<td>Dalia B.</td>
<td>This drug can be a favorable option to improve the quality of life and the independence of my family member.</td>
</tr>
<tr>
<td>Dan B.</td>
<td>Yes my son V. would like to be one of the patients who would have the possibility of being treated by Omaveloxolone</td>
</tr>
<tr>
<td>Daniel B.</td>
<td>Yes, to give the chance to find something against FA</td>
</tr>
<tr>
<td>Daniela B.</td>
<td>Yes. My nephew is 30 years old and omaveloxolone is his only chance.</td>
</tr>
<tr>
<td>David B.</td>
<td>Currently there is no cure for FA nor is there an approved drug treatment programme. FA is a progressive disease that diminishes faculties resulting in a shortened life span. Time is of the essence as far as any treatment is concerned. Recent trials of omaveloxolone indicate that it all but halts FA's progress, thus providing the first and only hope of successful treatment. As said earlier, time is of the essence in tackling FA, so any delay in the approval of omaveloxolone for universal use loads sufferers with increasing faculty failures that cannot be reversed. In light of all that has been revealed about omaveloxolone to date I, and my immediate family, would have no hesitation in allowing our 12 year old grandson to take the drug immediately. Given his young age, he is an optimum candidate to gain maximum benefit from early treatment. In other words, in his case, the quicker the better!</td>
</tr>
<tr>
<td>David B.</td>
<td>My family member with FA has faith and hope in this</td>
</tr>
<tr>
<td>David B.</td>
<td>Yes, they would look positive on assisting with further trials to eradicate this horrible disease.</td>
</tr>
<tr>
<td>De-Arne B.</td>
<td>Yes, time is running out for my daughter. Every year her symptoms are worse.Anything that gives her some quality of life for her time left would be amazing.</td>
</tr>
<tr>
<td>Deb B.</td>
<td>Yes. Hey have been on the drug trials and are keen to see a flexible approach</td>
</tr>
<tr>
<td>Deirdre B.</td>
<td>Yes if it would slow the progression of FA</td>
</tr>
<tr>
<td>Denise B.</td>
<td>FA is such a devastating progressive &amp; life shortening condition with absolutely NO APPROVED treatment that we have no time to wait for another trial of omaveloxolone. My 12 year old grandson has FA &amp; each week we can see normal activities deteriorating &amp; it’s so hard for him. My family would not hesitate in allowing my grandson to take Amov once approved. We need this to happen NOW it is extremely urgent, we cannot wait so please approve this drug, it is the only hope at this stage to help all sufferers of FA.</td>
</tr>
<tr>
<td>Dianne B.</td>
<td>This is a much needed opportunity to lessen the ataxia progress in my twin granddaughters .</td>
</tr>
<tr>
<td>Doug B.</td>
<td>Yes. Please allow</td>
</tr>
<tr>
<td>Dylan B.</td>
<td>Yes if there's anything to help improve there condition I think it should be made available</td>
</tr>
<tr>
<td>Eleni B.</td>
<td>Most probably yes.</td>
</tr>
<tr>
<td>Elizabeth B.</td>
<td>Yes we would want the option of taking the drug/medicine. Any opportunity to better the quality of life will be taken</td>
</tr>
</tbody>
</table>
COMMENTS FROM FA COMMUNITY
Parents & Family Members Outside the US

Emily B. Most definitely, as a disease with no other treatment options any treatment is worth taking.

Emina B. Yes, my daughter suffers from FA, she would take medication so she can be cured.

Emma B. Yes. From looking at all the data available I am hopeful that this drug will stop or rapidly decrease the progression of this disease any further. I have identical twin girls who are still able to live as normal a life as possible (although very off balance) and this drug could enable them to continue this way if we can get the drug to them quickly. Due to the age of their onset we only have a couple more year before they are likely to struggle with their fine motor skills and require the use of a wheelchair full time. There speech is already showing signs of getting worse. Time is of the essence with this disease.

Fikret B. Yes of course. We want to try omaveloxolone.

Francisco B. Yes. My cousin G. is so young, intelligent, compassionate and so full of energy that the family could not believe when we heard the news that she was diagnosed with FA. She has just started her medical studies and has so much to offer to the community around her. Considering the safety of this drug - Omaveloxolone - that was verified in trials, G.'s parents, her relatives like myself and her friends are all full of hope and looking forward to the approval and change that this medicine can make on her life. Thank you.

Francisco Javier De B. It continues.

Franco B. Not sure.

Frank B. My family members want the option as their functions gradually and irremediably diminish. They want a chance for themselves and to advance progress of a cure through their shared experience.

Glenda B. Want the drug.

Graham B. Yes. There needs to be progress on curing or helping to live with FA.

Heidi B. My daughter-in- laws sister, who is in a wheelchair would definitely take it.

Hélène B. My two children want to take this medicine.

Ian B. Yes. Willing to take the drug/medicine.

Ingunn B. YES my cousins want the option to take the medicine!

Isabelle B. Yes, so he can finally get again more independent and enjoy life.

Ivana B. My brother in law would want the option of taking this medication.

Jagruti B. We are delighted with the results. Wish to get it ASAP.

James B. My cousin would happily take the medicine.

Jane B. My cousin has lived with this disease for 53 years. This medication is something she wishes to use to have continued treatment of symptoms.

Jigar B. Yes. Member need it on immediate basis because of the current condition of his health. So need omav to be approved as soon as possible.

Joanna B. Yes, based on the data currently available on safety and efficacy of omav, I want my daughter to have the option of taking it. The results of this trial give us so much hope for a treatment which can slow FA’s progression, keep maximum amount of capability and capacity, while we wait for a cure. From what I’ve read and learned about this trial and drug, and in discussion with my daughter, we are comfortable tolerating the risk of not performing another trial, in order to have the benefits of Omav as treatment sooner rather than later, for what it has shown to do: slow the progression of FA. I hope you will please take our voices into consideration. Thank you.

Jocimário B. Wants to take it to have a better quality of life. Hasn’t taken yet.

John B. Yes my Son would be willing to take the drug/medicine in the above proposed trial. It is only through trials like this that any progress will be made.

Juan B. Yes, my daughters would take it.

Katie B. Defiantly yes.

Keila B. I have a family member with FA and this medicine helps to decrease the symptoms.
### COMMENTS FROM FA COMMUNITY

#### Parents & Family Members Outside the US

<table>
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<tr>
<th>Name</th>
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<tbody>
<tr>
<td>Ken B.</td>
<td>Yes Early treatment always preferable</td>
</tr>
<tr>
<td>Leticia B.</td>
<td>Because my family and I are convinced that the results demonstrate a significative benefit and a low risk. We would like that our family member gets access to this drug.</td>
</tr>
<tr>
<td>Liz B.</td>
<td>My daughter was diagnosed 18 months ago. Prior to the start of her symptoms she was a talented sports person. Over the last 2 years we have sadly watched her sporting ability decline to the point now where she is no longer able to play her much loved sport of netball at any form of competitive level. She no longer wants to play as she says she is too uncoordinated and is embarrassed for others to see her. She is also now experiencing problems with her fine motor skills and struggles to write. Currently she looks like a clumsy child but is not at the point where her peers would realize that there is anything wrong. We would love the opportunity to be able to access Omav so that our daughter can continue to move through her teenage years without facing too many of the losses that many other children with this disease have already faced. We strongly believe that the benefits of Omav far outweigh any associated risks. We encourage you to look beyond the red tape and show compassion to all people living with this devastating disease.</td>
</tr>
<tr>
<td>Louise B.</td>
<td>Yes I would do anything to help with the problem</td>
</tr>
<tr>
<td>Lucy B.</td>
<td>My mother would definitely take omaveloxolone</td>
</tr>
</tbody>
</table>
| Luis Gustavo B.| Yes, because I think that the improvement that this drug can bring to the life quality of the individuals that has FA.  
                 |                                                                                                                                                |
| Luiz B.        | Yes, I would, because this could give a better opportunity to live her life without or less disease.                                                                                                          |
| Maria B.       | I would be happy if the drug can also be used on my granddaughter.                                                                                                                                       |
| Mariana B.     | My cousin would be the perfect person to receive treatment, is a woman, 30-year-old, active mental health, and physically well.                                                                        |
| Marie B.       | Yes my niece and nephew would definitely want the option of taking this drug. They have been waiting for this day since being diagnosed 18 years ago. Both are confined to wheelchairs and have no quality of life. This is the breakthrough we have all been waiting for, a glimmer of hope. Please let the FDA pass this and give FA sufferers a chance to improve or stabilise this horrific progressive disease. |
| Marie Jo B.    | Thank you                                                                                                                                                                                                |
| Marina B.      | Yes to have a better quality of life.                                                                                                                                                                     |
| Marta Da B.    | So that she has a better quality of life. She never took MOXle.                                                                                                                                           |
| Martine B.     | We need to help him leave better. Thanks!                                                                                                                                                                 |
| Mathilde B.    | Yes, of I could, I would give it to my child, because it seems to be one of the best drugs that could be available for now to help fighting FA.                                                              |
| Mayara B.      | It would be extremely important to bring the medicine to Brazil, thus making it possible for low-income people to have access to the medicine.                                                              |
| Melissa B.     | I ask you this, if you were in the shoes of being a parent of an FA individual (we have 2 kids sick with it) or a direct patient of FA most likely your given answer would be yes I would trial this in a heartbeat. I watch day in day out my boys both suffer hugely. Both seem to be serve symptoms, from hypertrophic cardiomyopathy, feeding tubes, daily nerve pain and these are just a couple with so many hospital and doctor appts as well. Its not only a HORRIBLE disease to watch someone have, it’s also so taxing on families day to day activities, schooling, social relationships, finances, healthcare ect. our family is heading into the 6yr since out 17yr was diagnosed. In these 6 years he has become chairbound. had feeding tube inserted, a loop recorder put in to monitor his heart condition (hypertrophic cardiomyopathy), to us losing all our savings to pay for therapies medications and equipment to having our cupboard turn into a mini pharmacy. Really ask yourselves does this treatment really need another 2yr study? Remember all of us family that are on a time limit, and in 2yrs may not have that chance to get this. |

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176
Melodie B. Yes. The drug trials have enough data to satisfy me of the drugs ability to slow or even stop the progression of the disease. A slowing would be acceptable and sufficient for me to give the drug to my child, a stopping would cause unbound joy, an even slight reversal in symptoms would be a miracle. My twin boys started walking at 9 months and talked before most children. At 2.5 years they were riding bikes without balance wheels. At 4 years they joined a cross country ski club, at 4.5 they were able to swim lanes, at 5 they hiked up mountains on 15 km return trips, at 5.5 years they downhill skied black Diamond runs, at 6 they started playing the piano, at 6.5 years one of them started tripping on flat ground. At 7 he couldn’t cross country ski anymore, at 8 he couldn’t swim anymore, at 9 he stopped playing soccer with this friends, at 10 he lost his last friend, at 11 he stopped biking, this year he stopped hiking even with our arms around him. He never did learn how to tie his shoes properly, open a can of soup or play tennis like his brother. If FA would stop progressing today, he would keep his ability to independently walk and move around the house. He would still be able to take a shower by himself and continue playing the drums. He could continue building robots with his Lego sets. He could still use voice to text technology because his speech issues are not that bad yet. But we do not have anything that could slow down or stop the FA progression. At a time when other families and children are planning limitless futures for their children, we are fighting an enemy without weapons. There are no treatments. There is no help. Nothing slows down the constant loss of ability, independence and opportunity. At a time when a child should have boundless excitement about the present and possible futures, my boy is retreating into himself. He is frustrated about his inability to pour milk without spilling it all over the counters and floors. He is helpless to control the vibration in his hand and the shaking off his legs. He is worried about what the next day may bring. Will he be too tired to wake up in the morning to go to school? Will he trip and again twisting his knee or ankle? Will someone sit with him for lunch or will they avoid him? Will the substitute teacher yell at him again because he couldn’t change from his boots to his shoes without help? As parents we are helpless. All we know, is that he will be in a better position if we can keep his muscles working. So, we equipped a home gym and have coached our then 7 year old to work out. He is now training with our help for 1.5 hours every day. It is frustrating work because instead of gradually getting better, he gradually gets worse. As a family we have given up our weekend skiing, hiking and biking. We have lost contact with our friends who were mostly as active as we used to be. We have diligently worked with speech therapists, physiotherapists, orthopaedic specialists to try to fight scoliosis, drop-drop foot, dyspraxia, muscle cramps and pain. As a family, we have by now fought, lost and grieved, only to pulled ourself together to again fight, loose and grieve. We know we will do it over and over because there really is no other acceptable choice. We have monitored the FA drug candidates over the years and are confident that Omaveloxolone would help us achieve our goal of slowing down and even stopping the progression of FA. This would prevent our son from having to loose his ability to walk in the next year or two. Time is of the essence in this disease, especially during the teenage years. We are asking the FDA to approve this drug for the FA community. Our family needs a chance to slow or to stop the progression of the disease before it robs my child of even more independence and capabilities than it already has. At the current progression, within a year my child will have to transition to a walker. He will have to switch schools because of access issues. We will need to sell our house in a downturn because of access issues. We will try to move to another city where snow does not hinder a person in a walker or wheelchair. Any slowing of the progression gives us and him the chance to be able to take advantage of future cures while he is still healthy and mobile enough to get the greatest advantage.

Michael B. Yes. My cousin wants to try the drug anda I fully support her

Mirela B. Yes, my sister would try to take the medicine, option of healing always exist so why not.

Mona B. Not sure

Monique B. Yes, as this is the only hope.

Nasser B. Please allow omaveloxolone for FA.

Natalia B. Yes, its her only option and we believe in it

Neyde B. Yes, she wants the option of taking the drug/medicine urgently, her quality of life is getting worse everyday, depending more and more of other people’s help to do simple things everyday.

Noel B. Yes absolutely anything to assist and slow down the progression.

Olivia B. Yes, with the hope it would slow down or completely stop the progression of the disease.

Paige B. We have to have the option of people with FA taking the drug. There is so little out there that helps anyone with FA, we need to give them a chance at life with any drug possible

Patrick B. Yes, I think it is safe enough to try to slow down the disease
<table>
<thead>
<tr>
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<tbody>
<tr>
<td>Paul B.</td>
<td>Yes absolutely my darling cousin L would want the option to take this drug as the disease is a ticking time Bomb. People with FA don't have years to wait this should be super tracked forward. Please give these beautiful people a chance and some hope at a better future.</td>
</tr>
<tr>
<td>Peter B.</td>
<td>Yes, each live matters we go for the best result</td>
</tr>
<tr>
<td>Rafael B.</td>
<td>Yes, my cousin would like to take this medicine</td>
</tr>
<tr>
<td>Raffaele B.</td>
<td>Yes, I am in favor of omaveloxolone</td>
</tr>
<tr>
<td>Regine B.</td>
<td>Yes my grandson is currently walking with a walker and we want to quickly slow down the effects of the illness because he will soon be unable to walk</td>
</tr>
<tr>
<td>Rosa Esther B.</td>
<td>Because my family and I are convinced that the results demonstrate a significative benefit and a low risk. We would like that our family member gets access to this drug.</td>
</tr>
<tr>
<td>Ryan B.</td>
<td>Yes - the results look promising and with such limited options it is a risk worth taking.</td>
</tr>
<tr>
<td>Sara B.</td>
<td>Helpful</td>
</tr>
<tr>
<td>Seamus B.</td>
<td>Yes my wife would love to have the opportunity to talk this</td>
</tr>
<tr>
<td>Sebastien B.</td>
<td>As the only current drug to have positive effects, even if not being a 100% treatment, having access to it will tamper the evolution of the illness until additional ones are made available. It is awfully important to provide a way to slow down the disease to keep hope in patients heart.</td>
</tr>
<tr>
<td>Shashwat B.</td>
<td>We are delighted with trial results and wish we get it ASAP</td>
</tr>
<tr>
<td>Simon B.</td>
<td>Yes. A horrible/cruel disease and if the drug/medicine can alleviate any of the discomfort my lovely 15yo niece is enduring - even in the early stages of FA - then any 'light' along this challenging journey will be so welcome.</td>
</tr>
<tr>
<td>Sinead B.</td>
<td>Yes in the hope for a better standard of living for them</td>
</tr>
<tr>
<td>Steve B.</td>
<td>Yes. Taking it should not be a privilege but a right. Our kids can't wait</td>
</tr>
<tr>
<td>Svenja B.</td>
<td>Yes, we would love to have the chance to take the medicine.</td>
</tr>
<tr>
<td>Toby B.</td>
<td>Having 2 children with the condition I would try anything that may extend or improve their daily lives. With one already in a wheelchair, with a feed tube and a loop recorder for his heart if we could stop the progress in its track I would be willing to try anything for my kids.</td>
</tr>
<tr>
<td>Tracey B.</td>
<td>If this drug was available my child would be open to taking the drug. Anything that slowed down the progression or symptoms of this disease would be literally life changing.</td>
</tr>
<tr>
<td>Traci B.</td>
<td>Yes please, we don't want to wait for any more trials, this drug needs to be related asap. Please help it happen.</td>
</tr>
<tr>
<td>Tracy B.</td>
<td>Yes we are willing, no more trials needed</td>
</tr>
<tr>
<td>Ulrich B.</td>
<td>Yes - we would appreciate much to have the chance to get the medicine omaveloxolone for our child: The results of clinical trials are really promising - so we are obliged to take every straw that helps to ease the symptoms and to go ahead to cure this terrible desease. To get the approval of the FDA is urgent !!!</td>
</tr>
<tr>
<td>Umut Yusuf B.</td>
<td>As we had no option until now and results of this drug is promising, yes we need to take this medicine. My sister is suffering from this illness and we need immediate cure.</td>
</tr>
<tr>
<td>Vandana B.</td>
<td>Urgently need omav for my son</td>
</tr>
<tr>
<td>Wesley Bruno B.</td>
<td>My son hasn't taken the medication yet</td>
</tr>
<tr>
<td>William B.</td>
<td>Yes. If there is something out there that can help, then the option needs to be made available, for Hope if nothing else.</td>
</tr>
<tr>
<td>Wilton B.</td>
<td>Yes. Attempt to cure the disease or stabilize its evolution</td>
</tr>
<tr>
<td>Aimée .</td>
<td>Yes i want, my friend needs this medicine to her healthy and i want to help her</td>
</tr>
<tr>
<td>Alan C.</td>
<td>Yes because the research is strong.</td>
</tr>
<tr>
<td>Albano C.</td>
<td>Its proven to be effective</td>
</tr>
</tbody>
</table>
Alex C. Yes, I feel given the data provided and testing to date, I feel confident this option could improve the daily life of my family member living with FA. The current symptoms and affects of FA are so severe, that any chance of a drug having an impact of improving daily life is urgently needed as soon as possible my family member living with FA, and all those currently living with FA. Time is of the essence, and immediate action is essential to give these patients a resource, hope, and their best chance to improve their quality of life.

Ana Luiza C. Yes, because I wish that my mother could walk independently.

Anastácia C. Yes. I want to have access to the medicine

Ann C. needed badly

Anna Clara C. So that my friend and others can have some treatment against this devastating disease FA

Anthony C. treatment gives hope, would prefer grandson to have the treatment.

Antonino C. I want to take the medicine to stop the progression of the disease and to improve the quality of living

Armando C. Yes, for sure.

Axel C. Yes, I would like to know more of omaveloxone

Bea C. My cousins have Ataxia and need the option of taking the drug

Bella C. Because it has been proven that the drug would help preventing disease progression, which is directly related to improving the quality of life

Bernard C. Yes, because no treatment is available currently. Patients need something to stop the devastating effects of the disease

Bernardo C. Yes. I want to have access to the medicine.

Bernie C. yes. I would want them to have the option of having this treatment to give them a chance of a relatively normal life...

Bruno C. My brother has the FA. I would like him to access the treatment with the omaveloxolone as soon as possible so he has a chance to recover some mobility, freedom, hope and dignity. I am well informed about the results of the clinical trials, i.e., their significant and strong positive effects and their negligible to mild side effects. I believe the potential benefits of the treatment surpass the risks by far. Waiting for the release of the treatment has been frustrating, agonizing and painful for the persons suffering from the FA as well as the people who love them.

Bruno C. Yes, it seems like a suitable option, that might greatly aid our situation.

Camilla C. Yes. The quality of his life is currently sliding down and it would be very beneficial to try this drug.

Candace C. Yes he would want the option to take the drug. Taking this drug might not let him walk again, but it would keep him at a progression that would allow him to live a much fuller life.

Carmen C. Yes! We want the drug!

Chandini C. Yes, my daughter would want to take this medicine

Christophe C. Yes, to improve her health physically and psychologically

Colette C. Yes....results of the trial very encouraging.
**COMMENTS FROM FA COMMUNITY**

Parents & Family Members Outside the US

<table>
<thead>
<tr>
<th>Name</th>
<th>Comment</th>
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</thead>
<tbody>
<tr>
<td>Concepción Gamarra Muzas C.</td>
<td>Two nephews. M. did not participate in the trial, but based on the results, and the testimonies of those whom did, we see Omaveloxolone as a glimmer of hope for our daughter. It will be the small differences that matter when it comes to her quality of life, of what M. can do independently. Omaveloxolone can be the small difference that will provide her with more time and enable her to live life with FA.</td>
</tr>
<tr>
<td>Craig C.</td>
<td>Yes, we would like our 3 children to have the option of taking Omaveloxolone. Based on the results of the trials conducted to date, we consider that the potential benefits of Omaveloxolone significantly outweigh the risk of possible harm caused by the drug. This opinion is strengthened by the fact that Friedreich's Ataxia is a neurodegenerative disease and its continuous progression makes life extremely challenging for patients. Therefore the chance of a therapy that can slow, halt or even reverse the symptoms of the disease is extremely valuable to patients.</td>
</tr>
<tr>
<td>Damian C.</td>
<td>Yes, I want to take omaveloxolone.</td>
</tr>
<tr>
<td>Daniel C.</td>
<td>Yes, I want to take omaveloxolone. The press demonstrates the symptoms / consequences and nothing is done.</td>
</tr>
<tr>
<td>David C.</td>
<td>Yes my niece needs this drug to better her quality of life. Any improvement is important.</td>
</tr>
<tr>
<td>Caroline D.</td>
<td>YES because there is currently no other treatment and patients need it!</td>
</tr>
<tr>
<td>Decima C.</td>
<td>Yes, absolutely yes. My niece and two nephews are suffering severely from FA and their condition is critical, they are in desperate need of hope and they cannot wait any longer for treatment and the idea of them being prevented from a possible cure is literally heartbreaking. They are desperate to take the drug/medicine and so out their parents completely behind the idea.</td>
</tr>
<tr>
<td>Declan C.</td>
<td>Yes. My brother has studied the research about Omaveloxolone and explained clearly to me the benefits of it.</td>
</tr>
<tr>
<td>Denise C.</td>
<td>Yes. My grandson is suffering and we would like to try anything that might help.</td>
</tr>
<tr>
<td>Diego C.</td>
<td>Based on the data currently available on safety and efficacy of omaveloxolone, I would like for them to have the option of taking it.</td>
</tr>
<tr>
<td>Dirk C.</td>
<td>Yes, my son has the FA. I would like him to access the treatment with the omaveloxolone as soon as possible so he has a chance to recover some mobility, freedom, hope and dignity. I am well informed about the results of the clinical trials, i.e., their significant and strong positive effects and their negligible to mild side effects. I believe the potential benefits of the treatment surpass the risks by far. Waiting for the release of the treatment has been frustrating, agonizing and painful for the persons suffering from the FA as well as the people who love them.</td>
</tr>
<tr>
<td>Elena C.</td>
<td>Yes, he wants the opportunity to live a life independently.</td>
</tr>
<tr>
<td>Éilis C.</td>
<td>Yes absolutely, the trials were very encouraging.</td>
</tr>
<tr>
<td>Eleanor C.</td>
<td>Definitely should be an option for any FA sufferer. In the past two years, in the test results, there were no major problems/side effects and many of the patients found that their physical condition improved considerably, demonstrating that FA symptoms could be reversed. The FDA MUST approve this drug ASAP!</td>
</tr>
<tr>
<td>Elisangela C.</td>
<td>The press demonstrates the symptoms / consequences and nothing is done.</td>
</tr>
<tr>
<td>Elsa C.</td>
<td>She need help.</td>
</tr>
<tr>
<td>Emirhan C.</td>
<td>Yes I want it.</td>
</tr>
<tr>
<td>Emmanuel C.</td>
<td>Yes, he wants the opportunity to live a life independently.</td>
</tr>
<tr>
<td>Name</td>
<td>Comment</td>
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<td>--------------</td>
<td>-----------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Emmanuela C.</td>
<td>It would be extremely important to bring the medicine to Brazil, thus enabling low-income people to have access to the medicine.</td>
</tr>
<tr>
<td>Esteban C.</td>
<td>Yes we need this drug/medicine</td>
</tr>
<tr>
<td>Faye C.</td>
<td>Yes. Our daughter M. (8) has recently been diagnosed and to watch her deteriorate and try to explain to her what is happening is the most devastating thing any parent should have to go through. Please give us access to this medication to slow this progression.</td>
</tr>
<tr>
<td>Federico C.</td>
<td>Yes, he does. At this point he’d take anything in terms to improve his life.</td>
</tr>
<tr>
<td>Felipe C.</td>
<td>Yes. Today there is no medication for AF and it is very difficult to live with a degenerative disease.</td>
</tr>
<tr>
<td>Fetije C.</td>
<td>Desperately waiting it</td>
</tr>
<tr>
<td>Fischer C.</td>
<td>Ready to use</td>
</tr>
<tr>
<td>Flávia C.</td>
<td>Yes. We believe in the effectiveness of the medicine. Any medication that can improve the life of the patient with ataxia is welcome, especially if it has no side effects.</td>
</tr>
<tr>
<td>Francesca C.</td>
<td>I want to take the medicine to stop the progression of the disease and to improve the quality of living</td>
</tr>
<tr>
<td>Fritz C.</td>
<td>To slow down FA</td>
</tr>
<tr>
<td>Gayle C.</td>
<td>Yes my son would take Omaveloxolone if available. The trial done has shown the drug to be beneficial in slowing down progression and has shown to not have significant side effects. My son has clinically progressed rapidly the past 18 months. No other drug is available to help. This is the only medicine in the pipeline to offer a degree of hope, and we need some hope with this disease.</td>
</tr>
<tr>
<td>Georgia C.</td>
<td>Because this medicine will help the people suffering from FA</td>
</tr>
<tr>
<td>Guilherme C.</td>
<td>Yes, he would</td>
</tr>
<tr>
<td>Guilherme C.</td>
<td>Yes, I want to take omaveloxolone</td>
</tr>
<tr>
<td>Guy C.</td>
<td>Yes. A horrible disease and any help would be a risk worth engaging with</td>
</tr>
<tr>
<td>Hanna C.</td>
<td>yes, as it seems like the best/only option at this time</td>
</tr>
<tr>
<td>Helen C.</td>
<td>Both of my children would be very happy to to take Omaveloxolone or any available treatment.</td>
</tr>
<tr>
<td>Henriette C.</td>
<td>My daughter would like to get the medicine</td>
</tr>
<tr>
<td>Hugo C.</td>
<td>Based on the available safety and efficacy data, we absolutely would be willing to use omaveloxolone on the the children. Why? Because the degenerative disease is killing the children, and the risk of side effects is overwhelmingly outweighed by the advantages the drug is likely to bring.</td>
</tr>
<tr>
<td>Inca C.</td>
<td>Yes, it would be amazing for my partners symptoms to be eased and to be able to become more independent which is so important to him as an individual and a father to a toddler.</td>
</tr>
<tr>
<td>Ioannis C.</td>
<td>Please we want to take Omav as soon as possible please approve it!Thank you</td>
</tr>
<tr>
<td>Irene Del Pilar C.</td>
<td>That all people have access to it so that they have a better quality of life</td>
</tr>
<tr>
<td>Ivoneide C.</td>
<td>So that my children have access to treatment against this debilitating disease</td>
</tr>
<tr>
<td>Izabela Carla C.</td>
<td>I have siblings with FA, this drug is a treatment against this disease</td>
</tr>
<tr>
<td>James C.</td>
<td>Yes, my brother is very keen for this to be taken, the research has been very positive and it’s time for the FDA to approve this try and improve my brothers life.</td>
</tr>
<tr>
<td>Jan N C. C.</td>
<td>taking medicine</td>
</tr>
<tr>
<td>Jane C.</td>
<td>My relatives would take part in taking the medication.</td>
</tr>
<tr>
<td>Jean-Pierre C.</td>
<td>I can’t answer for my two children who are suffering from this disease</td>
</tr>
<tr>
<td>Jessica C.</td>
<td>So they can improve their quality of life and be more independent</td>
</tr>
<tr>
<td>Jeton C.</td>
<td>As soon as possible</td>
</tr>
<tr>
<td>João C.</td>
<td>Propor die whitout this medications !</td>
</tr>
</tbody>
</table>
COMMENTS FROM FA COMMUNITY
Parents & Family Members Outside the US

John C. Yes, we would want the option of taking omaveloxolone. FA is already having a significant effect on our child’s physical capabilities and mental well-being, and given the very positive results of the trial and demonstrated safety of the drug, we feel it would be beneficial for our son to receive this drug as soon as it becomes available and his age allows.

Jonathan C. Yes, any promising possibility is a good possibility.

Jos C. I see our granddaughter’s ataxia, speech, walking, writing, .... deteriorate rapidly. This drug is urgently needed and I know she wants this drug.

Jose Wilson G C. Please give us a chance to be able to take the medicine because we have no other opportunity, we already know that it worked. We have no other option! I hope you release the medicine ... God bless!

Juan C. Yes he participated on the study and wants to take the medicine.

Jurij C. Yes, my family member would take omaveloxolone because that’s the chance to save his health and life. If we don’t have soon the medicine his health would seriously deteriorate. This is the real chance to cure him.

Karen C. If my relative would decide to take the drug, it is the only hope to improve his quality of life as this drug shows significant changes in slowing the disease.

Karen C. Yes to give my son in law a better quality of life. Such a beautiful Father, husband and Son. He has worked so hard to achieve his goals. He is a very giving person and makes a difference in the lives of many. Would love for him to have this chance. Thank you for your time.

Kathleen C. If you see her suffering physically and mentally every day, every hour, every minute,... my child would like to take the medicine right away, without any doubt.

Katie C. Yes, my stepfather would love to take this drug.

Aline C, Calu C, Keeyan C, Mary Stela F, Saquina G, Sonia G, Yassira G, Yussaira H, Mahomed I, Anik K, Momed K, Soraya K, Taila S, Najma V. Because base on the information available I believe that omavelozolone is safe and effective in the treatment of Ataxia and it will improve the motor coordination of my family members who are suffering from this disease and as well as bullying because of that, taking away their freedom to fully live their youth.

Kelly C. Our son K is 16 years old and we have been painfully watching him lose his independence and abilities on a daily basis at a time in his life where he is seeking independence. Each year there is a considerable and measurable difference in his activities and the loss of his abilities has really had an affected him socially, emotionally and physically. We truly believe there is a cure in the future and we want so much to slow the progression so that when the time comes, a cure is found, K will be able to benefit from it. The progression is rapid and K deserves the best option to preserve what he has now and omaveloxolone can give him this with no adverse side effects. Please give him the opportunity to slow the progression and give him the best quality of life for as long as possible. Time is of the essence. K has hypertrophic cardiomyopathy as a condition of FA. Slowing the progression is the only option available at this time.

Kerry C. Yes they would try anything if they thought it would help even the smallest bit.

Kevi C. Yes as it has already been shown in trials to slow the rate of FA.

Kevin C. Both my children would partake in the hope of any treatment to help their situation.

Kevin C. Yes my family member is open to taking the drug/medicine. Please make it happen.

Kevin C. Yes. Slowing down the progression of this disease would be a gift. My sister is at an age where she is starting her career and to have the progression slowed down would be so important for her confidence.

Kieran C. Family members of mine have been diagnosed with F.A, and any treatment or medication which could increase their quality of life would be eagerly accepted. It would be a tool to help them fight back against this horrible condition and would help them live fuller, healthier and happier lives. I would and I know they would be eternally grateful if this treatment was made available to offer them some hope against this condition.

Kirstin C. They are entitled to drugs to benefit them just as others with life delimitating illness & or disease are which assist in A better quality of life.

Konstantinos C. Yes in absence of better therapies I would take this treatment option.
Leandro C.  
Yes, I want to have access to the medicine.

Liesbeth C.  
I see her getting worse and worse. So yes

Lisa C.  
Our 12 year old son was diagnosed with FA less than 12 months ago. The severity of his diagnosis was a huge shock to our entire family and we were completely devastated. To then learn that there are no approved treatments or cure for this disease was equally as devastating. He is only in the early stages of FA but every week we see normal daily activities becoming harder and harder for him. We need to act NOW and cannot wait 2 years for another clinical trial. We need to slow the progression to give him a chance at living an independent life. The omaveloxolone is his chance for independence. It’s his chance to be just like every other kid going about their day. We feel strongly that the omaveloxolone would be completely life changing for him and we would not hesitate in allowing him to take it once it is approved. Please consider our position and the position of so many other parents & patients by allowing us access to a proven drug that will change FA patients lives forever.

Louis C.  
Absolutely! we strongly feel that given the positive results of drug trials so far, everyone with the crippling disease FA should be given the option to take the drug, even if there are risks involved.

Luine C.  
Yes, i would like to take the remedy

Lynda C.  
My brother would definitely want to avail of the opportunity to take the drug. His life has been severely impacted by this condition

Madeleine C.  
Yes, because we think the potential rewards outweigh the risks. The results up to this point have been good.

Manon C.  
As my daughter is 24, I will let her answer this question. She already subscribes.

Marcela C.  
Yes, I want him to take it and that he can have a better quality of life, although he was diagnosed about two or three years ago, his body became quite acute with the disease so any hope or improvement that may be there would be very good for FA

Margaret C.  
Absolutely Yes. The condition is neuro degenerative and is fatal. There are currently no treatment. Therefore participation provides the only hope. The person remains of sound mind whilst body and organ functioning deteriorates including the heart - currently the later is only at 45% of capacity. We pray that the use of this drug, will as a minimum, halt the deterioration and allow life to be sustained longer than otherwise. Thank you for your consideration and providing hope to life.

Margaret C.  
Yes, would take drug, a glimmer of hope.

Maria Laura C.  
Yes. Omaveloxolone would be a promising alternative for treating neurological function in people with Friedreich's ataxia from what I have read. It would be very hopeful for me to be able to give my son a treatment that helps improve his quality of life, I hope it is approved as quickly as possible.

Maria Ursula C.  
Yes, he would want the option if taking the drug. He/We have no other option.

Marina C.  
Waiting for the new terapi

Marisa C.  
I need the drug for my daughter to see her improving

Marlene C.  
Nowadays we don't have any treatment. This drug effectively stops the course of the disease. There are publications that support it. Please ask FDA to help us making the criteria more flexible so all FA patients can access this drug

Marta C.  
Yes, because there is no other way

Mary C.  
It would help him enjoy more of a life

Mary Jean C.  
Yes he would
<table>
<thead>
<tr>
<th>Name</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maryteresa C.</td>
<td>Help</td>
</tr>
<tr>
<td>Matthew C.</td>
<td>Yes. From the research and feedback, MOXIe has a position Tove impact with very few side effects.</td>
</tr>
<tr>
<td>Megan C.</td>
<td>Yes. The efficacy and safety of the drug has been sufficiently proven with trials. There is no treatment for FA currently so anything that may even slightly improve quality of life for patients is essential. FA patients cannot wait for more trials to be carried out</td>
</tr>
<tr>
<td>Mehmet Ali C.</td>
<td>Yes I want it</td>
</tr>
<tr>
<td>Michel C.</td>
<td>I signed to provide support and help to your organization, to provide the standard of care of FA patients</td>
</tr>
<tr>
<td>Michele C.</td>
<td>I am sorry but I did not understand the text in English</td>
</tr>
<tr>
<td>Miles C.</td>
<td>Yes we would consider any opportunity to better or keep the quality of life of my son.</td>
</tr>
<tr>
<td>Mohamad C.</td>
<td>I had someone in the family that died with this its very hard to the ones who are taking care, if there is a medicine need to be experience asap</td>
</tr>
<tr>
<td>Muhittin C.</td>
<td>Our family member is interested to participate. We would like to get in contact to have More insight. Thank you for the contribution and research</td>
</tr>
<tr>
<td>Natacha C.</td>
<td>Yes, my 2 girls have nothing to loose! They lost many coordination and one of them have difficult to walk at 10 years old!</td>
</tr>
<tr>
<td>Nelly C.</td>
<td>An experiment must take place. It is about time for the patients.</td>
</tr>
<tr>
<td>Nikisha C.</td>
<td>Yes, D. would love anything to possibly help her.</td>
</tr>
<tr>
<td>Noelia C.</td>
<td>My son, who participated in the Frames trial, was diagnosed when he was 11 years old and this year he will be 14 years old. I would like you to continue in the trial and for you to give that medicine for compassionate use, to all the people who suffer from this serious disease ... I would like to thank you, from the bottom of my heart, for all you are doing to find an effective treatment</td>
</tr>
<tr>
<td>Noreen C.</td>
<td>Yes I think they would benefit from it.</td>
</tr>
<tr>
<td>Oscar C.</td>
<td>Yes I would want them to take it ASAP</td>
</tr>
<tr>
<td>Osmar C.</td>
<td>Please for all FAers</td>
</tr>
</tbody>
</table>
COMMENTS FROM FA COMMUNITY
Parents & Family Members Outside the US

Padraig C.

For our 10-year-old son with FA, I would really love to have the option of trying Omaveloxolone to slow/halt the progression of this terrifying disease... I would give up every possession I hold dear for it! In the three years since his diagnosis, I have learned that there is hope of a treatment in the years/decades ahead, but at the moment we have no treatment options available to us. Hope for the arrival of these treatments is something that I was initially very positive about, but as each year goes past, I see the slow cruel degradation in my son's health, yet these treatments are still years away due to the laborious burdensome nature of drug/therapy development. So many of these treatments in development have failed to deliver in the past, and whilst others present great prospects, years of time is not a luxury we can afford. Yet, now with Omav, we are almost within touching distance of a treatment that could well buy time for my son, and thousands of other FA patients, but the final important hurdle of FDA approval has yet to be crossed. My wife and I have had to watch the early effects of FA taking their toll on our beloved boy. I hereby implore the stakeholders at FDA and Reata to take immediate action so we can ignite some real hope that our son can be spared from the future cruel impacts of FA – impacts that will steal so much from his life through teenage years and beyond... provided FA doesn't steal him from us before then. As the frequency of our son's falls and bumps increase, we exchange knowing glances of heartache and inevitability as this disease takes hold. He has had to drop out of his beloved football team because he simply can't participate with his team mates anymore – although, his resilience to get up time-after-time for years, knowing that he'll never close the gap to his peers, has been a true inspiration! Despite lots of attempts, he never had the trust in his body or balance to manage cycling, so he tries to participate with his friends on a go-kart; of course it's not the same nor is he able to keep up with them. His loss of fine motor skills is another tangible setback that he has to contend with, and his handwriting is reaching the point of being illegible. However, he makes twice the effort writing, just so he can handwrite at school the same as his classmates. Speech is becoming a little bit problematic for him, so he now speaks at a slower rate than his peers and has difficulty with some pronunciations. In addition to these visible losses, his heart needs to be regularly monitored to observe the most fatal feature of FA – his cardiomyopathy. This was diagnosed soon after his FA diagnosis and is an obvious source of stress and concern for us and his broader family. When reflecting on these losses we have seen in the few years so far, we feel great sorrow and wish with every ounce of will that things could be different for our innocent young boy who was the victim of the genetics lottery. However, this sorrow is greatly overpowered by the dread, fear, and helplessness we feel when we visualise the challenges that lay ahead for our son... as well as the things he will never experience because of FA. We are currently having to plan a new single storey home to better suit the needs ahead, but this means leaving behind his closest friends in the neighbourhood where we currently live. I don't expect that Omav can give us back what we have lost, or what we will lose in the coming months. However, should Omav become available, the prospect of delaying some of the dark days ahead is something that I would be eternally grateful for... days like: when my son is no longer able to walk; when his family and friends struggle to understand his speech; when he is unable to feed or wash himself; when his cardiomyopathy threatens his life. We currently go to alot of expense and effort to provide some of the supplements and vitamins that are thought to possibly help FA patients, but we know all too well that the evidence is unreliable. Yet, we try whatever we can in order to give our boy whatever little chance we can of fighting back the unrelenting advancement so that a more reliable treatment becomes available - something like Omav. In addition to the quality-of-life impacts for our son, the emotional impact has started taking its toll on him, and we fear that much darker times lay ahead for him as he comes to terms with his disease. It is already causing significant anxiety and depression to his close family as we attempt to cope with it all. I realise that Omav has not achieved the FDA's traditional regulatory standard of two randomised placebo-controlled trials, but the evidence that I have seen demonstrates to me that the potential risks are far outweighed by the proven life-altering benefits. For this reason, I appeal to FDA to exercise the flexibility granted by law and FDA guidance in considering approval of Omav in FA – in the event that Reata submit the NDA. The safety demonstrated in the three Omav studies gives me confidence that we wouldn't be taking unreasonable risk by giving it to our son. The MOXie Part 2 Trial results data and statistically significant p-value demonstrate very solid evidence of benefits that my son could achieve. Additionally, hearing the testimonies of trial participants and observations of the doctors gives me reason to hope that Omav could help alleviate the most painful aspect of my life. It gives me hope to imagine...Imagine a safe treatment available that has solid evidence of slowing down this monster, we know as Friedreich's Ataxia. Imagine avoiding a child's loss of some of the basic human activities like walking, eating, talking. Imagine giving time to somebody to hold on for a more comprehensive treatment or cure in the years ahead. Imagine giving hope to parents of a better future for their young child. Please give our hopes and imagination a chance of becoming reality! Sincerely, Loving Parents in Need of Hope

Popi C.

Yes I believe my family member should have the option to take omaveloxolone based on the information we have

Ramiro C.

Yes, I want to take omaveloxolone

Roberta C.

Yes. I want to have access to the medicine.
<table>
<thead>
<tr>
<th>Name</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Robynne C.</td>
<td>Yes, may help.</td>
</tr>
<tr>
<td>Rodrigo C.</td>
<td>To improve his quality of life.</td>
</tr>
<tr>
<td>Rodrigo C.</td>
<td>So that all those who suffer from this disease can have a better quality of life</td>
</tr>
<tr>
<td>Rosie C.</td>
<td>my brother would want to take the medicine, cause he believes it would make his life much better</td>
</tr>
<tr>
<td>Ross C.</td>
<td>Yes, want an opportunity to halt and improve my wife’s condition and lifestyle as affected by FA.</td>
</tr>
<tr>
<td>Roy C.</td>
<td>Yes as there is no alternative</td>
</tr>
<tr>
<td>Ruben C.</td>
<td>Its is secure, it will changes lifes.</td>
</tr>
<tr>
<td>Ryan C.</td>
<td>Yes. Because there are no options so anything is worth a go.</td>
</tr>
<tr>
<td>Sallyanne C.</td>
<td>Yes as there is no other options</td>
</tr>
<tr>
<td>Sandra C.</td>
<td>Based on the information available I believe that omavelozolone is safe and effective in the treatment of Ataxia and it will improve the motor coordination of my family members who are suffering from this disease and as well as bullying because of that, taking away their freedom to fully live their youth.</td>
</tr>
<tr>
<td>Santiago C.</td>
<td>Thank you</td>
</tr>
<tr>
<td>Scott C.</td>
<td>Yes. Our child is losing functions every day and we need to slow the progression. I feel this is a safe drug and the possibility of any side effects is outweighed by the chance to slow this horrible disease.</td>
</tr>
<tr>
<td>Shane C.</td>
<td>Yes, with no other therapeutic alternative at the moment I think it would be a good option to take this drug as it seems well tolerated.</td>
</tr>
<tr>
<td>Shaun C.</td>
<td>Yes. Anything to possibly improve quality of life, positive change and provide hope.</td>
</tr>
<tr>
<td>Stanislaw C.</td>
<td>My cousin would take this medecine as the unique solution that the farmacological investigation offers to cure FA. I hope the good decision will be taken and the drug will be legalized. I want my cousin to be healthy, that's why I appal to authoryties not to make us wait any longer...</td>
</tr>
<tr>
<td>Stephen C.</td>
<td>Makes a huge difference to someone with FA.</td>
</tr>
<tr>
<td>Steven C.</td>
<td>Yes. This is a devastating disease and the trial showed real positive benefits with no significant side effects and there are no other options available at the moment so real hope. Thank you.</td>
</tr>
<tr>
<td>Stuart C.</td>
<td>Save my wee neice please we need ur help</td>
</tr>
<tr>
<td>Suna C.</td>
<td>I would definitely want the option of accessing and taking the medicine for my son.</td>
</tr>
<tr>
<td>Susan C.</td>
<td>Yes as my granddaughter is deteriorating with this disease</td>
</tr>
<tr>
<td>Tammy C.</td>
<td>Family members would like the option to take omaveloxolone as it may help to improve symptoms at this late stage of FA.</td>
</tr>
<tr>
<td>Taylor C.</td>
<td>Yes I would want my brother to have access to this drug as soon as possible to help slow/stop the progression of the disease as time is critical with FA</td>
</tr>
<tr>
<td>Tayná .</td>
<td>Yes. I want to have access to the medicine.</td>
</tr>
<tr>
<td>Valdemir C.</td>
<td>Yes, I want to take omaveloxolone</td>
</tr>
<tr>
<td>Valdomiro C.</td>
<td>Yes, she wants to have a life, as normal as possible</td>
</tr>
<tr>
<td>Vanessa C.</td>
<td>My Family member has FA and want the option of taking the drug/medicine</td>
</tr>
<tr>
<td>Vera C.</td>
<td>Based on the data currently available on safety and efficacy of omaveloxolone, I would like for them to have the option of taking it.</td>
</tr>
<tr>
<td>Veronique C.</td>
<td>Yes, my son agrees to try any treatment giving hope for a cure or for an amelioration. He is followed at the Pitié Salpetriere hospital and he has already participated in a clinical trial, don’t recall its name</td>
</tr>
<tr>
<td>Yashmin C.</td>
<td>My sister and brother has FA, It hurts me to see them like that.</td>
</tr>
<tr>
<td>Yenny C.</td>
<td>Because I want everyone who has this disease to have the opportunity to improve their quality of life</td>
</tr>
<tr>
<td>Yoann C.</td>
<td>Yes, I accept the option of taking the medicine, because it could improve the daily life.</td>
</tr>
</tbody>
</table>
Zanita C.  Yes, it could change to life of my sister and all of those who love her and are watching her deteriorate.

Robin Ç.  Yes I want

Ahmet D.  Yes i would try the drug

Akshaj D.  Yes if the medicine is likely to show result in affirmative, then definitely we’ll take the medicine

Alejandro D.  Positive

Amine D.  Yes a family member wants to take

Ana D.  Yes, it would be able to greatly improve their standard of living and ensure the best life.

Ana Ramona Isabel D.  My cousin has received the treatment

Anthony D.  Yes. I would like to have the opportunity to halt the condition whilst waiting for other pharmaceutical innovations / cures.

Antonia D.  I would like to take the medicine

Antonio D.  I am completely agree with this option, because me and my family believe that this can be an important chance to let my loved child and anyone who fight against FA overcome this disease and as much as possible give to this affected individuals a bit of happiness. So, I want that you regard the option of administering this dose, please listen to us.

Aris D.  They would like to take the drug

Baptiste D.  Yes, he is gradually losing his motricity. He used to fall in his house.

Beverley D.  My granddaughter has FA and yes I would definitely like her to have the option to have access to omaveloxolone as there is no treatment whatsoever available for friedreich ataxia.

Bruno D.  We believe that omaveloxolone is a safe and efficient treatment, which will result on netter motor coordination of my family member and also decreasing the consequences of daily bullying she goes through, that helping her build her self confidence and living an happier life.

Carmela D.  My nephew A... has been living with FA for 10 years and it is imperative that he takes this drug

Carolina D.  My family member wants to take the drug.

Caroline D.  Yes - if there is a chance to improve the quality of life then that is great

Carolyn D.  Absolutely, it should be available ASAP. The data provided by part one and part two of the study along with the open label extension provided adequate and sound proof of the efficacy of MOXie.

Cindy D.  My sister-in-law is very interested in the option of taking the drug, or even be part of the next study - anything that would assist with her movement as the degeneration is rapidly changing for her now

Coral D.  Yes my grandson would love to take the medication if it helps in even the smallest way.

Cristian D.  Yes. My cousin is living with FA for many years and he is willing to try the medication.

Danny D.  Niece was newly diagnosed with FA and with a 1 year old child, wish this could help her continue being the mother she could and needs to be for her beautiful child, she will need her mother

Dar D.  Yes I do want, because I believe that it Will Help her do reduce the FA symptoms and it Will improve her live.

Debbie D.  Yes definitely

Dino D.  I’ll be very brief. My child walks, runs and I know it is now and I know what his future holds. I also see that his condition is getting worse. This medication could help him never sit in a wheelchair and you can make it possible. Slowing down or stopping this disease is a chance for a normal life. When I look at vaccines for covid19 it is always said that the risk of vaccination is less than the gain of vaccination. Same thing with us FA parents. We are willing to take the risk (if there is any risk at all when we look at the research results) and therefore we ask you to have mercy and help us. Yet they are children (mostly). Please help

Dinoia D.  yes, I would like to use the drug

Domenica D.  Yes there is great advantage in him taking omaveloxolone. Would improve his everyday life
<table>
<thead>
<tr>
<th>Name</th>
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<tbody>
<tr>
<td>Eirian D.</td>
<td>Yes would like her independence back and hopefully a prolong life</td>
</tr>
<tr>
<td>Elena D.</td>
<td>yes ... on the advice of a professional</td>
</tr>
<tr>
<td>Emine D.</td>
<td>Please help us</td>
</tr>
<tr>
<td>Emmanuel D.</td>
<td>Yes. I support the view of AFAF in France.</td>
</tr>
<tr>
<td>Eralda D.</td>
<td>Yes, I would like to take MOXIE</td>
</tr>
<tr>
<td>Evaldo D.</td>
<td>Omaveloxolone is necessary to improve the patient’s quality of life!</td>
</tr>
<tr>
<td>Evdoxia D.</td>
<td>I am a sister of two brothers with Friedreich Ataxia who living with symptoms of for less and more than 15 years respectively and I would like the option of taking the drug/medicine because they are 28 and 35 years old and i believe the access to the drug is a nececity now on and possibly could help in health improvement and maybe (?) life expectancy increase.</td>
</tr>
<tr>
<td>Frans D.</td>
<td>Yes, we need a cure or treatment asap</td>
</tr>
<tr>
<td>Gabrielle D.</td>
<td>Yes. We are desperate to halt the progress of this debilitating condition.</td>
</tr>
<tr>
<td>Abadjyan A, Alex-</td>
<td>Please approve the drug as soon as possible! Thank you very much!</td>
</tr>
<tr>
<td>andros C, Irene D,</td>
<td></td>
</tr>
<tr>
<td>Irini D, Savas K,</td>
<td></td>
</tr>
<tr>
<td>Tania K, Soumela S,</td>
<td></td>
</tr>
<tr>
<td>Stelios S, PafsaniasT, Xrysa T.</td>
<td></td>
</tr>
<tr>
<td>Jake D.</td>
<td>Yes, it will give my mum some independence and help her tackle this debilitating disease.</td>
</tr>
<tr>
<td>Jane D.</td>
<td>Yes family members would want the option of taking the drug</td>
</tr>
<tr>
<td>Jelena D.</td>
<td>Hi, my son will take drug we will be very happy if is available. Little help is very big for FA.</td>
</tr>
<tr>
<td>Jeroen D.</td>
<td>Yes because there us nothing yet and now they hace a change</td>
</tr>
<tr>
<td>João Paulo D.</td>
<td>Yes we would like my daughter to take the medicine for better quality of Life and in search of a cure against a terrible disease.</td>
</tr>
<tr>
<td>John D.</td>
<td>The more trials the better</td>
</tr>
<tr>
<td>Jorge D.</td>
<td>We are very hopeful with this drug. We hope it will be urgently approved. We have no other options</td>
</tr>
<tr>
<td>Julie D.</td>
<td>Yes also my 39son is in the later stages of fA</td>
</tr>
<tr>
<td>Karen D.</td>
<td>Yes of course . Anything to slow the progression of this terrible condition until a cure is found . First potential treatment we have had .</td>
</tr>
<tr>
<td>Karl D.</td>
<td>Yes, based on results available.</td>
</tr>
<tr>
<td>Kathy D.</td>
<td>Yes, my husband would take it right now if possible. He is 60, late onset, and is really in need of this medication to be able to have some quality of life with the years that he has left.</td>
</tr>
<tr>
<td>Kevin D.</td>
<td>YES,over 50 years with FA!,</td>
</tr>
<tr>
<td>Krasimira D.</td>
<td>Yes, I would want my daughter take Omaveloxolone for FA, because the present data from clinical trials is very positive! This is real chance for life for the FA-people!</td>
</tr>
</tbody>
</table>
Laura D. Allow Individuals with Friedreich Ataxia Access to Omaveloxolone
Lavinia D. Yes. I would like her to use the medication for a possible cure or improvement in the disease
Liniker D. Yes! It’s very important. Thanks
Liz D. yes, want the option
Louise D. Yes I would want any FA sufferer to be able to have the choice to take this drug and stall the progression of the disease, and by doing so provide addition information on its effectiveness.
Lyn D. Yes we want J. to take the drug/medicine so he can live a life like a normal child without the disability.
Malcolm D. Yes, to improve quality of life
Marcela D. Yes. Today there is no medication for AF and it is very difficult to live with a degenerative disease.
Marco D. Yes, she want’s to take those drugs in a matter of hope ... mainly ’cause it could slow down the progress.
Maria D. Yes. I saw and heard the voice of the participants. FA is progressing and impacting my daughter’s quality of life and independence. We need to stop FA before it is too late for her and all FAers.
Maria D. Yes, i would like to take the remedy
Maria Do Socorro D. Yes - Our research was satisfactory on the medication. We would like our family to have a better quality of life.
Maria Eduarda D. yes, because I know someone who needs it
Maria Grazia D. I would like my grandchildren to use the drug because they have at least some chance of getting better or worse
Maria Luiza D. We want our daughter to take the medication to have a better life.
Marko D. I would love for the drug to be approved as soon as possible. My son would very much like to start using a treatment to improve his condition and to slow down the progression of the disease. Thanks
Marouschka D. Yes sure
Martina D. My niece should have the option to this medication with great hope it helps her as she has went through so much
Mehmet Ali D. Please help us.
Michele D. I think, or better, I believe that ‘omaveloxolone’ is a good possibility to avoid and to prevent the course of the disease from taking over the people most dear to us. It is wrong to consider FA as something which will never go away, something which we can’t overcome. I don’t want to accept that people I love most in my life continue to endure such pain. So, if there is even one way to let FA disease slow down or a way to cut it out from our life, this must be not only necessary, but dutiful. So, please, we definitely want the option of taking this medicine.
Michelle D. Yes I would be very happy as the results from the company and feedback from people who were on the trial is very promising. To watch your child losing function is devastating and being deprived the opportunity of the only drug with results is devastating. The thought of at least 2 years of a waiting game is heart breaking.
Miguel André D. Yes, I want to take omaveloxolone
Mike D. Without intervention, our daughters face a catastrophic outcome, which justifies taking a higher risk than would be considered for a wider population of healthy individuals. Doing nothing is not a viable option.
Natalie D. Yes. The results of the trial are very encouraging.
Nigel D. Yes - there is a need now to address the lack of any form of treatment. Omav presents an opportunity to provide some hope to patients who have endured this terrible affliction for years and also for younger patients to prevent their symptoms worsening
Pablo D. For being the first drug tested against the disease, to see if it can at least stop its effects on each of those who suffer it. Family members have high hopes for its effectiveness.
Parbati D. Definitely yes.
Paula D. Access to this drug to guarantee a better quality of life to all carriers of this disease
Parents & Family Members Outside the US

Peter D.  yes, the presented data show that there is no other treatment, data shows furthermore that using the treatment is safe and that the treatment has a statistically sound effect on quality of life.

Plamen D.  Yes, I would want my child to receive the chance to take Omaveloxolone for FA. The data from clinical trials is very good and positive! This is real chance for life for all FA-punished suffered people! Please, give this chance!

Raessah D.  Bullying and difficult to walk

Rannaug L D.  I suppose they want the possibility to try the medication

Reginaldo D.  Yes, I believe it will have a great effect on the treatment of my niece

Riana D.  Yes, we would do anything possible to slow the progression for our kids

Rob D.  Breaks my heart to see my grand daughter struggling with FA, she is in the prime of her life and uses a wheelchair to get around, her ability to walk is limited. She has a desire to go to university but travelling makes it difficult. R. is supported by her single mother who works full time which means she is alone most of the day, PLEASE consider her for trials.

Rosa María D.  I have been living with FA for more than 30 years and I do need help for everything. I am confined to a wheelchair.

Rosana D.  I would like, because it’s a chance to continue to fight for a better life for my nephew

Sampaoli D.  Yes. My daughter would like to get this drug to stop the progression of the disease. She can walk using a walker at home and uses a wheelchair for long distances. She would like to get a better daily life as she has a child of 6.5 years old

Sara D.  Yes. Results of trials are very encouraging

Shanice D.  Yes, because my niece has taken part in a study and benefited from it quite a bit (healthwise).

Shannon D.  My cousin participated and it worked very well for her

Sophie D.  My daughter who already uses a wheelchair needs help with many activities of daily life. I would like her to be able to access this medication to limit the development of dysarthria and dysphagia. I would also like to prevent the loss of upper limb functions

Sophie D.  Yes we want to take this médication to improve the health of my child

Sotirios D.  I am a father of two individuals with FA disease and i believe that through the administration of the drug the simplest thing will stop looking like a feat and from that moment on my children start to be more independent and feel better inside them.

Sunan D.  My daughter and us would to participate at this Clinical Trials. You are really motivated

Tania D.  Yes!!!!!!! It is devastating to see all my daughters dreams of how her life should be come crashing down. If this medication can help her live a normal life then we want it now. She pretty much sits at home and does nothing. Please let us have this medication, we need it desperately before she gets worse. Please please please. This would be my one and only wish if I was ever granted one.

Tatiana D.  Yes, I want to take omaveloxolone

Theresa D.  The person with FA is my sister’s granddaughter. The gene responsible runs on the D. side of the family. We have cousins that also have FA. 3 out of 4 have passed away from it. This drug sound very promising and my sister said if it were approved, they would be very interested in taking the drug.

Tina D.  Not sure

Toñi D.  She wants the medicine

Tony D.  Yes if it helps i would want them to take it.

Tracey D.  Unknown

Vasiliki D.  Yes I would because I think it can help a patient/ family member.

Veronique D.  Yes my family would like to take the drug

Woudy D.  I dont no
## Comments from FA Community

### Parents & Family Members Outside the US

<table>
<thead>
<tr>
<th>Name</th>
<th>Comment</th>
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<tbody>
<tr>
<td>Yvonne D.</td>
<td>Two of my nieces are diagnosed with FA, and both would take the medicine to slow down the progress or stop it.</td>
</tr>
<tr>
<td>Albrecht E.</td>
<td>I want the option of taking the drug/medicine immediately because the sickness goes on very fast</td>
</tr>
<tr>
<td>Andre E.</td>
<td>Yes. I want to have access to the medicine.</td>
</tr>
<tr>
<td>Andri E.</td>
<td>I would give it to my relative. Its worth trying.</td>
</tr>
<tr>
<td>Andy E.</td>
<td>Yes, I would take the drug. There is not a treatment available for FA and the results of the phase 2 trial were promising. Given the rare nature of the disease it is difficult to gain critical mass for clinical trials.</td>
</tr>
<tr>
<td>Anne E.</td>
<td>Yes, my family member wants to try the medicine really bad.</td>
</tr>
<tr>
<td>Antonia E.</td>
<td>it is absolutely necessary to improve the quality of life</td>
</tr>
<tr>
<td>Arzu E.</td>
<td>My nephew FA patient</td>
</tr>
<tr>
<td>Aysenur E.</td>
<td>I want my mom to recover and I want this drug approved</td>
</tr>
<tr>
<td>Bjørn E.</td>
<td>Yes, it is important to develop a good medicine</td>
</tr>
<tr>
<td>Cecilia E.</td>
<td>Yes, she wants to have the option of taking Omav. Taking omav offers the possibility of slowing the progression of the disease which can have a real impact in improving the quality of life.</td>
</tr>
<tr>
<td>Elisa E.</td>
<td>Because this disease has a evolution very quickly... the medical search it’s very important!!</td>
</tr>
<tr>
<td>Emma E.</td>
<td>Yes my cousin’s 7 year old daughter needs to take it to help her FA.</td>
</tr>
<tr>
<td>Esra E.</td>
<td>My brother has FA, I would like him to have the opportunity to take any medication that could help him in this situation. We want to take the medicine because I believe in the safety and efficacy of Omaveloxolone.</td>
</tr>
<tr>
<td>Esra E.</td>
<td>We would like to use and access the medicine</td>
</tr>
<tr>
<td>Ger E.</td>
<td>Yes, we need to stop the progression of the disease.</td>
</tr>
<tr>
<td>Heidemarie E.</td>
<td>I want the option of taking the medicine, because the disease is progressing dangerously fast.</td>
</tr>
<tr>
<td>Ibo E.</td>
<td>Let's move on to phase 3 for my sisters</td>
</tr>
<tr>
<td>Ingo E.</td>
<td>Yes, absolutely. My boys would be happy to have the option of taking this medicine. Every week, every day counts in slowing down the progression of this disease.</td>
</tr>
<tr>
<td>Jacqui E.</td>
<td>We definitely want our daughter to have access to Omaveloxolone - currently there are no treatments for FA, we need something to slow the progression of this horrible disease.</td>
</tr>
<tr>
<td>Jan E.</td>
<td>it is absolutely necessary to improve the quality of life</td>
</tr>
<tr>
<td>Jeniffer E.</td>
<td>This medication is very important for the future quality of life of my 10 year old daughter. Therefore, approval of the drug is very important to us.</td>
</tr>
<tr>
<td>Kader E.</td>
<td>We would like to use and access the medicine</td>
</tr>
<tr>
<td>Kirsty E.</td>
<td>Yes, my family member is only 8 years old and her parents would love the option of this drug for her to give her the best chance at as normal a life as possible.</td>
</tr>
<tr>
<td>Leyla E.</td>
<td>We would like to use and access the medicine</td>
</tr>
<tr>
<td>Markus E.</td>
<td>This medication is very important for the future quality of life of my 10 year old daughter. Therefore, approval of the drug is very important to us.</td>
</tr>
<tr>
<td>Melanie E.</td>
<td>We live in Germany - Hamburg - and our two sons would love to have the opportunity to take Omaveloxolone. Thanks and best.</td>
</tr>
<tr>
<td>Milena E.</td>
<td>Yes, I want this medication</td>
</tr>
<tr>
<td>Natalie E.</td>
<td>We want to have the opinion to choose.</td>
</tr>
<tr>
<td>Osmar E.</td>
<td>Yes, a hope for a better life</td>
</tr>
<tr>
<td>Pablo E.</td>
<td>I agree to give the medication to my child. Did not participate in the clinical trial</td>
</tr>
<tr>
<td>Pamela &amp; Vic E.</td>
<td>Yes C. our granddaughter is suffering from FA and urgently needs this medication to stop further deterioration in her condition. Please help thank you</td>
</tr>
</tbody>
</table>
# Comments from FA Community

## Parents & Family Members Outside the US

<table>
<thead>
<tr>
<th>Name</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Paul E.</td>
<td>Its good to have hope and something to give my child hope not to lose everthing.</td>
</tr>
<tr>
<td>S E.</td>
<td>Absolutely 100% , in a heartbeat- with no treatment available the medical profession owe it to FA sufferers to provide them with something that may relieve symptoms and prolong independence whilst research can continue to find a cure. Seeing my daughter gradually deteriorate every day and not being able to do anything is heartbreaking but even more so with the knowledge that there is something out there that may be able to provide some relief ,however small.</td>
</tr>
<tr>
<td>Sabine E.</td>
<td>This medication is very important for the future quality of life of my 10 year grandchild. Therefore, approval of the drug is very important to me.</td>
</tr>
<tr>
<td>Sevim E.</td>
<td>Mu cousin FA patient</td>
</tr>
<tr>
<td>Yunus E.</td>
<td>I want my wife to heal and want this drug approved</td>
</tr>
<tr>
<td>Yvonne E.</td>
<td>Yes as 99% success rate is far more beneficial than having nothing . Anything that offers even the slightest improvement in quality of life is worth trying.</td>
</tr>
<tr>
<td>Zeynep E.</td>
<td>I have 2 girls with FA, our only hope is this drug</td>
</tr>
<tr>
<td>Aisha F.</td>
<td>It coulp help a lot</td>
</tr>
<tr>
<td>Ália F.</td>
<td>Very well</td>
</tr>
<tr>
<td>Ana Clara F.</td>
<td>Yes, I want to take omaveloxolone</td>
</tr>
<tr>
<td>Anne F.</td>
<td>My family members are suffering greatly, whether my niece and nephew or their parents and siblings. For them, their siblings and the community, we owe it to accelerate everywhere we can. Time is of essence for those affected, and the clock can’t turn back. Please.</td>
</tr>
<tr>
<td>Ann-Sophie F.</td>
<td>Want to help him</td>
</tr>
<tr>
<td>Arnaldo Jose F.</td>
<td>Yes, I wish I could have access to this medicine that apparently is giving positive results</td>
</tr>
<tr>
<td>Asma F.</td>
<td>Yes for sure</td>
</tr>
<tr>
<td>Beate F.</td>
<td>I am the mother of a child with FA. The option of taking the drug/medicine would be great. Based on the currently data it would make every daily activity easier for both the assisstance and the person with FA.</td>
</tr>
<tr>
<td>Brigitte F.</td>
<td>Yes, definitly</td>
</tr>
<tr>
<td>Bruna F.</td>
<td>we would like to have the option of taking the medicine</td>
</tr>
<tr>
<td>Ciara F.</td>
<td>Yes, my family member would want the option of taking the drug</td>
</tr>
<tr>
<td>Craig F.</td>
<td>Yes, my family member most definitely wants access to this drug!</td>
</tr>
<tr>
<td>Cristiana F.</td>
<td>Of course. Any method than can mitigate this disease, is a hope for those who suffer daily, with the difficulties that this causes.</td>
</tr>
<tr>
<td>Cristina F.</td>
<td>Yes, I’d really like it</td>
</tr>
<tr>
<td>Cyntia F.</td>
<td>Yes, we accept the option. It is a great opportunity to at least stop the progression of this devastating disease</td>
</tr>
<tr>
<td>Daniel F.</td>
<td>Yes, the results look promising</td>
</tr>
</tbody>
</table>
Dominique F. We would want the option of taking the medicine. Our son is loosing capabilities constantly. He is only 9 years old.... I would give anything for him to get better and to slow down the process. This illness is so brutal, and to know that there is a medicine that exists, so close, and that it is not made available feels so unfair.... That puts a big toll and uncertainty on our family and my son’s future. This medicine has to be available to everybody, everywhere that endures this injustice.

Edel F. Yes. It will improve the quality of his life.

Eduardo F. My cousin has had this disease for many years, when I met him at the age of 6, we played together and since then we have been best friends. That same friend, for me, brother, we played ball together and today he cannot stand or even sit, he cannot afford to have the best legs, the best conception with the internet ... he lives in the countryside, when is this just going to give value or a little importance to people who really need it? Please help my cousin ...

Eleftheria F. Yes my family member would want the option of taking the drug so that she has a chance to be stable and have the hope not to worsen more over the years, as much as she could.

Ellie F. Definitely would like the opportunity to try the drug and definitely feel it is our responsibility to give any possible improvement to FA sufferers.

Felipe F. Yes i do.

Flora F. Yes, we would want the option of taking the medicine.

Florence F. I don’t know it’ my niece.

Florencea F. Yes. It has a good response from FA patients.

Frédéric F. Yes we would. We must try to save their life, or at least try to improve their daily life.

Georgios F. Immediate approval of omaveloxolone is important for stabilizing my child. Time is precious for patients with FA.

Giuliana F. Yes, I would like to receive the medicine.

Harry F. Yes I stand behind the administration of the medicine.

Heiko F. Yes she would. I will do everything to help her.

Isabel F. I am looking forward to my child have an opportunity to take the drug to have a better quality of life. To assure to my child that some symptoms of this disease could be minimized.

Isadora F. Yes, because this medicine could be the treatment for FA, and in Brazil don’t have drugs for this.

Iulian Lucian F. My son would want the option of taking omaveloxolone. Based on the data currently available, omaveloxolone significantly delays the progression of the disease. It is crucially important for an advanced FAer to gain time waiting for a cure.

Jackie F. Yes my sister definitely would.

Jane F. If it helps and gives people an improved quality of life then it should be available to them at an affordable price.

Joana F. Yes, I would like to take the medicine.

Kelly F. Yes, I believe this option should be available to anyon suffering from FA. I have a family member who has been involved in trials and why I dont know much about how it is helping against the underlying issues of the disease and what that means for symptoms of FA my family member feels positive about taking this medication and the positive effects it is having for her. It should be hers or anyone else suffering from FAs option to use this medication.

Kerri F. Yes 100%

Klaire F. The time is important for all patients FA.

Klairi F. Yes I want to take the medicine so as he can be better physically and mentally.

Klaus F. The debilitating effect of FA on my friends duhter and the emotional turmoil it causes his famely leavers them wanting the option of takin the drug to provide their daugter with the best opportunities in life.
<table>
<thead>
<tr>
<th>Name</th>
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</thead>
<tbody>
<tr>
<td>Liana F.</td>
<td>Being healthy is the right of any person, even if it is for the relief and prolongation of life. Think about whether it is you or a person you love! Empathy, compassion, feeling what the other feels... Don't be oblivious to the pain of others.</td>
</tr>
<tr>
<td>Lisa F.</td>
<td>Yes my cousin would want to try this</td>
</tr>
<tr>
<td>Luis F.</td>
<td>The FDA should approve the release of the drug because there is currently no approved drug that shows that it is capable of having any benefit for the disease. However, omaveloxolone has been shown to slow the disease in their studies, and knowing that AF patients do not have any medication, no matter how little benefit omaveloxolone provides, it should be approved.</td>
</tr>
<tr>
<td>Luiz F.</td>
<td>It is a medicine that will change the lives of many people, many people will have a better quality of life, if the medicine is authorized, we can change the lives of those in need!</td>
</tr>
<tr>
<td>Luiz Felipe F.</td>
<td>Yes, I want to take omaveloxolone</td>
</tr>
<tr>
<td>Luminita F.</td>
<td>My son would want the option of taking omaveloxolone. Based on the data currently available, omaveloxolone significantly delays the progression of the disease, which is important for an advanced FAer waiting for a cure.</td>
</tr>
<tr>
<td>Marc F.</td>
<td>Yes, whatever could help to decelerate or stop the evolution of the disease had to be tried</td>
</tr>
<tr>
<td>Márcio F.</td>
<td>Yes, because she has difficulty taking a bus, standing for a long time, working comfortably, driving, cycling.</td>
</tr>
<tr>
<td>Maria F.</td>
<td>My family member would definitely want to take Omaveloxolone</td>
</tr>
<tr>
<td>Maria F.</td>
<td>Yes, he has not participated in the study.</td>
</tr>
<tr>
<td>Maria F.</td>
<td>To improve the quality of life and have a better life and not be dependent</td>
</tr>
<tr>
<td>Maria Leticia F.</td>
<td>Yes. My mother wishes</td>
</tr>
<tr>
<td>Mariana F.</td>
<td>Yes, we wanna take</td>
</tr>
<tr>
<td>Marie F.</td>
<td>Yes, I would like my daughter to have the option of taking this drug as currently she has no treatment for her condition of FA, which is progressing rapidly &amp; impacting significantly on her quality of life.</td>
</tr>
<tr>
<td>Marie-Christine F.</td>
<td>Yes, but our children are able to decide by themselves. We have two children with FA, 33 and 34 old.</td>
</tr>
<tr>
<td>Mary F.</td>
<td>My son who has fa definitely needs something to help him walk and do other things without assistance. We would like to try omav.</td>
</tr>
<tr>
<td>Mauro F.</td>
<td>Yes, because it is a sign of hope for them</td>
</tr>
<tr>
<td>Michael F.</td>
<td>Yes, I/ we would take this opportunity. This gene defect is so horrible. For my child and for us parents.</td>
</tr>
<tr>
<td>Nadjma F.</td>
<td>Yes, I would like my nephew to be able to take the drug/medicine as this would improve his quality of life</td>
</tr>
<tr>
<td>Natalia F.</td>
<td>Yes, he participated on the study and wants to take the medicine</td>
</tr>
<tr>
<td>Pablo F.</td>
<td>Of course I would let my girlfriend take the drug. The information I got from omaveloxolone is that this drug has the potential to prevent the disease to get worse, and I would understand that if there was another drug to give to FA patients, FDA could make a more exaustive test to approve the drug, but knowing that there isn't any other drug for them by now, this should be already out, because there are people that needs so bad.</td>
</tr>
<tr>
<td>Pampos F.</td>
<td>And of course I would like it for my children since there is no approved treatment. They did not participate anywhere</td>
</tr>
<tr>
<td>Paul F.</td>
<td>Yes - an informed choice can only be made if there ARE choices - there’s precious few other options.</td>
</tr>
<tr>
<td>Paulo F.</td>
<td>Yes, I will take the option to take a medicine, because we are fighting Against a rare disease with few people available to participate in research to secure a drug compared to other pathologies.</td>
</tr>
<tr>
<td>Peta F.</td>
<td>Yes, hope for a better life</td>
</tr>
<tr>
<td>Rafaela F.</td>
<td>Yes, it’s our only hope now</td>
</tr>
<tr>
<td>Raquel F.</td>
<td>Yes, I want to take omaveloxolone</td>
</tr>
<tr>
<td>Rodney F.</td>
<td>Yes we are keen to participate</td>
</tr>
<tr>
<td>Sarah F.</td>
<td>Yes he would want the option please.</td>
</tr>
</tbody>
</table>
Shaline F. Yes- FA is a debilitating neurodegenerative disease that sees many suffering from it see a detrimental effect to their quality of life. Being given the opportunity to access Omaveloxolone would provide an amelioration to everyday life and also give much needed hope to live with this disease.

Simon F. Yes they would

Stefanie F. I think it’s very valid and we want to test the medicine

Tatiana F. Yes, because she has difficulty taking a bus, standing for a long time, working comfortably, driving, cycling.

Tatiany F. They have never participated in any experimental medicine, they would rather take this.

Theodora F. Immediate approval of omaveloxolone is important for stabilizing my child. Time is precious for patients with FA.

Tim F. While other kids are growing and enjoying life more and more we have seen that the kid of a good friend of us needs more and more help in her life due to the progression of this ugly disease’s.

Victor F. Yes. Because there is Hope that this drug can get better prospects for my cousin.

Víctor F. Yes, I want to grow my son as a healthy person.

Victoria F. My daughter has FA and I believe this drug could be life changing for her. I believe this drug should be available for all people with FA.

Wasia F. Yes . we will definitely take this medicine.

Zidane F. She needs and a person with a good heart has been an example of overcoming

Ana G. Yes, I would like it very much

Angela G. Yes, because it would be the first and only treatment available in the world for AF

Ann G. Yes, any help with this condition should be available to the person affected. This could be a game changer for all FA patients and they should be given the option to trial it.

Anna G. We are waiting for a trials

Armando G. Yes, my child want the option of taking the drug/medicine Your friend participated the MOXle part 1 and part2

Aurea G. Yes, my child want the option of taking the drug/medicine My friend participated in the MOXle part 1, part 2

Axel G. yes please

Beth G. Yes. There currently is no drug at the moment. Based on the science and this trial we would want to take this drug.

Brian G. Yes we would take it. Based on the research and testimonials it makes a difference.

Brian G. granddaughter so can’t pass an opinion.

Carly G. My sister wants the option to take this and that is hers as any other persons right living with this condition.

Caroline G. Yes, as the first results show a stop in the disease and an improvement in daily life

Cecília Yukimi G. yes, because her life can be better.

Christoph G. Based on the promising study results we would, under the guidance of our doctor, strongly wish for our daughter to receive omaveloxolone in order to slow down the ongoing degeneration of our daughter’s coordination, ability to move and her heart condition. The certain degeneration clearly outweighs potential risks.

Cláudia G. Yes, she would like to take the drug.

Daniele G. My son has the FA. I would like him to access the treatment with the omaveloxolone as soon as possible so he has a chance to recover some mobility, freedom, hope and dignity. I am well informed about the results of the clinical trials, i.e., their significant and strong positive effects and their negligible to mild side effects. I believe the potential benefits of the treatment surpass the risks by far. Waiting for the release of the treatment has been frustrating, agonizing and painful for the persons suffering from the FA as well as the people who love them.
COMMENTS FROM FA COMMUNITY
Parents & Family Members Outside the US

Deborah G. Yes. Hoping to get a better quality of life.

Deborah G. Yes, any benefit would make a huge difference.

Dimitris G. I know that my family member would take this drug.

Edgardo G. Taking the drug/medicine, hopefully will give my grandson a chance to enjoy life longer.

Eleni G. My child would like that. She hasn’t participated in MOXIE part 1,2 or open label extension study.

Eleni G. Yes there has been an improvement.

Ellen G. “There is finally an effektive drug to stop Fridreichtaxia (my grandsons diease ),which is currently incurable and Worsenig !”

Emiliano G. Because I been watching how she has been losing her strength and sadly part of her life, we’ve been looking for a lot of cures, therapies, etc, but with not success, but I really believe that Omaveloxolone will give her back her life and her happiness.

Eva G. For the improvement of my daughter.

Fabienne G. Based on the information of the study, we are willing to give this drug to our kid. We have read the document and we don’t expect major side effect from the outcome of the study. As from now, we are ready for it and looking forward for the agreement.

Fiona G. My son is desperate to take this medication as it is the only glimmer of hope for treatment. His condition has deteriorated so much that he feels he cant go on living. He needs assistance in every area of life and can no longer see, or hear effictively which really has made him very very depressed and aside from his physical afflictions managing his poor mental state is the biggest battle with his condition.

Florin G. Yes, no other treatment available!

Fons G. He would like to have the option to take the medicine, since deadling with this condition puts stress on his body both mentally and physically. Hope is a powerful thing and I really feel that this potential medicine gives me and more importantly him the hope to cope with this condition in a sustainable way.

Gaea G. Yes they would be interested. The hope is that it would improve their quality of life.

Gemma G. Yes I would want my brother to take the medicine. The results are already amazing why are you even considering delaying the time longer when we have family members desperate to start this drug to help them. The effect of my brother taking this drug would have a massive positive impact on our family! PLEASE ROLE OUT THE DRUG!

Gianfranco G. Yes we need these drugs

Gizem G. we tried many different drugs which havent been had any positive effects. But we can try again if you believe this one will more affectively.

Hilde G. Yes. I would take the medicine. And I would give it to my children. The chance of getting better is worth the risk.

Indianara G. I would of taking the drug for my family member. This is save your life.

Ingeborg G. There was no participation.

Inmaculada G. Yes, It si a chance to get

Isabel G. If Z. (21) wanted to take the drug, I’d be for it. Of course, I wouldn’t force her. If it is suitable for children, I would recommend it to L. (12).
**Parents & Family Members Outside the US**

<table>
<thead>
<tr>
<th>Name</th>
<th>Comment</th>
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<tbody>
<tr>
<td>Jackie G.</td>
<td>Yes we would like the option to be able to have the medicine</td>
</tr>
<tr>
<td>Jamie G.</td>
<td>Yes I would like the option of this drug for my sister as, I feel it would be beneficial for her</td>
</tr>
<tr>
<td>Jan Erik G.</td>
<td>Yes. (Not me, but family member(daughter in law)) The symptoms have accelerated (speech, swallowing, curved spine, movements etc.)</td>
</tr>
<tr>
<td>Jane G.</td>
<td>Yes I would like my son to be able to have access to this medication I’ve read so much positive feedback re the trials and my son is getting worse as time goes on I am desperate for him to have a better quality of life and for this heavy dark cloud we are constantly under to see some light.</td>
</tr>
<tr>
<td>Jaqueline G.</td>
<td>So that thousands of people are entitled to treatment against this disease so devastating that it is FA</td>
</tr>
<tr>
<td>Jean-Luc G.</td>
<td>I would like that my family member gets access to Omav to stabilize his condition and slowdown the progression of the disease. This is urgent. An action needs to be done quickly because the disease progresses quickly.</td>
</tr>
<tr>
<td>Jenny Adriana G.</td>
<td>My sister did not take this medicine</td>
</tr>
<tr>
<td>Joaquim G.</td>
<td>To have a better life with FA</td>
</tr>
<tr>
<td>Joaquin G.</td>
<td>Yes, they want the medicine ! Because is effective</td>
</tr>
<tr>
<td>Jose G.</td>
<td>Yes, because is the only true option that we have for help to my daughter</td>
</tr>
<tr>
<td>José G.</td>
<td>yes, because her life can be better</td>
</tr>
<tr>
<td>Josh G.</td>
<td>My son would take omaveloxolone. As parents would do anything to get our hands on it. We’re desperate.</td>
</tr>
<tr>
<td>Josh G.</td>
<td>Yes it could help others in the future and hopefully work</td>
</tr>
<tr>
<td>Joyce G.</td>
<td>Yes. We really want to see her better. We want this drug for her cause now we have the hope that she can get a better in the future.</td>
</tr>
<tr>
<td>Karyn G.</td>
<td>Yes my sister would like to try the medication</td>
</tr>
<tr>
<td>Laura G.</td>
<td>Family member with FA would like to</td>
</tr>
<tr>
<td>Laurence G.</td>
<td>Please . help us</td>
</tr>
<tr>
<td>Leen G.</td>
<td>Sure my family member would take omaveloxon</td>
</tr>
<tr>
<td>Leonardo G.</td>
<td>Yes he really need it</td>
</tr>
<tr>
<td>Liliana G.</td>
<td>We need the drug</td>
</tr>
<tr>
<td>Linda G.</td>
<td>Not sure</td>
</tr>
<tr>
<td>Louise G.</td>
<td>My son has had FA for 23 years and can no longer do anything for himself or speak. He would love the chance to try something that in the very least would improve any of the many issues he has.</td>
</tr>
<tr>
<td>Louise G.</td>
<td>Yes absolutely my son has been waiting for 23 years for anything that might at the very least slow down this awful disease</td>
</tr>
<tr>
<td>Lucia G.</td>
<td>Absololutely. My relative has not been able to lead a normal life for a long time and I think it is something that everyone deserves. Many times she tells me that he does not remember what it is like to walk and that breaks my heart. I hope that soon her illness will not progress further or that she will even be able to do more things again.</td>
</tr>
<tr>
<td>Luz Stella G.</td>
<td>Yes, because she can have considerable limitations and cannot fend for herself</td>
</tr>
<tr>
<td>Luzviminda G.</td>
<td>My grandson is 9 years old diagnosed with FA. If this medication will be approved by the FDA, it will help my grandson to be better and hopefully prolong his life too.</td>
</tr>
<tr>
<td>Marcello G.</td>
<td>I would certainly be in favor of administering omaveloxolone to my daughter</td>
</tr>
<tr>
<td>Marco Antônio G.</td>
<td>yes, because the life gets better</td>
</tr>
<tr>
<td>Marcus G.</td>
<td>Given the expected trajectory for my 18 year old cousin, he (and the family standing behind him) believes the option of taking Omaveloxolone is a rare and crucial opportunity. Time is nevertheless scarce!</td>
</tr>
<tr>
<td>Mari Luz G.</td>
<td>Yes, because it looks promising</td>
</tr>
<tr>
<td>Maria G.</td>
<td>Both my nephew and niece (25 and 33 years old) suffer from FA and would like to take the medicine.</td>
</tr>
<tr>
<td>Name</td>
<td>Comment</td>
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<td>-----------------------</td>
<td>---------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Maria Elens G.</td>
<td>We will like yo try, but need more informaron about second art effects</td>
</tr>
<tr>
<td>Mariano G.</td>
<td>They need the drug asap</td>
</tr>
<tr>
<td>Marie G.</td>
<td>Yes with more help and research to the omaveloxoone drug I would be very happy with my daughter taking the possible cure.</td>
</tr>
<tr>
<td>Marisa G.</td>
<td>Yes I want</td>
</tr>
<tr>
<td>Mark G.</td>
<td>Yes - he is happy to be involved</td>
</tr>
<tr>
<td>Marta G.</td>
<td>Too late for us probably, my aunt is already 74 and heavily affected in her daily life</td>
</tr>
<tr>
<td>Mary G.</td>
<td>Yes I would want my daughter to take it. She has late onset FA and my brothers daughter in the U.K. has just passed away recently from FA. She had early onset of FA and was diagnosed at 11 years old.</td>
</tr>
<tr>
<td>Mathilda G.</td>
<td>Yes! It’s been proven to help.</td>
</tr>
<tr>
<td>Matias Juan G.</td>
<td>Yes, my girlfriend want the medicine, because she never had a medicine that help her.</td>
</tr>
<tr>
<td>Matthew G.</td>
<td>Yes most definately, any chance of quality of life, especially if had proven positive results</td>
</tr>
<tr>
<td>Micah G.</td>
<td>I have 2 cousins with FA that are in their late 20's, which is well past their expected life duration. This could truly save their lives. PLEASE release it.</td>
</tr>
<tr>
<td>Mike G.</td>
<td>My friend live with fa. And i like to help him to destroy this kind of sickness.</td>
</tr>
<tr>
<td>Myriam G.</td>
<td>My daughter has FA and is interested in taking the drug. Please contact me.</td>
</tr>
<tr>
<td>Nabil G.</td>
<td>Yes , because this medicine proves to correspond positively in the treatment of the person and if she continued with this treatment, the results would be positive</td>
</tr>
<tr>
<td>Nessa G.</td>
<td>Yes! Please! We want very much!</td>
</tr>
<tr>
<td>Neva G.</td>
<td>She becomes my aunt. We heard that those who participated in the phase trials and were satisfied, we wait for the drug to be approved soon</td>
</tr>
<tr>
<td>Niamg G.</td>
<td>Yes. Any treatment is welcome for this cruel disease.</td>
</tr>
<tr>
<td>Nicola G.</td>
<td>Yes. We have been hoping for Moxie to be available since last year. We have closely followed the trials and the FDA’s response to them . We’ve been very disappointed for our son who would benefit enormously from this drug. It would be life changing for him.</td>
</tr>
<tr>
<td>Nigel G.</td>
<td>Yes would like the option to pursue an alternative that seems to be safe instead of being helpless in our day to day life that we’ve been led to believe that there is no hope for.</td>
</tr>
<tr>
<td>Owen G.</td>
<td>Yes. This is the only drug so far that I have seen seems to have a strong effect.</td>
</tr>
<tr>
<td>Ray G.</td>
<td>She would</td>
</tr>
<tr>
<td>Renaud G.</td>
<td>Help us</td>
</tr>
<tr>
<td>Richard G.</td>
<td>Yes, my sons condition is getting worse and there is no cure available.</td>
</tr>
<tr>
<td>Rob G.</td>
<td>Yes. A good chance It will help with pain and suffering and to help gain back some independence.</td>
</tr>
<tr>
<td>Rose Blanche G.</td>
<td>Yes, because my grand-daughter needs this drug to slow down the progression of her disease. We have high hopes for this drug.</td>
</tr>
<tr>
<td>Santiago G.</td>
<td>Yes, my wife has FA and she would take it.</td>
</tr>
<tr>
<td>Sissel G.</td>
<td>Omaveloxolone is at this moment the only hope my family member has to get a better quality of life.</td>
</tr>
<tr>
<td>Tâmara G.</td>
<td>Yes, i would like to take the remedy</td>
</tr>
<tr>
<td>Theodora G.</td>
<td>Immediate approval of omaveloxolone is important for stabilizing my child. Time is precious for patients with FA.</td>
</tr>
<tr>
<td>Thiago G.</td>
<td>My 37-year-old sister has had this disease since she was a teenager. The hope that exists in the institution is its only strength to continue living in search of a better quality of life.</td>
</tr>
<tr>
<td>Tina G.</td>
<td>Watching our little daughters motor skills slowly decreasing and her heart condition weakening... PLEASE... speed up and help all the people living with FA to give them access to omaveloxolone as fast as possible!!!!!! THANK YOU</td>
</tr>
</tbody>
</table>
COMMENTS FROM FA COMMUNITY
Parents & Family Members Outside the US

Ursula G. My close friend’s 17yr old son was diagnosed 12 months ago, he is deteriorating very rapidly and needs this medication urgently in my opinion.

Valeria Cristiane G. Yes I would like to take the moxle

Virgilio G. If the medicine (omaveloxone) to help to reduce the impact of ataxia in their bodies and their quality life will better I think that you can to continue looking for the improvement of the people with ataxia. Note: Never we used the MOXle part 1 and 2

Yvan G. My sister would love to have the choice to take it or not.

Adrian H. Yes. If it is shown to offer improvement without any noticeable side effects, then why not.

Alexandre H. Yes, she want to take this medecine

Alison H. yes to start the trial.

Amanda H. My 3 New Zealand cousins all have FA, 2 have passed away because of FA and my surviving cousin is 41 and in a great deal of pain and has heart failure because of FA, he has always said he would do anything so no more kids ever got FA again, he’s an amazing man, they all were/are.

An H. Yes, i always hope that everyone can get medicine to be better

Annabel H. Yes, because the illness is getting worse by itself. Having an option that might help is at least a chance which we dont have otherwise.

Annette H. The debilitating effect of FA on the patient and the emotional turmoil it causes leave us wanting the option of taking the drug to provide the patient with the best opportunities in life.

Armin H. My Child would like to have the Option to try the medicine!

Arthur H. Yes, my mother needs this drug, it’s her hope for have a better lifestyle.

Axel H. Perhaps, because ist don’t know so much about it

Bernadette H. My Brother wants the option of taking the medicine

Bill H. Yes she would take this drug to hopefully slow the progression of this disease until a cure could be found

Christine H. Yes, this is a wonderfully important opportunity to help those with FA

Claude H. Yes i would.

Danyal H. I thing based on studies it’s a good medicine

Darcy H. Any drug that can help my family members improves their quality of life is paramount to me. If there tests have been verified by the approiapate regulatory authorities then that’s good enough for me

David H. Yes she would be interested for sure

Desirae H. Yes he wants to take it

Elaine H. Yes would want to take it. Results show it is safe and effective

Eleanor H. Yes definitely. Results have been good to date with few side effects.

Eleanor H. Yes, happy to try anything that might help.

Elida Inés H. Yes, would participate in taking the drug.

Elodie H. Yes my sister would like to take the medicine. Considering that there’s no other medical option to cure ataxia, she will like to take the risks of taking this medication even though there might be only a small impact on her quality life.

Emma H. Yes, it is an exciting breakthrough which we have been waiting decades for and which brings great hope.

Fiarta H. Yes my family member would take the drug.

Florence H. Yes - from the trails it seems that the drug will help to lessen progressive symptoms and as a by product may provide much needed emotional support and relief from the anxiety and emotional suffering associated with the FA diagnosis.
COMMENTS FROM FA COMMUNITY
Parents & Family Members Outside the US

France H. Yes, my sister will absolutely take omaveloxolone to have the chance to improve her capacity with activities of daily living and have the chance to keep her autonomy for as long as it possible! It will be a great opportunity for her because there is no other option available now to help her.

Francis And Angela H. The two nephews and one niece do not have time on their side and are already in wheelchairs. They are in their early twenties. They have nothing to lose and everything to gain.

Gay H. To give a chance to my son to stop his disease progression and to give him some hope

Gisela H. Yes, my child would like to try the medicine!

Gregorio H. YES. I agree, you do not know how terrible this disease is and to see my son how he is losing his motor functions without being able to do anything ... He is a martyrdom, but today we have hope with this drug, with clinical trials, please FDA and Reata laboratory help us !!! May it be so. Thank you.

Guy H. Yes - absolutely, a drug with this much investment so far should be taken seriously and gives good cause for optimism, we just have to get it through to the right people.

Ibraihim H. Definitely yes! What is worse in a disease than doing nothing and let things run their course?

Irina H. My boy got the placebo. But there is the love to my son and I would give my life to help him

Isabell H. My affected sister would like to have the option of taking the medicine!

Jacqui H. Heartbroken parent watching my beautiful daughter loose her ability to walk, talk and become isolated from friends and enjoying life due to progression of FA. Omav is the first but if hope and we would love the chance to be able to pause this progression give her a better quality of life. This would be a much better option than sitting with nothing watching this take away her life.

Jane H. FA is already having a significant effect on my nephew’s physical and mental health and my family feel that it would be beneficial for him to receive this drug as soon as possible.

Jane H. I would do anything to make this disease treatable

Janice H. Yes my daughter would like to take this medication, anything that would slow down this terrible disease.

John H. Yes I would like my daughter to have the chance to participate .Please !

John H. Yes, anything for a better quality of life.

Jorge H. Yes because it is the last opportunity

José Alonso H. Yes, because in clinical trials they have come out with favorable results and for us it is a great alternative since it is a disease that we have not had a solution for and we hope for a cure.

Josh H. Yes we would love to try it

Julien H. Yes, rabdomized results in d’avoir of efficacy.

Justyn H. Yes, anything that would help mitigate the disease is worth legalising.

Karyn H. Yes, they should have access to drugs that reduce their symptoms

Kathy H. Yes. She has not had a chance at a normal life, and any improvement would be most welcome. She is looking at spine surgery within the year and such a daunting surgery is very tough on a young woman at 22 years old.

Laura H. Yes, he would participate in taking the drug.
<table>
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<tr>
<th>Name</th>
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<tbody>
<tr>
<td>Leann H.</td>
<td>I most definitely would like my child with FA to have access to and to take Omaveloxolone. We are 3 years post diagnosis (just before his 7th birthday) and in these 3 short years I have watched K. deteriorated rapidly, much more quickly than I expected. He has gone from an independent walker to using a crocodile walker, then in a wheelchair and now a electric wheelchair to get around school. His handwriting is much worse and nearly illegible. He is struggling to last the whole day due to mental and physical fatigue. As a single parent and his sole carer, it is extremely hard for me to watch him struggle all day, everyday, decline and deteriorate week by week especially when there is a medicine that can help slow down his progression and increase his energy levels. Compared with other peoples FA journeys, other families have been fighting FA for many, many years. Our three years is short, in comparison but all of our Family lives are a constant battle every single day. There is no break from the fear of 'what will your child lose next?', no break from the fear of 'will this chest infection be too much for him ?', no break from the fear of ultimately, 'losing your child's life' to this horrendous disease. Persistently fighting, every day, to get the right 1-1 support needed in school, physiotherapy sessions, speech and language interventions, appointments with numerous clinicians, home adaptations, orthotics, wheelchair service - this list goes on and on. Covid 19 has made this situation even more diabolical. K. has been 'shielding' for 6 months last year and again now, at the beginning of 2021, he is shielding again. Because of Covid 19 and the restrictions, he has missed out on nearly a years worth of swimming lessons, gymnastics, horse-riding not to mention the important physiotherapy input - which has added to his decreased mobility and decline. We know, if you don't use it you lose it! We are living in a inaccessible home where he has to crawl upstairs, the bathroom is tiny, crawling around each room on all fours as we can't get his wheelchairs inside the house at all. All because Covid has put major delays on our home adaptation project. No-one should ever live like this especially not a 10 year boy! FA is a very rare neuromuscular condition and as such the FA community is spread far and wide throughout the whole world, even though we are all separated by distance we are one great, big Family, connected by FARA, FAPG, Ataxia UK, numerous Facebook pages; celebrating with each other through our successes; supporting and consoling one another through our losses. Each and everyone of the Family feels the pain of one family losing the battle against FA. It is heart wrenching. Friedreich's Ataxia has already taken away K.‘s childhood, he has already spent more than 6 years being prodded and poked by every doctor imaginable to reach a diagnosis and his continued care. FA has already taken away so much of K.'s life and taken away so much from us as a family. Please don't let it take any more away from him. Please, please, please help us - by giving us a chance to use Omaveloxolone to slow down K.'s progression and increase his energy levels. This is a really meaningful to both of us, our family, our community who know and love K. and the whole Family all over the world. This gives us HOPE for a better future. Thank you.</td>
</tr>
<tr>
<td>Louise H.</td>
<td>Yes. H. is 7 years old and, right now, can still walk and run and keep up with his peers on the playground and participate with his class during sport. He works incredibly hard every day just to do the basic things most people take for granted. Any treatment which has the potential of slowing progression could gain him years of mobility, years of keeping up with his friends on the playground. We would absolutely want the option of taking this drug if it were available.</td>
</tr>
<tr>
<td>Lovis H.</td>
<td>Yes she would take omav to stop/slow the progression!</td>
</tr>
<tr>
<td>Lucy H.</td>
<td>We have 2 children. They both have FA. On a day-to-day basis, we see a deterioration in them, a relentless progression of this horrendous disease. Their ability to complete normal daily tasks independently is decreasing. They are both currently still ambulant but, despite endless rehabilitation exercise, their balance and gait, fine and gross motor skills are progressively worse and we are researching walking aids and adaptive equipment around the house. We are on constant alert that a symptom like choking or cardiomyopathy could be fatal. Our daughter has already had a full spinal fusion surgery for severe scoliosis, our son is being monitored for the same condition. They are intelligent, determined young adults and should have a bright future ahead of them, however, without a cure, FA will rob them of this and my husband and I face a bleak future where we will likely outlive both our offspring. Omav represents the biggest glimmer of hope, the biggest potential breakthrough for our FA community. We need it now. Our children simply don't have time to wait. The delay from a further clinical trial will result in the continued worsening of their condition. Their neurologist, Professor P. G. in London, is a strong advocate for our children to receive this treatment. Our family was not eligible for either trial. We ask please that the FDA and Reata work together to make Omav available urgently to all sufferers of FA.</td>
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<tr>
<td>Maartje H.</td>
<td>Yes, my niece want the option to take the medicine. This gives her hope for the future.</td>
</tr>
<tr>
<td>Maria Aascensión H.</td>
<td>Newly diagnosed</td>
</tr>
<tr>
<td>Marie-Claire H.</td>
<td>I want my sister to have the hope of living longer</td>
</tr>
<tr>
<td>Maris H.</td>
<td>I think he would want to take part, as it has the potential to improve his condition, which would be better than letting it progress. He is still very independent and want to do things on his own so the chance of a treatment is very exciting</td>
</tr>
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<td>Megan H.</td>
<td>Yes definitely! There is currently nothing available as a treatment to help FA and if Omav is effective then why not give people the chance to try it. They have nothing to lose. People with FA are in desperate need of anything that will help slow the progression of the disease.</td>
</tr>
<tr>
<td>Melanie H.</td>
<td>Yes, definitely. I myself would feel the same if I was suffering with this awful way of life.</td>
</tr>
<tr>
<td>Neli H.</td>
<td>I have a cousin with FA who doesn’t use any medication but I would like him to use it.</td>
</tr>
<tr>
<td>Pam H.</td>
<td>She would like to try it as her situation is getting worse</td>
</tr>
<tr>
<td>Phil H.</td>
<td>Yes, as we are hopeful of at least a slowdown of the effects of FA as a minimum</td>
</tr>
<tr>
<td>Rebecca H.</td>
<td>Yes. I believe it is really important if it can prevent the deterioration of people diagnosed early.</td>
</tr>
<tr>
<td>Rebekah H.</td>
<td>Yes. We believe slowing or stopping progression of FA can increase life expectancy and gives all hope for the future.</td>
</tr>
<tr>
<td>Scot H.</td>
<td>Yes she will.</td>
</tr>
<tr>
<td>Shane H.</td>
<td>yes my daughter has it</td>
</tr>
<tr>
<td>Stuart H.</td>
<td>Yes. Due to the progressive degenerative nature of the disease, sufferers are suffering life reducing and severe life limiting symptoms. This medication is an opportunity for those with no real treatment option survive this disease, especially those in the early stages, who may not have suffered the debilitation of longer term sufferers. Issue the drug, even for clinical trials in the initial phase, please.</td>
</tr>
<tr>
<td>Susan H.</td>
<td>He and his parents want the option.</td>
</tr>
<tr>
<td>Tania H.</td>
<td>would love to see my loved one get better</td>
</tr>
<tr>
<td>Teodor H.</td>
<td>Yes, I want my son take Omav</td>
</tr>
<tr>
<td>Timmy H.</td>
<td>Yes I would like her to take the drug</td>
</tr>
<tr>
<td>Tomáš H.</td>
<td>Hell yea, if it helps slow/stop the progression, my kids might have chance to have their mother still relatively ok, but there is no etin time to waste. If this is safe and has good results, we would be quite optimistic to take it.</td>
</tr>
<tr>
<td>Wayne H.</td>
<td>Yes. My son K. (28 years old) is living with Friedreich’s ataxia. He has been confined to a wheelchair for 10 years and presently requires round the clock assistance in his daily living. In the early 2000’s, when my son was 7, I was in contact with Dr. P. R. in France, and his promising research with Idebenone as a potential treatment for heart hypertrophy. Dr. R. forwarded me some of his literature and I sourced the Idebenone in the United States. As it was not FDA approved, it was manufactured as a dietary supplement (it was available to me). With consultation with his cardiologist at BC Children’s hospital my son was administered the drug. Within an extremely short period of time, his heart wall had shrunk 30% and was considered “normal”. This result was overwhelming to us and also his cardiologist. If we could treat his heart, he may have an opportunity to live long enough to see a day when medical advances could provide for a treatment. We had bought him some time. To this day, after 20 years, his heart remains within the “normal” description. This drug had limited affect on the neurological symptoms however. The prospect that there may now be something available to slow/halt/reverse the neurological components of this disorder is a glimmer of hope for patients and families as any retained or reversed functions, regardless of how minor, are incredibly valuable to patients living with Friedreich’s ataxia. I will advocate for the approval of any drug which has documented evidence of safety and efficacy. Without the Idebenone drug which my son took so many years ago, I am unsure of where his progression would be today. I would like to have FA patients uttering the same words with respect Omaveloxone in the near future. Please examine the existing research and approve this drug based on the evidence it has presented and the potential life changing results it may give to patients and families who potentially may not have to suffer through the ravages of this cruel disorder. Look through the lens of someone with FA and the hope that this may bring.</td>
</tr>
<tr>
<td>Yasmin H.</td>
<td>Yes whatever it takes to help for a better living life.</td>
</tr>
<tr>
<td>Abdul I.</td>
<td>Yes we would like that she could have the opportunity to take the medicine. That could help her to minimize the effects of the disease. Thank you</td>
</tr>
<tr>
<td>Anaiza Márcio I.</td>
<td>My friend wants the option to take the drug because she believes it will give her a chance of having a new life, fill happy, confident, and able to fill free!</td>
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<tr>
<td>Name</td>
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<tr>
<td>Breno I.</td>
<td>Yes, she would like to take the medicine, because it will help her dealing with the symptoms.</td>
</tr>
<tr>
<td>Carol I.</td>
<td>Yes. Anything that can help my daughters progression slow down or cease is a godsend</td>
</tr>
<tr>
<td>Claraa I.</td>
<td>Yes, my cousin would want to take the medicine because this way, It will alleviate the symptoms of the disease</td>
</tr>
<tr>
<td>Dobrinka I.</td>
<td>Yes, i want my son take Omav.</td>
</tr>
<tr>
<td>Elias I.</td>
<td>She needs to take de medication soonest</td>
</tr>
<tr>
<td>Katia I.</td>
<td>Yes. It will help reduce the symptoms of FA</td>
</tr>
<tr>
<td>Myriam I.</td>
<td>Definitely yes! It seems a very good treatment and the fact that there is no cure makes it really challenging for all families with a FA member.</td>
</tr>
<tr>
<td>Narcy I.</td>
<td>Thank you</td>
</tr>
<tr>
<td>Radyy I.</td>
<td>Tnk you</td>
</tr>
<tr>
<td>Stefania I.</td>
<td>Stopping the disease</td>
</tr>
<tr>
<td>Sumeya I.</td>
<td>yes she want</td>
</tr>
<tr>
<td>Van Vliet-Belin I.</td>
<td>young girl ready to use as soon as possible this treatment</td>
</tr>
<tr>
<td>Yuri I.</td>
<td>Yes , as it would minimize the pain that the person has and that he/r could live a normal life</td>
</tr>
<tr>
<td>Zamir I.</td>
<td>Yes, please lets promote a cure for FA</td>
</tr>
<tr>
<td>Andrea J.</td>
<td>My cousin is 11 years old. She was diagnosed with FA when she was 5 years old. Throughout the years she had been getting worst. Right now she needs a walker to walk but it is still hard for her. The medicine will help her a lot physically and emotionally. She will have bigger hopes on waking again!</td>
</tr>
<tr>
<td>Annemarie J.</td>
<td>We are constantly observing how my Family L. symptoms intensify and make independent living difficult and even impossible. So it’s a pleasure to read about the success of the Omaveloxolone studies The results give me hope that the quality of patients’ lives will improve. I have faith in the studies and in medicine. We definitely want the option of taking the medicine. Thank you.</td>
</tr>
<tr>
<td>Ashiraf J.</td>
<td>Wants the option to take the medicine</td>
</tr>
<tr>
<td>Carina J.</td>
<td>Yes, to improve their quality of life</td>
</tr>
<tr>
<td>Dieusaert J.</td>
<td>We would like cure FA</td>
</tr>
<tr>
<td>Ellen J.</td>
<td>Yes, there is no other drug/medicine available with good results. So it is important that patients can take this medicine to improve their quality of life.</td>
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<tr>
<td>Comments from FA Community</td>
<td></td>
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<tr>
<td>Parents &amp; Family Members Outside the US</td>
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**Emmanuel J.**

YES. Based on the data currently available on safety and efficacy of omaveloxolone, I, my family and my child would want the option of taking the drug/medicine. My daughter has been diagnosed a year ago with FA and we have already started to see the devastating effect of the disease at play. She is in constant pain, misses school often, can't participate in sports activities, falls regularly and has a very constrained social life. We know this is just the beginning and we have already seen how the disease progressively incapacitates her more every year. We know that if nothing is done she will progressively lose more functions and eventually die as a young adult. Lining with this knowledge is devastating for our family. With the Moxie trial came a lot of hope and we were able to convey this message of hope to our daughter when the disease was impacting her most physically and psychologically. The announcement by Reata of the results of the phase 2 clinical study was a day of celebration and hope for our daughter, our family and friends. We understand that Omav has a clear mechanism of action that was demonstrated on models. This effect was confirmed in humans through 3 clinical studies in a very consistent manner. It was very impressive to see that the positive results were consistent across the three studies and statistically significant. Obtaining in 48 weeks only a comparative regression of the disease that is the equivalent of its normal 2 year progression is an incredible achievement, especially noting that these effects are maintained over time. It was impressive for us that the results were statistically significant despite the small sample size. Very important to us was also the fact that the drug didn’t come with significant side-effects. The testimonies of patients were an incredible message of hope for us. The recent news that there might be a need for further studies in order to make the drug available, causing a potential delay of several years was extremely distressing. It is very hard for us to understand the rationale for such a delay. We know that time is of the essence for FA. For our daughter, accessing the drug might mean the difference between being able to stand and talk and being in a wheelchair and having significant communication difficulties. It can mean the difference between having irreversible damage to her heart and dying early or having a normal longevity. We also want to stress that no equivalent treatment is likely to be available for years. So, while we wait for an authorisation, the condition of our daughter will deteriorate and her life will become more difficult. Considering the extremely positive results obtained by Omav across three studies with a high level of statistical significance and the absence of side effects, we don’t understand the recommendation for a second clinical trial. This is because FA is a very rare disease and that in the current Covid context organising a second trial would be very challenging and unnecessarily delay access to the drug. If we consider a basic principle of potential benefit to patient and risk, the risk in that case is in not encouraging, submitting and accepting a NDA. Indeed, in discouraging the submission of a NDA at that stage, the FDA creates a significant delay that will result in patients dying and seeing their symptoms degrading to a point that will make their life extremely difficult (and costly for the community). The fact that there is no current alternative for treating FA and that the drug is well tolerated means that patients should be given the choice, in collaboration with their support medical teams, to access Omav. At the moment, we feel that this choice should be granted to us and that it would be unfair to further delay access to those patients who want to access the drug. It is extremely distressing to know that there is a drug that has been demonstrated to be efficient and well tolerated and that our daughter can’t access it. We would do anything to provide her with the drug and the joint action of Reata and the FDA could achieve just that. We want and need access to Omav now. We thus fully embrace the call for action from the FA community and ask Reata to submit a New Drug Application (NDA) on an urgent basis and FDA to exercise the flexibility granted by law and contained in FDA guidance in considering approval of an NDA for Omav in FA based on the existing evidence from clinical trials.

**Evanthia J.**

Please approve the drug! My daughter can’t walk anymore and everyday asks me when she will have something to delay or stop this awful disease! We were waiting for years to have a drug and now we can have it! Thank you

**Grand J.**

No other existing drug that could improve the daily life as omaveloxonlone could do.

**Helena J.**

Yes. It will allow some independence

**Ian J.**

Yes, if it will benefit FA its a no Brainer!!!

**India J.**

Yes! She would like the opportunity to take the medicine.

**Jean-François J.**

Yes because we have nothing else!

**Jose Cardoso De J.**

Yes , would like to have access to the medicine

**Leyandra J.**

Yes I would like to see them taking some medicine to get better , and have their lives in some better way too.

**Louise J.**

Yes would definitively want the option of taking the drug. It is hell watching my child’s body slowly breakdown.

**Louisette J.**

Omav is the only medicine having results for FA. Omav does not seem to provoke bad sides effects. So I think that it is all right for my grand daughter.
<table>
<thead>
<tr>
<th>Name</th>
<th>Comments</th>
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<tbody>
<tr>
<td>Magdalena J.</td>
<td>we would like to be able to start therapy because of the hope of a normal life</td>
</tr>
<tr>
<td>Marcelo Luiz J.</td>
<td>Yes, I would like to take moxie medicine</td>
</tr>
<tr>
<td>Marie Claire J.</td>
<td>yes because we have nothing else</td>
</tr>
<tr>
<td>Martinho J.</td>
<td>Yes, i would like him to take the medecine</td>
</tr>
<tr>
<td>Megan J.</td>
<td>Signing on behalf of my 5 year old niece, diagnosed when she was 3 and is progressing rapidly. Her mother had Expressed this drug would improve the quality of life for my niece.</td>
</tr>
<tr>
<td>Milton J.</td>
<td>My siblings</td>
</tr>
<tr>
<td>Nikita J.</td>
<td>Yes, it would improve her quality of life</td>
</tr>
<tr>
<td>Nishant J.</td>
<td>Yes i want that medicine to be trialed for person who wants to get the medicine</td>
</tr>
<tr>
<td>Pascal J.</td>
<td>She would probably want to try it</td>
</tr>
<tr>
<td>Peter J.</td>
<td>Yes. She will regain a small amount of independence</td>
</tr>
<tr>
<td>Sandra J.</td>
<td>Yes, because it is a hope of improving their quality of life</td>
</tr>
<tr>
<td>Sarah J.</td>
<td>Yes, I would. There is not a treatment available for FA and the results of the phase 2 trial were promising. Given the rare nature of the disease it is difficult to gain critical mass for clinical trials.</td>
</tr>
<tr>
<td>Shakil J.</td>
<td>It makes them better</td>
</tr>
<tr>
<td>Shanilla J.</td>
<td>Yes, because she feels like this will improve her sensority and movement skills .</td>
</tr>
<tr>
<td>Sheila J.</td>
<td>Of course we would want the option. Everyone should have the option to decide if they want to go along that pathway.</td>
</tr>
<tr>
<td>Tamara J.</td>
<td>If this drug was available to my daughter I would not hesitate to give it to her based on the evidence of the studies already done. My daughter was showing symptoms at age 3 and diagnosed at 4 years of age. She already uses a wheelchair daily, fatigues rapidly, has slurred speech and has a moderate-severe enlarged left ventricle. With a drug that already has been proven to work and work well I don't understand why it isn't available to us. Please approve omaveloxolone for FA patients. Time is so valuable to our community as we don't have any to waste. Please.</td>
</tr>
<tr>
<td>Valdenir J.</td>
<td>Yes. Today there is no medication for AF and it is very difficult to live with a degenerative disease.</td>
</tr>
<tr>
<td>Victor J.</td>
<td>It would help with her menatl health</td>
</tr>
<tr>
<td>Zofia J.</td>
<td>Yes. I think that the benefits of taking omav are grater than the possible side effects risk.</td>
</tr>
<tr>
<td>Adil K.</td>
<td>I think it can give hope to them.</td>
</tr>
<tr>
<td>Adnan K.</td>
<td>My wife has FA. I want this drug approved to cure FA</td>
</tr>
<tr>
<td>Anila K.</td>
<td>two sister who is living with FA</td>
</tr>
<tr>
<td>Anthoula K.</td>
<td>Yes of course.. it is the only thing that we can hope for.. without it we are helpless..</td>
</tr>
<tr>
<td>Antonis K.</td>
<td>Yes surely.. now we have hope that something is going to change..</td>
</tr>
<tr>
<td>Ayse K.</td>
<td>My children are sick. Now I want their improvement and I want this drug to be approved.</td>
</tr>
<tr>
<td>Ayşegül K.</td>
<td>My girl friend has been looking at the drug for years. They are very pleased to participate in the phase trials.</td>
</tr>
<tr>
<td>Bernice K.</td>
<td>Definitely yes, to stop the progression of FA And to enhance D.'s daily functions.</td>
</tr>
<tr>
<td>Carol K.</td>
<td>Results are very promising</td>
</tr>
<tr>
<td>Christine K.</td>
<td>My cousin would be willing to try anything to reverse or slow down the symptoms of FA</td>
</tr>
<tr>
<td>Crystal K.</td>
<td>My sons girlfriend. She has expressed that she would be very interested to take this medication. She is hoping for any help to get it to Canada but is will o go to the US for treatment.</td>
</tr>
<tr>
<td>Donna K.</td>
<td>Yes we definitely want to be on the trial . Our 12 yr old is rapidly declining and any hope is better than nothing</td>
</tr>
</tbody>
</table>

205
COMMENTS FROM FA COMMUNITY
Parents & Family Members Outside the US

Eamon K. The results look very exciting

Eleni K. I want my child to take this medicine because it is safe and since there is currently no other treatment for the FA even with minimal positive results, it will be beneficial for my child.

Emine K. Yes, I would take this drug.

Eva-Maria K. Yes, we want the option. For a better live for our daughter.

Evirina K. Absolutely yes... because this medicine is our only hope... without it we are totally hopeless..

Fatima K. Because based on the available information, I believe that an omaveloxolone is safe and effective for the treatment of ataxia, which results in the improvement of my cousins motor coordination (a symptom of ataxia). In addition, the treatment will minimize daily criticisms and the consequences of bullying, increase her self-confidence and provide her with freedom of life.

Fiona K. Yes, the results of the Trial are very encouraging.

Frank K. Yes so my 2 children can live normal lives like children should.

Georg K. Im sure my wife, whos living with fa, would try taking medicine. We know a girl, who took part of the moxi studys.

Giorgos K. They would like the option of taking the drug

Greg K. I would want my daughter to have omaveloxolone as the MOXle trial has shown clearly that it delays the progression of FA and with minimum risk. I understand the FDA need for more data - however with the small number of patients available for analysis and previous FDA precedents in such cases - we believe the benefits far outway the issues associated with continued FA progression. A delayed progression would be a godsend compared to the difficulties she will face if her FA progresses as predicted. My daughter has a double degree and to lose all means of communication, to go through constant pain because of muscle spasticity (which has begun) and face the prospect of death through heart or other organ failure - when a delaying drug is at hand, is something that requires compassionate decision making. We ask the FDA and REATA to consider these facts when making their upcoming decisions.

Gulam K. Yes . Because seems to be the best and unique medicine that can help, and give a quality life.

Ioanna K. Of course everybody must have the option to take the medicine and have a better life. Please

Irina K. Please help these children to live a normal life.I have my niece with this awful disease.Omav will help her! Thank you for everything!

Isabel K. Yes, any chance to make her life improve.

Isie K. Yes, in my aunt and uncle have the two most beautiful kids, L. and S. They are two kind hearted souls with the most bubbly personalities. Unfortunately both have been diagnosed with FA, any hope or even a shed of light to bring happiness to the family is something I pray for every night. If there is hope in a FA research field, I want them to be part of that, in any possible way.

Jack K. Yes of course as things are only getting worse.

Janice K. Yes my niece needs it

Jennifer K. Yes absolutely

Kai K. Of course! Every Person concerned must have this option. This disease is one of the worst stroke of fate I know. Every little step forward to make such a life with FA more bearable should be supported.

Kalltrina K. She cant walk.

Karol K. FA going to be worser and worser, covid don’t help with this situition.

Kim K. My cousin would like to have the option of taking this medication to perhaps slow the progression of the disease and thus have a few more years of life

Konstantina K. Yes, my relative A. D. wants to take thw drug/medicine for his health improvement.

Kristina K. My brother is diagnosed with FA and would profite by taking the medicine due to his severe symptoms.

Leanna K. Please get this med to Ireland to help my sisters
<table>
<thead>
<tr>
<th>Name</th>
<th>Comment</th>
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<tbody>
<tr>
<td>Leona K.</td>
<td>Yes they would do anything to stop this.</td>
</tr>
<tr>
<td>Lutfee K.</td>
<td>Yes to become better</td>
</tr>
<tr>
<td>Maria K.</td>
<td>Absolutely, it should be available As soon as possible to all patients. The data provided by part one and part two of the study along with the open label extension shows significant statistical improvement when looking at the activities of daily life and measures on the FARS Scale. This is adequate and sound proof of the efficacy of MOXie.</td>
</tr>
<tr>
<td>Marian K.</td>
<td>My family member would want the option of taking the medication immediately</td>
</tr>
<tr>
<td>Matiida K.</td>
<td>I know my brothers and sister would like the option of taking this drug, they have followed the trials in the US and have been hoping for UK approval.</td>
</tr>
<tr>
<td>Megan K.</td>
<td>Yes the results of the trials are very encouraging!</td>
</tr>
<tr>
<td>Michelle K.</td>
<td>Yes people living with FA deserve this medication as soon as possible without delay</td>
</tr>
<tr>
<td>Mrika K.</td>
<td>My family member will use it</td>
</tr>
<tr>
<td>Mubina K.</td>
<td>Yes, because it can work and make the progress of FA goes slow! it can possible more chances to have a live without depend to others!</td>
</tr>
<tr>
<td>Muhamad Yasser K.</td>
<td>If the medicine helps to improve the patient’s condition, and doesn’t show any serious collateral effects (which has been in this particular case of testing), I believe that the product should be available to all of those who suffer from this disease</td>
</tr>
<tr>
<td>Natasa K.</td>
<td>Yes it would be great if we had that option. Especially now that we have nothing else to use in order to ease the disease’s symptoms</td>
</tr>
<tr>
<td>Nicole K.</td>
<td>Yes , because we Need something to slow the Progress.</td>
</tr>
<tr>
<td>Nikos K.</td>
<td>It will help people with FA to become healthy</td>
</tr>
<tr>
<td>Rohan K.</td>
<td>Definitely yes. My son has FA and is impacting his life which this drug can halt progression of the disease meaning he can live a normal life and also have a greater contribution the society. Having the ability to finish school and attend university and live a long life in a chosen career can provide for greater benefit to all of society.</td>
</tr>
<tr>
<td>Ross K.</td>
<td>Yes, the trials seem promising and effective.</td>
</tr>
<tr>
<td>Ryan K.</td>
<td>My girlfriend had been living with FA for almost 7 years now, and she is absolutely glowing. She just heard about this news, and she can’t believe it. I haven’t talked to her about trials, but this needs to be pushed for the community. This drug will save lives.</td>
</tr>
<tr>
<td>Sally K.</td>
<td>Yes definitely</td>
</tr>
<tr>
<td>Sarah K.</td>
<td>Yes - we would want the option of accessing the drug. Our daughter has been recently diagnosed with FA and is already suffering as a consequence. Any potential treatment - particularly one that slows the progression of symptoms - is essential for prolonging a decent quality of life for those with FA including our daughter.</td>
</tr>
<tr>
<td>Shamir K.</td>
<td>My Family need urgent the Drug/medicine</td>
</tr>
<tr>
<td>Stavros K.</td>
<td>Institutions are made to safeguard both the safety but also the well being of civilians. Now we have an opportunity to bring a therapy for FA on approval, if we loose this opportunity, we loose our goals and all those thing we frighted for.</td>
</tr>
<tr>
<td>Commenter</td>
<td>Comment</td>
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</tr>
<tr>
<td>Suzan K.</td>
<td>My niece has been struggling with this disease for years and I want this drug to be approved.</td>
</tr>
<tr>
<td>Theresa K.</td>
<td>Yes, to have a better chance in live and to slow down the progression of FA.</td>
</tr>
<tr>
<td>Timo K.</td>
<td>Yes, my Cousin would appreciate top Take the medicine</td>
</tr>
<tr>
<td>Únal K.</td>
<td>My daughter has been sick for 25 years and wants to try this drug, but we cannot reach it because it is not approved, we ask for it to be approved</td>
</tr>
<tr>
<td>Vasileios K.</td>
<td>It is very important for patients to receive a drug that slow their disease progression. This will mild their pathology and have a positive effect on the performance of daily activities. Neurologically using all or the most of the muscles has an impact on retaining this capacity. Losing a capability in such a devastating degenerative disease means that even in the future would be available, the patient is unlikely to gain it back. Time is now in our side. The COVID19 pandemic proved that global response and science could win. We ask for the same effect. We represent globally the Friedreich Ataxia community, each and every one in his/her respective country. FDAs’ approval is the key and would message the regulatory authorities globally. Now is the time for all to act and for FDA to lead.</td>
</tr>
<tr>
<td>Willy K.</td>
<td>Yes sure</td>
</tr>
<tr>
<td>Xristos K.</td>
<td>Absolutely.. this drug is our only hope</td>
</tr>
<tr>
<td>Yasmin K.</td>
<td>Yes. Because base on the information available I believe that omavelozolone is safe and effective in the treatment of Ataxia and it will improve the motor coordination of my family members who are suffering from this disease and as well as bullying because of that, taking away their freedom to fully live their youth. Because base on the information available I believe that omavelozolone is safe and effective in the treatment of Ataxia and it will improve the motor coordination of the people who are suffering from this disease and as well as bullying because of that, taking away their freedom to fully live their lives.</td>
</tr>
<tr>
<td>Yiannis K.</td>
<td>it should be available As soon as possible to all patients. The data provided by part one and part two of the study along with the open label extension shows significant statistical improvement when looking at the activities of daily life and measures on the FARS Scale. This is adequate and sound proof of the efficacy of MOXie.</td>
</tr>
<tr>
<td>Agustina L.</td>
<td>So that my aunt gets better and all those who have the same disease get better</td>
</tr>
<tr>
<td>Alejo L.</td>
<td>Yes, because she needs it</td>
</tr>
<tr>
<td>Alex L.</td>
<td>Yes he wants to trie because he already has it for long time</td>
</tr>
<tr>
<td>Ana L.</td>
<td>Yes. My cousin wants to take the omaveloxolone.</td>
</tr>
<tr>
<td>Andrew L.</td>
<td>Yes we would love to have the option, to take the drug/medicine to see an improvement on all things daily life: Speech; walking; holding items etc.</td>
</tr>
<tr>
<td>Angela L.</td>
<td>My sister would like to take omav, hoping that her neurol. functions will improve, though she has had FA for about 35 years (she is now 51y old) and that her everyday life will be easier.</td>
</tr>
<tr>
<td>Angela L.</td>
<td>yes, because it would be the first and only treatment available in the world for AF</td>
</tr>
<tr>
<td>Angelica L.</td>
<td>Yes we would love to have the option, to take the drug/medicine to see an improvement on all things daily life: Speech; walking; holding items etc.</td>
</tr>
<tr>
<td>Ann L.</td>
<td>Yes. Any hope welcomed</td>
</tr>
<tr>
<td>Anna Carolina L.</td>
<td>I would like to have a better quality of life!</td>
</tr>
<tr>
<td>Astride L.</td>
<td>Yes we would.</td>
</tr>
<tr>
<td>Barbara L.</td>
<td>We would desire and pray for the chance for our great nephew to improve his quality of life and a better longevity.</td>
</tr>
<tr>
<td>Bronagh L.</td>
<td>Yes absolutely</td>
</tr>
<tr>
<td>Caitriona L.</td>
<td>Yes we would like to take the drug however it would be very important to have this available sooner rather than later!</td>
</tr>
<tr>
<td>Carissa L.</td>
<td>Yes I would want the option to take the drug/medicine for my family member</td>
</tr>
<tr>
<td>Name</td>
<td>Comments</td>
</tr>
<tr>
<td>--------------</td>
<td>---------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Carlos L.</td>
<td>Yes it would be great for my brother to have access to this medication to see an improvement in his life.</td>
</tr>
<tr>
<td>Christos L.</td>
<td>Yes please, we want to take this medicine as soon as possible! My cousin is in bad condition! She needs to take it immediately!</td>
</tr>
<tr>
<td>Daniel L.</td>
<td>To pursue the investigations so that the medication comes out soon</td>
</tr>
<tr>
<td>Danielly L.</td>
<td>My cousin has ataxia, her name is I, I’m very attached to her, and I know the seriousness of this disease, all of my family are praying that this bad phase will pass soon, and this medication will help, so this it is very important not only for me, but also for my family and for I. herself, I would be forever grateful if this medicine helps her to be cured.</td>
</tr>
<tr>
<td>David L.</td>
<td>Yes would want the option to take</td>
</tr>
<tr>
<td>Denise L.</td>
<td>Now medical</td>
</tr>
<tr>
<td>Dermot L.</td>
<td>Yes, anything that slows progression would be Brilliant. Means holding on to pieces of independence</td>
</tr>
<tr>
<td>Doris L.</td>
<td>To improve the quality of life of many people with this disease</td>
</tr>
<tr>
<td>Duncan L.</td>
<td>Yes, we would like the option. We’re friends with people who were in the study and the results have been very promising. If there is a risk of bad side effects, they’re still not worse than the actual disease</td>
</tr>
<tr>
<td>Eduardo L.</td>
<td>So that my nephew and others have some treatment against this devastating disease: FA</td>
</tr>
<tr>
<td>Eliana L.</td>
<td>So that my son and others have some treatment against this devastating disease: FA</td>
</tr>
<tr>
<td>Elizabeth L.</td>
<td>So that all who suffer from this type of disease have the opportunity to have better mobility and well-being.</td>
</tr>
<tr>
<td>Emilia L.</td>
<td>YES, VERY GOOD IF HE TAKES THE MEDICINE</td>
</tr>
<tr>
<td>Fatima L.</td>
<td>Yes, we want to take the medicine</td>
</tr>
<tr>
<td>Francine L.</td>
<td>Yes we want the option of taking the drug medecine</td>
</tr>
<tr>
<td>Fredy L.</td>
<td>To improve people’s lives</td>
</tr>
<tr>
<td>Gary L.</td>
<td>Absolutely. FA suffers are in a race against time to receive treatments with therapeutic benefits given the neuro-degenerative, invariably fatal nature of the condition. Omaveloxolone is the first such treatment and is safe and well tolerated based on trials already conducted. It should be made available to all FA suffers who chose to take, as for them, the alternative is unacceptable.</td>
</tr>
<tr>
<td>Gaspar L.</td>
<td>Yes, my son is getting worse and he urgently needs that medicidne</td>
</tr>
<tr>
<td>Gay L.</td>
<td>I signed this petition because my little brother has FA since he is 5 years and the is fighting every day against the progression of the disease. I would like his efforts to be rewarded.</td>
</tr>
<tr>
<td>Gisara L.</td>
<td>My sister’s daughter is FA. She is a beautiful young lady, she is 13, she is still independent for activities. Please help</td>
</tr>
<tr>
<td>Gordon L.</td>
<td>She is taking Lyrica. Maybe it is time to switch medication and see if it will help her.</td>
</tr>
<tr>
<td>Guiherme L.</td>
<td>Yes, my cousin wants to take this medicine</td>
</tr>
<tr>
<td>Gustavo L.</td>
<td>We think we can improve the daily independence and fatigue. We also expect to prevent the advance of the disease.</td>
</tr>
<tr>
<td>Heidemarie L.</td>
<td>My niece T. suffers from this bad disease and is very restricted in her movement. So we hope, that this medicine can help her to improve her situation. Please help, that patients can get this treatment!</td>
</tr>
<tr>
<td>Herbert L.</td>
<td>I would be happy if the drug could help my daughter too.</td>
</tr>
<tr>
<td>Hildegard L.</td>
<td>I would be happy if the drug could help my daughter too.</td>
</tr>
<tr>
<td>Ida L.</td>
<td>Yes, my siblings would be grateful to try medicine that could help. They did try etravirin but the government didn’t help so after 1 year they had to stop because of economy.</td>
</tr>
<tr>
<td>Ine L.</td>
<td>No medication yet</td>
</tr>
<tr>
<td>Jaimi L.</td>
<td>Yes my family member would want the option of taking the medication.</td>
</tr>
<tr>
<td>Jean-Ljc L.</td>
<td>Yes, is actually the best option</td>
</tr>
</tbody>
</table>
**COMMENTS FROM FA COMMUNITY**
Parents & Family Members Outside the US

<table>
<thead>
<tr>
<th>Name</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jhossimary L.</td>
<td>Yes, i would like him to take the medecine</td>
</tr>
<tr>
<td>Jules L.</td>
<td>Yes we would want that option</td>
</tr>
<tr>
<td>Karine L.</td>
<td>Yes, he would</td>
</tr>
<tr>
<td>Kathryn L.</td>
<td>My Family member (9 year old boy) was diagnosed a year ago. I understand that this drug could improve his quality of life and longevity and therefore would like him to have the opportunity of taking the medicine. Additionally, if it provides further knowledge for future developments in the treatment for himself and others, or allows him to progress to a place where he may be eligible for new medical developments in FA in the future, my hope would be that this option provides this intelligent and vibrant boy the chance to blossom to his full potential.</td>
</tr>
<tr>
<td>Kerry L.</td>
<td>Yes. FA is a painful disease. Anything that alleviates chronic pain and improves mobility must be approved.</td>
</tr>
<tr>
<td>Kirsten L.</td>
<td>Yes - we want it desperately to save our boy.</td>
</tr>
<tr>
<td>Kirstyn L.</td>
<td>Yes. They 100% want the option. Their options are currently limited and any shimmer of hope is welcome.</td>
</tr>
<tr>
<td>Kostas L.</td>
<td>My father is suffering with FA! We have heard this drug is good! So, yes, we need to take it!</td>
</tr>
<tr>
<td>Laure L.</td>
<td>My father is 70 years old this year and he’s baeting against the FA for years. If a drug/medecine exist, it will be good for him to test it (he has nothing to loose!). He’s doing bicycle every day and kiné and lots to win against the deases...</td>
</tr>
<tr>
<td>Lucie L.</td>
<td>Yes, waiting for another 2 years for a second clinical trial is a torture for families fighting against this neuro-degenerative disease. Thanks!</td>
</tr>
<tr>
<td>Magalie L.</td>
<td>Yes for an easier daily life</td>
</tr>
<tr>
<td>Maria L.</td>
<td>Yes I would use the medication for my son who suffers from FA. I will support the decision of FARA.</td>
</tr>
<tr>
<td>Marie L.</td>
<td>I wish it because it is a terrible suffering for my brother. he wants this experience.</td>
</tr>
<tr>
<td>Marjorie L.</td>
<td>We want to test this medecine to try to give another future to our child</td>
</tr>
<tr>
<td>Martina L.</td>
<td>It would be wonderful and nothing we would want more than to see my sister happy. This drug is a chance for you to stop this disease maybe even hope for improvement we dont want to leave any stone unturned! Everyone is unique and especially these hard-fithing people deserve to lead a happy symptomfree live with as few obstacles as possible. We wish it for all who have to go through this terrible disease, also for us relatives it is dificult to see and not be able to change anything!</td>
</tr>
<tr>
<td>Maurice L.</td>
<td>Yes to access to the drug</td>
</tr>
<tr>
<td>Mayra L.</td>
<td>Que need the drug!</td>
</tr>
<tr>
<td>Melissa L.</td>
<td>Yes. Would want the option given to my sister and brother-in-law for my nephew who is 11 currently to be able to take the drug.</td>
</tr>
<tr>
<td>Milagros L.</td>
<td>Yes, she never take a drug and she need it to have a better life</td>
</tr>
<tr>
<td>Monique L.</td>
<td>I hope that my grandson will benefit of thé treatment to stop the disease</td>
</tr>
<tr>
<td>Nathalie L.</td>
<td>Yes, to stop the disease and improve her health</td>
</tr>
<tr>
<td>Nathaly L.</td>
<td>Hello. Yes, I would. Yes, I want my son to take the medicine since it has been shown to have a good result.</td>
</tr>
<tr>
<td>Nicky L.</td>
<td>Yes, if it can make a child’s life a little easier I think it should be an option.</td>
</tr>
<tr>
<td>Pierre L.</td>
<td>Yes my family member would like the option of taking it. They believe that current evidence is convincing enough given the lack of alternatives</td>
</tr>
<tr>
<td>Ronny L.</td>
<td>No medication yet</td>
</tr>
<tr>
<td>Ryan L.</td>
<td>Yes, my brother would appreciate the use of this drug/medicine. His quality of life has stagnated, though quite clearly started to lose logical sense. He no longer sees friends and rarely sees family. Cannot perform most day to day activities.</td>
</tr>
<tr>
<td>Sandra L.</td>
<td>Yes please</td>
</tr>
<tr>
<td>Shanna L.</td>
<td>Yes my child would takeThe Medication</td>
</tr>
</tbody>
</table>
Steve L.  Yes we definitely want omaveloxolone!!!!
Telma L.  Yes. The family member wants to take the medicine.
Thiago L.  She need medicine
Tihare L.  so that everyone with this disease improves their quality of life
Tristan L.  He wants the medication because he has it for more than 10 year
Vanessa L.  Yes, i would like him to take the medecine
Vasiliki L.  Yes we want this medicine! Please approve it as soon as possible!
Veronique L.  As parents of children suffering from FA, we would like them to start having a panel of treatments to slow the illness down, till a more complete - definitive treatment could be found. Even if omaveloxodone seems a new solution, without a long history of usage in other deases, trials were very promising in MOXle studies, so it could be at least a first step in the very long curing path for FA. Besides, thinking about patients older than our children, this could be a saving solution in a very degrading illness. So we first sign in priority this petition for them, adult patients, for the use of omaveloxolone on FA patients, and also for our children, for them to have a slow down in degenerative process. Omaveloxolone could be a transitional drug until new/better ones could be found. Curing FA is a potential start to cure degenerative diseases that are even more costly to the society. Thanks for your action.
Vipen L.  I want my daughter to consume the drug so that she gets better in terms of deterioration
William L.  Yes to access to the treatment
Nelsimara .  Yes, i would like him to take the medecine
Abdul M.  Yes I want to take the medication. As I feel it is pretty safe and effective medication which would help the patients directly and also the family members and friends and community indirectly
Adil M.  Because based on the available information, I believe that omaveloxolone is safe and effective for the treatment of Ataxia, which will result in the improvement of all patients who suffer from this disease.
Adolf M.  Yes, it’s a great chance!! We have no other choice, let’s do it!
Agnaaldo M.  Yes, I want to take omaveloxolone
Agustin Eloy M.  Yes, my family member would want the option of taking the medicine.
Aisha M.  Yes, to help my family member with her motorskills and help her in not relying upon other people as well as decrease the bullying and to simply let her have a better life
Alex M.  I want people to have a better quality of life.
Alexa M.  My partner is currently living with FA and most definitely wishes to take this drug/medicine.
Alexander M.  Yea I would like her to take the drug
Allana M.  Yes, would want the option of taking the drug/medicine
Amanda M.  Yes, if it means even slowing this awful disease we would do what is best for our child and to help the FA community. Stronger together.
Amanda M.  Yes. It would help so much
Ana M.  I’m doing this, because I believe this medicine can help my cousin, and Our hope’s lays on this
Andrea M.  I agree with the distribution of the drug
Anette M.  I can see my son is getting worse every week. It makes me really sad when I now that there is no cure or medicine that can delay his FA. He is fateing but he need help as soon as possible. He has no time to wait.
Ann M.  YES ABSOLUTELY. PLEASE AS SOON AS POSSIBLE.
Annmarie M.  Yes. It’s 99% certain it’s fit to use and will drastically help FA sufferers. Some people don’t have time to wait for more trials.
Araciel M.  Better quality of life. Believe that it is possible to count on government aid
<table>
<thead>
<tr>
<th>Name</th>
<th>Comments</th>
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<tbody>
<tr>
<td>Arthur M.</td>
<td>To slow progression of the disease is so important in the daily lives of FA patients</td>
</tr>
<tr>
<td>Athina M.</td>
<td>I have two sons 28 and 35 years old living with symptoms of FA for less and more than 15 years respectively and I want the option of taking the medicine so that my children have a better quality of life.</td>
</tr>
<tr>
<td>Berna M.</td>
<td>Just waiting for it</td>
</tr>
<tr>
<td>Bill An Vicki M.</td>
<td>Any help for our grandson most welcome</td>
</tr>
<tr>
<td>Bob M.</td>
<td>Yes...approve for taking if some slowing of symptoms is at all possible.</td>
</tr>
<tr>
<td>Bonnard M.</td>
<td>My grandson has FA since 10 years. I would be so happy if Omav could cure him, heal him.</td>
</tr>
<tr>
<td>Bruno M.</td>
<td>Yes. My brother has AF and would like to have access to this medication to experience the benefits, since we have no other drug options for treatment.</td>
</tr>
<tr>
<td>Callum M.</td>
<td>Brother followed this research.</td>
</tr>
<tr>
<td>Carla M.</td>
<td>Yes. Efficacy and safety data look promising.</td>
</tr>
<tr>
<td>Carol M.</td>
<td>It is not easy to live with a disease that is not cared for without all the problems involved, and this study represents a hope for all people suffering from this disease in order to have a better and dignified life. So if this medicine can be a cure, any person with a haf would like to take it</td>
</tr>
<tr>
<td>Chelsio M.</td>
<td>Yes. Because she might be able to fell better</td>
</tr>
<tr>
<td>Claribel M.</td>
<td>The approval of a drug that is confirmed helping in FA gives greater life expectancy to those who have this disease, that is why we support this initiative</td>
</tr>
<tr>
<td>Colette M.</td>
<td>Yes. This drug could transform my wonderful brave nieces, who is the mother of two wonderful boys, life.</td>
</tr>
<tr>
<td>Courtney M.</td>
<td>Yes he would like the option to take the drug</td>
</tr>
<tr>
<td>Craig M.</td>
<td>I have undertaken extensive research of the medication option in question. The data speaks for itself. The associated risks will always be inherently present however, I believe the data provides a sufficient amount of evidence supporting the underlying safety of the remedy in question</td>
</tr>
<tr>
<td>Cristina M.</td>
<td>Definately, my child wants to try this medicine to see if anything improves such as her walking, balance...</td>
</tr>
<tr>
<td>Debbie M.</td>
<td>Family wants the option of taking the drug/medicine</td>
</tr>
<tr>
<td>Devaides M.</td>
<td>I think its very good</td>
</tr>
<tr>
<td>Didier M.</td>
<td>Our daughter L., 17 years, is actually taking Mnesis. Being followed by Dr. H. at Robert Debré hospital in Paris. She agrees that we offer this medicine to our daughter</td>
</tr>
<tr>
<td>Dineke M.</td>
<td>My cousin has the disease. I think she would take the medicine.</td>
</tr>
<tr>
<td>Diosy M.</td>
<td>Mu cousin needs the drug or he can dies so young.</td>
</tr>
<tr>
<td>Edona M.</td>
<td>Yes we are waiting for it</td>
</tr>
<tr>
<td>Edwige M.</td>
<td>Yes, whatever could help to decelerate or stop the evolution of the disease had to be tried</td>
</tr>
<tr>
<td>Eileen M.</td>
<td>OUR GREAT NIECE IS IN NEED OF THIS DRUG</td>
</tr>
<tr>
<td>Elena M.</td>
<td>Yes. The illness increase very fast and currently there is not any available medicine</td>
</tr>
<tr>
<td>Name</td>
<td>Comment</td>
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<tr>
<td>Eleonor M.</td>
<td>Yes, I wish that my daughter could walk again independently.</td>
</tr>
<tr>
<td>Elisa M.</td>
<td>Yes most definitely. It is horrible to watch someone you love live with FA and struggle with everyday life.</td>
</tr>
<tr>
<td>Emilio M.</td>
<td>I want all people with FA to have access to a better quality of life.</td>
</tr>
<tr>
<td>Ennio M.</td>
<td>Yes we want.</td>
</tr>
<tr>
<td>Erin M.</td>
<td>There is no limit to what I would do to have my son take a medication that could slow or halt the progression of FA. Given the data available I would be first in line to have this prescribed for my child. As I watch the disease take hold, my son is losing so much of what he loves. Last summer he ran with his cousin while on summer vacation, this year he sat on the bench and envied their abilities. Last year he did karate three times a week, but now it is now too difficult. It has been said that Omav is not a cure, not a miracle. But to a parent of an FA’er, an approved treatment that will slow and or halt progression is a miracle. I understand that this is not a vaccine for a global pandemic, or a treatment for cancer that may impact millions, but for an FA patient and their family, this is a life changing opportunity. There are already races he cannot run, and games he can’t play. but right now he can still walk and if Omav can help him keep this ability for longer we would be so incredibly blessed.</td>
</tr>
<tr>
<td>Evelyn M.</td>
<td>It’s a great chance. We need urgently a therapy for FA!</td>
</tr>
<tr>
<td>Evie M.</td>
<td>Yes. I think it’s a good opportunity to improve the patients life.</td>
</tr>
<tr>
<td>Fanny M.</td>
<td>Of course she would.</td>
</tr>
<tr>
<td>Farad M.</td>
<td>If it’s to get better taking the medicine is the best way out of this.</td>
</tr>
<tr>
<td>Fionnula M.</td>
<td>Yes the results of the trials are very encouraging.</td>
</tr>
<tr>
<td>Francisco M.</td>
<td>Yes, of course because it will improve her life.</td>
</tr>
<tr>
<td>Francois M.</td>
<td>Yes, she would take the medicine.</td>
</tr>
<tr>
<td>Frank M.</td>
<td>My brother has a poor quality of life and no treatment available. He should have the chance to try a treatment that may be beneficial.</td>
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<tr>
<td>Frank M.</td>
<td>My wife would be willing to be a part of a drug trial, in the hope it may benefit herself and others in the future.</td>
</tr>
<tr>
<td>Frederic M.</td>
<td>Yes our child is currently walking with a walker and we want to quickly slow down the effects of the illness because he will soon be unable to walk.</td>
</tr>
<tr>
<td>Gabriela M.</td>
<td>I will like my nice have a better life quality, and do stuff that 11 year old girls do by her own</td>
</tr>
<tr>
<td>Gaetan M.</td>
<td>We want to try anything could change my sister’s life. It’s so complicated.</td>
</tr>
<tr>
<td>Georgina M.</td>
<td>Yes my daughter would like to take this drug.</td>
</tr>
<tr>
<td>Gesa M.</td>
<td>Yes, I every day counts in “pausing” the progression and keeping quality of life. I feel very confident regarding the trials efficiency and safety. Seeing normal life skills taken away rapidly is heartbreaking. Our son does everything in his power to slow down the progression like attending the gym at 5.30am (3-5 times/weekly) before school but his mobility is still deteriorating so fast that we can’t wait! We need Omaveloxolone asap! For our son’s wellbeing but also for all other family members (brothers, parents) involved and for mental stability. Apart from the physical deterioration, FA has an enormous impact emotionally, socially, mentally... for everyone involved. Please listen to the patients and the people supporting them.</td>
</tr>
<tr>
<td>Giannis M.</td>
<td>Thank you for everything! Please hurry up for our children!</td>
</tr>
<tr>
<td>Gustavo M.</td>
<td>Yes, my friend that lives in Brazil have a lot hope in this drug. So it will be very cool if legalization happen.</td>
</tr>
<tr>
<td>Hannah M.</td>
<td>Yes they would want the option, they need to have hope that they can be helped, that there’s a chance the progression on FA can be slowed.</td>
</tr>
<tr>
<td>Hautmont M.</td>
<td>Yes it seems very interesting To me that my little girl benefits from this drug. To advance research while giving Her a chance to stop this disease</td>
</tr>
<tr>
<td>Hennie M.</td>
<td>I don’t know.</td>
</tr>
<tr>
<td>Inger Lise M.</td>
<td>Omaveloxolone will be a great help for FA patients until a permanent cure is available. Please give this petition a positive answer.</td>
</tr>
</tbody>
</table>
Isabel M.  The drug/ is Very efficacy
Isabell M.  Hope
Isabelle M.  My brother has passed at the age of 33. My sister has 49 years but has a poor quality of life, may be is too late for her as well... Let us give a chance to those who can still get a benefit from this treatment. Thanks
Isabelle M.  Yes our child is currently walking with a walker and we want to quickly slow down the effects of the illness because he will soon be unable to walk
Isidora M.  I want everyone with FA to have an opportunity to improve and do their daily things.
Ivanka M.  I would consider it after talking with neurologist.
Jacqueline M.  My nephew wants to live a life as normal as possible he would like the option to take the drug...his mother has exhausted ever other Avenue, and this I'd her last hope.
Jahangir M.  I, as the brother of the patient(B), am really eager for her to have access to the omaveloxolone treatment as soon as possible. I have seen my sister struggling with FA for years and how she has always hoped to have access to this treatment. It is true that the omaveloxolone needs a few more steps for its final approval, but I believe some steps can be taken sooner. I beg for FDX and Reata Pharmaceuticals to hear our voices again, as they have always, so that patients can have access to this treatment sooner. At last, I want to thank you with all my heart for your tireless efforts. God bless you all.
Jan Robert M.  Omaveloxolone would greatly help FA patients while waiting for a permanent cure. Please open up for use!
Janine M.  Absolutely yes. My sister has been following closely for my nephew and was so hopeful and excited about the pending approval. Her family is willing to pay until it is approved in Canada. I watched the FA webinar and was so touched and inspired by the individuals with FA that shared their stories, and the strength, balance, improvements and hope that the drug gave the individuals that were fortunate enough to participate in the trial and are now in the open trial.
Jasmim M.  Better results of the motor condition on the patients.
Javier M.  my cousin, who has FA, is looking forward to taking the drug.
Jean Noel M.  No I can’t answer positively because my daughter do not trust in such clinic trials as she was not convinced by her last trials (Frames).
Jelena M.  YES, YES, YES!!! OMAV will help my daughter A. gain back her strength, endurance, joy, speech, her smiles, her independence and reduce her fears! Her HEALTH is her WEALTH! Why would you delay that?? The neurological losses that my daughter has endured so far are: • Difficulty walking and poor balance. She went from holding onto to things, then using a walker to now using a wheel chair. • Slowness and slurring of speech (dysarthria). To afraid to talk to other people. Speaks in a low voice and for only a short period of time as she doesn’t want people to hear her voice crackle. • Difficulty coordinating movement of all her muscles. It gradually worsens and the muscle weakness progresses making it harder to do everyday activities like brushing her teeth. • She developed scoliosis (upper thoracic) and had spinal fusion when she was 14. She now has to endure another surgery for her lower back called lumbar scoliosis. Do you know how painful that surgery is and the recover time and how it changes her movement even more? • Fatigue. She tires very easily and finds that she requires more rest and takes a longer time to recover from common illnesses such as colds and flu. The future losses are: • FA people develop difficulty swallowing, due to difficulty coordinating the muscles of the tongue and throat. • Hearing and vision loss. • Heart palpitations and shortness of breath. These symptoms are the result of various forms of heart disease that often accompany Friedreich ataxia, such as enlargement of the heart (hypertrophic cardiomyopathy), formation of fiber-like material in the muscles of the heart (myocardial fibrosis), and heart failure. Heart rhythm abnormalities such as a fast heart rate (tachycardia) and impaired conduction of cardiac impulses within the heart (heart block) are also common. • About 50 percent of people with FA develop carbohydrate intolerance and 30 percent develop diabetes.
Joanne M.  Not my decision as the grandmother but I think they likely would want to. It is absolutely heartbreak to watch the deterioration of this bright and beautiful person. We understand this is not a cure but anything with such apparent low risk would be so meaningful to be able to even slow, and or stall the progression and any improvement would be a total gift. Please approve this asap.
Jodi M.  Yes! Anything to try and help rid or slow down this disease.
John M.  yes to give them a chance in life
### COMMENTS FROM FA COMMUNITY

**Parents & Family Members Outside the US**

<table>
<thead>
<tr>
<th>Name</th>
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<tbody>
<tr>
<td>Jorge M.</td>
<td>Yes, we are doing all that’s possible to increase their quality of life and their life expectancy.</td>
</tr>
<tr>
<td>Juan Pablo M.</td>
<td>Yes, to make her life better.</td>
</tr>
<tr>
<td>Julia M.</td>
<td>We looking for opportunity to take the omaveloxolone. She did not take it before.</td>
</tr>
<tr>
<td>Justinianno Joseph</td>
<td>Yes, my daughter would like to take and participate in the program</td>
</tr>
<tr>
<td>Wilhelmmina M.</td>
<td>Yes, without a doubt. We have not participated in the study. Based on the information available, this drug would bring great relief to our lives. Since our daughter’s diagnoses, we have endured the challenge of consistent deterioration of her quality of life. Every year presents new challenges for our daughter, and our family. Friedreich’s Ataxia, untreated, is like watching your loved one die a little bit each month, for years, with your hands tied behind your back. Please keep up the good work to bring this treatment to all FA victims, and those that love them.</td>
</tr>
<tr>
<td>Karyne M.</td>
<td>Yes, i would like him to take the medicine</td>
</tr>
<tr>
<td>Kathleen M.</td>
<td>I want my daughter to have whatever she needs to have a normal life.</td>
</tr>
<tr>
<td>Kathrin M.</td>
<td>Yes, we would try to take the medicine. Actually we have no other option.</td>
</tr>
<tr>
<td>Kácia M.</td>
<td>My family member want the option of taking the medicine to improve the life quality.</td>
</tr>
<tr>
<td>Kirti M.</td>
<td>As a family member, it’s our true desire to see our neice become healthy and joyful again so that he can enjoy his life now as he used to do before. May he live his life to the fullest and may his each day of life become memorable. We all want that he gets cured of this illness and may he live and fulfill his dreams and become who he is destined to be.</td>
</tr>
<tr>
<td>Kjetil M.</td>
<td>Want the choice off take the medicine if she wants it herself.</td>
</tr>
<tr>
<td>Kshitij M.</td>
<td>Yes, I would want my Cousin “V” to take the medicine for FA. As his big brother, I really want that he enjoys his life and fulfills his dreams without any problems. He is a very wise, calm and joyful child and as a brother to me, he will always be the best. “V” has really handled his tough days very nicely and I really want that he remains happy throughout his life and may all the problems coming in his path to become who he is destined to be get away. I hope that the FDA Authority takes the most correct decision and may the medicine turn out to be a success so that everyone can live their life with happiness and joy.</td>
</tr>
<tr>
<td>Lasse M.</td>
<td>I hope to have this drug for my daughter as soon as possible. She is getting worse, and time is critical.</td>
</tr>
<tr>
<td>Leah M.</td>
<td>She already has medicine</td>
</tr>
<tr>
<td>Leonardo M.</td>
<td>Yes. He needs to have the option to fight back!</td>
</tr>
<tr>
<td>Liliana M.</td>
<td>With such excellent results that is really the only medication that has shown a substantial improvement in quality of life</td>
</tr>
<tr>
<td>Lindsay M.</td>
<td>Relative would like to participate as she has FA</td>
</tr>
<tr>
<td>Lisbela M.</td>
<td>Yes, she wants the option of taking the drug.</td>
</tr>
<tr>
<td>Louise M.</td>
<td>My brother in-law has fa and is in pain everyday of his life. My family and I would love new medicine to help him</td>
</tr>
<tr>
<td>Lovanna M.</td>
<td>Yes. There is currently nothing available to stop or slow the progression of FA.</td>
</tr>
<tr>
<td>Lucas M.</td>
<td>Yes! To provide a better quality of life to my young brother.</td>
</tr>
<tr>
<td>Lucas M.</td>
<td>Yes, because it’s already a deadly disease. So my cousin is willing to take that risk.</td>
</tr>
<tr>
<td>Luiz M.</td>
<td>It is important give a chance with this medicine to all people with Ataxia disease around the world. For this reason I’m applying to you this request for my cousin treatment and for her family. Give her a little bit hope to change her life and mobility to do the simple things in the life.</td>
</tr>
<tr>
<td>Luke M.</td>
<td>Yes. The benefits are clear to see</td>
</tr>
<tr>
<td>Marcelo M.</td>
<td>Yes. It has shown remarkable results.</td>
</tr>
<tr>
<td>Maria M.</td>
<td>I would like to take it.</td>
</tr>
<tr>
<td>Maria M.</td>
<td>We want Omav for our children please help them! Thank you</td>
</tr>
</tbody>
</table>
COMMENTS FROM FA COMMUNITY
Parents & Family Members Outside the US

Maria Jose M.  She want the option of taking de drug
Mario M.  It is important to stop and/or improve the progression of the disease for the benefit of all patients in the world
Marit M.  She is willing to participate in studies.
Marla Teresa M.  Yes, i have Hope in this medication
Mary M.  This is the answer to our prayers. My son is progressing fast and is only 17. This hateful disease is taking away his quality of life. He deserves a chance to try OmaV to hopefully stop progression and give him a better quality of life.
Mary M.  Yes. I would want my brother to participate in all medicinal benefits.
Matias M.  I would like my relative and all the people who suffer from FA to have the possibility to get this medicine and to be able to see their daily lives getting better
Matthias M.  Yes, my relative wants the Option. No Part in trials.
Matta M.  Possibility of receiving the drug
Mauell M.  Can we launch the petition in German?
Mayan M.  Because it's a new hope and better than nothing
Mikael M.  Yes my son wants the option to take the drug/medicine! He is getting worse day by day. It is a nightmare as parent to standby not having any cure for FA. Please let him get the new drug available so he can get better, at least slow down the progress!
Mireille M.  This unique medicine represents a glimmer of hope for our granddaughter
Mirza M.  Will improve her life quality and less bullying
Montserrat M.  Yes. He has not participated in trials, neither phase I nor phase II
Mylene M.  Yes, would like him to take the drug to slow down the effects of FA
Namrata M.  Yes, I want to take the medicine for my Family member because it delays or may be even stops the progression of FA as shown by the data. Hence please make the medicine available to the FA community ASAP.
Nancy M.  I am the grandmother of a 9 year old who was diagnosed with FA over a year ago and see his deterioration with each passing day. This drug has been shown to pause that and I think that is evidence enough to make it available to the FA COMMUNITY
Naylla M.  Yes - I would like to have access to the medicine
Niovi M.  I hope the drug/medicine will help her to make her life easier!
Nour M.  Not sure
Ottavio M.  Yes, I want my niece to have the opportunity to take the drug.
Patrick M.  Yes  Trials very positive
Paula M.  I am her auntie, not her parent. But her parents would like the option to take it.
Paula M.  Yes. The results of the trial are very encouraging and seem like a good step in the right direction
Peer M.  I want this drug to be allowed to those with FA. This is because it will enhance their chance of going into the outdoors with friends and family with confidence and not being judged by others who do not suffer from this disease. I want my brother to have quality of life
Penny M.  Yes, my family member would like the option to receive the drug.
Poppy M.  Yes, anything which could help them
Rafaela M.  It's very hard to live with this. AF limited the quality the live the person have this and this don't permit a normal life
COMMENTS FROM FA COMMUNITY
Parents & Family Members Outside the US

Raul M. I want a better quality of life for all people with FA and that there will be an improvement in their daily lives.

Raúl M. I need an improvement even if minimal for my family member and for all the FA community. Let them have access to this drug.

Regina M. My niece L. needs the medication. She isn’t able to live by herself. She needs help to do almost everything.

Richard M. It would not be my decision, however, I would encourage my granddaughter to take the drug and/or participate in an extension study.

Rik M. Yes, research looks more than promising and need to be followed up on. The FA community needs this medicine since so many have already benefited off of it.

Roberto M. I agree with the distribution of the drug.

Roger M. She will take the medicine.

Ron & Beverley M. As Grandparents it is terrible watching our Grandson decline and feeling helpless when there is a drug which would make his life so much better. Every move he makes is calculated and it is really cruel to think there is a drug which could help and is being denied.

Roseli M. Yes I would like to use MOXIE.

Sam M. As a parent, it’s devastating to see your children deteriorate every day… waiting and requesting FDA to plz approve Omaveloxolone so that we can pause this deteriorating disease from making my kids life miserable. Thanks you!

Sarah M. Yes, I would take the drug. There is no treatment available for FA and the results of the phase 2 trial were promising. Given the rare nature of the disease it is difficult to gain critical mass for clinical trials.

Scarola M. To slow symptoms.

Scott M. Absolutely yes. Watching our son visibly regress on a monthly basis with no cure in sight is cruel and unnatural. With this drug we can at least slow down this rapid progression. As humans it’s in our power to make this happen.

Shawndel M. That’s a question for my brother living with FA.

Shyloe M. Unsure as I have not heard of this study, will have to have a look at the research, a fellow FA mum posted this and anything that is going to help with FA is what we need.

Simon M. Yes my brother is currently walking with a walker and we want to quickly slow down the effects of the illness because he will soon be unable to walk.

Sinead M. Yes he would. He is 21 diagnosed at 9 years old. In the last 3 years, he has lost the ability to walk independently and uses his wheelchair full time. He needs assistance with all basic needs as his coordination and condition has deteriorated drastically. This has impacted his own independent physical needs and has impacted him socially.

Sofie M. Absolutely, almost daily my son pleads for a cure or a way to enhance his chance at living a better life. I would love to be able to give him that.

Stefan M. Yes, we want to take the medicine, because my daughter is very young and I wish her an easier life.

Stentelaire Soliman M. Because, it is the first time that a therapeutic try seems to work without bad effects. Sicks persons with Fiedreich don’t have the same time perception and suffer a lot. We have to respect their choice.
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<tr>
<th>Name</th>
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<tbody>
<tr>
<td>Steven M.</td>
<td>Want access in uk</td>
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<tr>
<td>Sunil M.</td>
<td>My daughter has not participated in the trial but given success of Reata in trials and no other medicine available, would request FDA to approve this on urgent basis.</td>
</tr>
<tr>
<td>Takis M.</td>
<td>Give us hope!Give our children their smile back again! Thank you ☺️</td>
</tr>
<tr>
<td>Tamires M.</td>
<td>Yes, because i believe that the Drug Will help my family member to feel good and it Will reduce the FA symptoms.</td>
</tr>
<tr>
<td>Teresa M.</td>
<td>To cure my daughter</td>
</tr>
<tr>
<td>Teresa M.</td>
<td>Yes, seems very positive results</td>
</tr>
<tr>
<td>Theotheoros M.</td>
<td>We would like to take the Omav for our children to delay the progression of this awful disease! Please help us</td>
</tr>
<tr>
<td>Therese M.</td>
<td>Yes! There are no form of treatment for people with FA. It is a terminal disease, and we really need a form of treatment as soon as possible!</td>
</tr>
<tr>
<td>Typhaine M.</td>
<td>Yes she has has FA for 33 years and it's so complicated that if something can change we will do it or take it!</td>
</tr>
<tr>
<td>Uliks M.</td>
<td>Praying for it</td>
</tr>
<tr>
<td>Uschi M.</td>
<td>My son is the victim and he did not participate in the study. nevertheless, he is impatiently waiting for omaveloxolone to finally be approved. He will of course be able to take the drug. It is eagerly expected of him - after all, the disease is progressing. For years we have wondered why it takes so long to find an effective therapy. We are all the more pleased about this initiative. Thanks!</td>
</tr>
<tr>
<td>Vilma M.</td>
<td>Yes, she wants to live, as normal as possible</td>
</tr>
<tr>
<td>Yonas M.</td>
<td>I want to spend time with my brother doing things that brothers should do and not being stopped by FA. The benefits of Omav outweighs another trial.</td>
</tr>
<tr>
<td>Alejandra N.</td>
<td>My family member want the option of taking this medicine based on the results and because there are not other treatment that works.</td>
</tr>
<tr>
<td>Alexandros N.</td>
<td>The patient would like the option of taking the drug. They haven't participated in any clinical trials.</td>
</tr>
<tr>
<td>Arjuna N.</td>
<td>Yes I would like to take a chance to use drug/medication to stop progress. But at the moment there is not available any thing in the world. It's very important to keep the nervesystem healthy. Please give the approval to save life's. Thank you</td>
</tr>
<tr>
<td>Cecylia N.</td>
<td>Of course my nephew would want the option of taking the medicine because it would be a great chance for him to save his health and even his life.</td>
</tr>
<tr>
<td>Christina N.</td>
<td>I would like them to have this option because maybe they would become well and live a normal life as they wish.</td>
</tr>
<tr>
<td>Claire N.</td>
<td>Yes - choice</td>
</tr>
<tr>
<td>Dimitar N.</td>
<td>Both my nephew and niece (age 25 and 33) suffer from FA and would like to take the medicine.</td>
</tr>
<tr>
<td>Elzbieta N.</td>
<td>Of course, my grandson would certainly take the medecine if he only could. There's no any other possibility to help him and cure FA.</td>
</tr>
<tr>
<td>Emma N.</td>
<td>Firstly, question 4 is stupid. It has been 4 years but she is very impaired. This is not FA lite! Question 5. Yes of course, anything to help this wretched disease.</td>
</tr>
<tr>
<td>Ernesto N.</td>
<td>Yes my 2 sons would take omaveloxolone, as they are only surviving as good and as long as possible and any treatment or medicine directed to improve their condition would be highly appreciated</td>
</tr>
<tr>
<td>Frank N.</td>
<td>Life expectations are poor. We need all the help we can get to develop a cure (for this rare disease.</td>
</tr>
<tr>
<td>Graham N.</td>
<td>My partner's little sister has the condition and would be more than happy to try anything if she taught it could help. She is a 17 year old girl living with the condition 15 years.</td>
</tr>
<tr>
<td>Gustavo De Andrade N.</td>
<td>Yes! My relative (P.) wants to use the medicine.</td>
</tr>
<tr>
<td>Jacileide N.</td>
<td>Yes I would like to see my brothers doing all the daily activities</td>
</tr>
<tr>
<td>Josefa Maria N.</td>
<td>YES, wish my son could take the medicine</td>
</tr>
<tr>
<td>Julie Lyn N.</td>
<td>The medication has a positive response to the patient</td>
</tr>
</tbody>
</table>
COMMENTS FROM FA COMMUNITY
Parents & Family Members Outside the US

Karlo N.
My family member has been recently diagnosed and it devastated whole family. First we stared searching and studying about the potential cure or medicine to help us somehow but none was found. Soon we realised that omaveloxolone exists and started learning more about it, watching experiences of patients taking it as well as going through the studies. It gave us hope and instilled optimism, a bit of positivity we really needed. For such rare diseases, anything showing signs of positive impact (omaveloxolone did much more than that) should be made available to the patients and therefore I kindly appeal to FDA, EMA and other authorities to consider approval of this rarely, but really much needed, medicine.

Kim N.
Absolutely. By chance this medication/treatment can provide our son a fulfilling life, where he is able to do the daily things many of us take for granted, he strongly desires this opportunity to try something (anything!). He has stated he’d rather have a shorter life if he was able to enjoy it than a longer life where he cannot move or even feed himself. We dream every day that FA can be cured and hope this treatment is approved to improve the every day of life for every FA patient. Should the FDA approve, our doctors in Canada will have strong supports to provide treatment here. Thank you all for your continue hard work, efforts and commitment.

Lidia N.
I would certainly want the option of my son taking omav due to convincing information concerning safety and efficacy of the drug. FA has changed my son a lot already both in terms of his physical and mental condition. As a parent I would be happy and relieved if the drug became available for my son and patients all over the world. Stopping the progression of this devastating disease (or making in slower) would certainly be a big step and a source of hope for all of us.

Mamodyly N.
FA is a debilitating neurodegenerative disease and makes my son suffer all along day and night. In consequence, I of course will accept my child to take Omaveloxone. Being given the opportunity to access Omaveloxone would give an improvement to every day life and also give much needed hope to live with this disease.

Marcelo N.
Yes. It will improve her life quality.

Maria N.
Yes, she wants

Maria N.
Both my nephew and niece suffer from FA and they would like to take the medicine.

Maria N.
Because my family and I are convinced that the results demonstrate meaningful benefit and low risk and would like our family member to have access to this medication. We believe that the studies completed to date provide sufficient evidence to support the approval of Omav.

Mark N.
Yes we want the option!

Peter N.
We are ready to participate on omav study at any time. Feel free to take the drug. Unfortunately, Bulgaria is not including in the study, I didn’t know about the same study. That is truly HOPE!

Renildo N.
Yes I would want that option

Selma N.
Yes, it seems to be efficient

Vanco N.
Yes...we want to try it cos is not any other options fot FA

Vedrana N.
Recent diagnose of my brother really hit us hard. My first reaction was fear, mostly of the unknown so informing and learning more was the best way to find some peace. Unfortunately, forecast isn’t really optimistic and the more you learn, more you worry. First and only ray of hope was omaveloxolone and after a thorough study we knew that this is something we need to get our hands on. I’m aware that caution is needed and that authorities need to be sure medicine won’t do any harm to people but from our perspective we’re totally convinced. Since alternative doesn’t exist we want to give omaveloxolone a try and kindly beg those in charge to ease the life for the patients and their families and to help us out in this life or death matter.

Volina N.
Both my cousins suffer from FA and they would like to take the medicine.

Witalis N.
I’ve got a grandson who suffers FA. I’m sure he would take omaveloxolone if it only was possible. It’s extremely difficult to see that some solution is near to come, but there are still some problems to legalise it. I really hope the medicine will be accessible to people who need it.

Abdelrhman O.
Yes I want and I have no clinical trials

Adriana O.
Yes. It’s a chance of having a better quality of life.

Aleksandra O.
Still waiting for miracle... The situation is really wrong... And Depression.

Alicia O.
My family members (2) want to try taking the medicine. Thank you!
## Comments from FA Community

### Parents & Family Members Outside the US

<table>
<thead>
<tr>
<th>Name</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Andre O.</td>
<td>I have two stepchildren with FA</td>
</tr>
<tr>
<td>Ann O.</td>
<td>Yes, both family members are young adults in late twenties, early thirties &amp; deserve the chance to avail of every possible treatment option for hope.</td>
</tr>
<tr>
<td>Audrey O.</td>
<td>This drug should be allowed to the people with FA in order for their lives can be improved</td>
</tr>
<tr>
<td>Bo O.</td>
<td>Yes. Seems safe to try.</td>
</tr>
<tr>
<td>Bonnard Gay O.</td>
<td>Given the promising results of omaveloxolone in patients with FA we are ready to try this drug for our son T. He has been living with FA for the past 10 years and has been followed by Dr. H.</td>
</tr>
<tr>
<td>Bruno O.</td>
<td>He want the option of taking the drug/medicine</td>
</tr>
<tr>
<td>Caio O.</td>
<td>Yes of course she would want to take the medicine.</td>
</tr>
<tr>
<td>Carla O.</td>
<td>My sister who is 17 has been living with FA since she was diagnosed at the age of 2, she needs help with all aspects of daily living and i know she would be willing to try anything if she thought it would even slightly help!</td>
</tr>
<tr>
<td>Celso Luiz O.</td>
<td>Yes we would like him to take omaveloxolone</td>
</tr>
<tr>
<td>Chantal O.</td>
<td>My nephew suffers from this scary disease. Let all people suffering from FA use this medicine. How is it possible! If the medicine is available, let it be for all patients!!! If FA was more frequent, the medicine would have been approved faster. Think of Covid-19 vaccines!! Help FA!</td>
</tr>
<tr>
<td>Christine O.</td>
<td>saw the effects that the tablets had on the participators i was amazed the difference that they made this would give my daughter a better quality of life. she could hopefully take her children to school and maybe cook a meal for the family.</td>
</tr>
<tr>
<td>Ciara O.</td>
<td>haven’t taken the moxie yet</td>
</tr>
<tr>
<td>Cristina O.</td>
<td>Given The results of The trials my family member would absolutely start taking the medicine in order to prevent the disease from developing abruptly. We would be delighted if we could start this journey at the earliest time possible because it would radically improve my family member’s health.</td>
</tr>
<tr>
<td>Dolores O.</td>
<td>My son would take it, of course, any point of hope is better than living without seeing a future for your son.</td>
</tr>
<tr>
<td>Elisangela O.</td>
<td>My sister was diagnosed in 2018, she walks on a walker and sometimes in a wheelchair, she feels pain and cramps in her legs, her progress has advanced a lot over the years and she needs the medicine a lot.</td>
</tr>
<tr>
<td>Esmeralda O.</td>
<td>Yes, because it’s the only option my nephew has</td>
</tr>
<tr>
<td>Hazel O.</td>
<td>Yes we are willing, no more trialing needed</td>
</tr>
<tr>
<td>Helen O.</td>
<td>Yes, we hope that it will improve the health.</td>
</tr>
<tr>
<td>James O.</td>
<td>My daughter would like to have the chance to test omaveloxolone.</td>
</tr>
<tr>
<td>Janelle O.</td>
<td>Absolutely. Any chance to help find a cure for FA.</td>
</tr>
<tr>
<td>Jean-Michel O.</td>
<td>Hope in efficacy for disathry and dysphasy.</td>
</tr>
<tr>
<td>Jeannie-Marie O.</td>
<td>Absolutely, because this treatment is an opportunity to develop a treatment. As quoted; ‘it would be difficult to carry out another pivotal study in FA, given the disorder’s slow progression, the small number of patients and trial investigators currently available to participate in studies, and limitations imposed by the COVID-19 pandemic’ (Joana Carvalho, PHD., 2020). In addition, ‘conducting a new pivotal trial at this point would delay the availability of omaveloxolone, a potentially effective therapy to treat people with progressive FA who have no other treatment options.’ (Joana Carvalho, PHD., 2020). References: Joana Carvalho, PHD., 2020., The News. <a href="https://friedreichsataxianews.com/news-posts/2020/08/13/reata-fara-physicians-propose-crossover-study-confirm-omaveloxolone-effectiveness/">https://friedreichsataxianews.com/news-posts/2020/08/13/reata-fara-physicians-propose-crossover-study-confirm-omaveloxolone-effectiveness/</a></td>
</tr>
<tr>
<td>Jo O.</td>
<td>Yes, most definitely!</td>
</tr>
<tr>
<td>João O.</td>
<td>Yes, I want to take omaveloxolone</td>
</tr>
<tr>
<td>Lena O.</td>
<td>Our daughter is extremely positive to try omaveloxolone based on the findings in previous trial</td>
</tr>
<tr>
<td>Lisa O.</td>
<td>Yes, our family member would like the option of taking the drug/medicine to help with her condition.</td>
</tr>
<tr>
<td>Name</td>
<td>Comment</td>
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</tr>
<tr>
<td>Lucimeire O.</td>
<td>Yes. I want to take omaveloxolone</td>
</tr>
<tr>
<td>Luzinete O.</td>
<td>Yes, I would like to take MOXiE</td>
</tr>
<tr>
<td>Marcus O.</td>
<td>Yes. Seems safe to try.</td>
</tr>
<tr>
<td>Maria Lucileide O.</td>
<td>Yes, it would certainly help to lessen the impact of degenerative disease.</td>
</tr>
<tr>
<td>Marina Maria B. O.</td>
<td>Yes, I would like it very much</td>
</tr>
<tr>
<td>Marizangela Franco De O.</td>
<td>Yes. To have a better quality of life.</td>
</tr>
<tr>
<td>Marleen O.</td>
<td>Yes, sure</td>
</tr>
<tr>
<td>Marlene O.</td>
<td>My cousin have FA since she was a LITTLE girl. Thais for everything.</td>
</tr>
<tr>
<td>Miriam O.</td>
<td>We don't know this drug. But if benefical we would like to have it</td>
</tr>
<tr>
<td>Nils O.</td>
<td>Sure we would, we would do anything that helps.</td>
</tr>
<tr>
<td>Olga O.</td>
<td>Yes, so that he can get better.</td>
</tr>
<tr>
<td>Ray O.</td>
<td>Yes we are willing, no more trials</td>
</tr>
<tr>
<td>Reginaldo O.</td>
<td>Yes, I want to take omaveloxolone</td>
</tr>
<tr>
<td>Renata O.</td>
<td>My daughter needs assistance for all activities of daily living. And taking omaveloxolone will improve many special moves that she is losing day by day</td>
</tr>
<tr>
<td>Robert John O.</td>
<td>This is the best thing i have seen for years and would love to see my daughter able put a little bit of a holt on this horrible disease, please accept this letter</td>
</tr>
<tr>
<td>Sabrina O.</td>
<td>Yes. We would like to have access to the drug in order to experience possible benefits that the drug may present, since there are no alternative drug options for treatment.</td>
</tr>
<tr>
<td>Samuele O.</td>
<td>I agree with the distribution of the drug</td>
</tr>
<tr>
<td>Sandra O.</td>
<td>Yes my daughter would love the opportunity to take this drug</td>
</tr>
<tr>
<td>Yasen O.</td>
<td>Certainly will do but of course it is the patient decision after all.</td>
</tr>
<tr>
<td>Arzu Ö.</td>
<td>Did not take part in this study, but would like this medicine to be tested here in Germany. So that people with this disease also have a chance to get well.</td>
</tr>
<tr>
<td>Claudio Giuseppe P.</td>
<td>Yes of course</td>
</tr>
<tr>
<td>Adamilson P.</td>
<td>Yes, I want to take omaveloxolone</td>
</tr>
<tr>
<td>Ademilson P.</td>
<td>My cousin</td>
</tr>
<tr>
<td>Afroditi P.</td>
<td>And of course I would like it for my children since there is no approved treatment. They did not participate anywhere</td>
</tr>
<tr>
<td>Agustina P.</td>
<td>My daughter need a drug.</td>
</tr>
<tr>
<td>Albjona P.</td>
<td>Yes. This would be life changing for my sister</td>
</tr>
<tr>
<td>Alexandra P.</td>
<td>They would like the option of taking the drug</td>
</tr>
<tr>
<td>Allies P.</td>
<td>FA IS TERRIBLE DISEASE, THAT GIVES MY NIECE LESS INDEPENDENCE IN HER LIFE.</td>
</tr>
<tr>
<td>Name</td>
<td>Comment</td>
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<tr>
<td>---------------</td>
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</tr>
<tr>
<td>Amelie P.</td>
<td>Yes. The results are probing and will give us time and hope for a cure in a near future. Also a better quality of life for my son meanwhile.</td>
</tr>
<tr>
<td>Anastasia P.</td>
<td>I know that my family member would take the medicine.</td>
</tr>
<tr>
<td>Andrea P.</td>
<td>I agree with the distribution of the drug</td>
</tr>
<tr>
<td>Ann Marie P.</td>
<td>If the drug has no side effects and slows the progression of the disease then it should be considered for approval</td>
</tr>
<tr>
<td>Annabel P.</td>
<td>Yes - my two relatives are in their teens, they are intelligent, have been sporty/active, have participated in voluntary charity events, &amp; if a drug would provide improved longevity for life’s activities, their independence &amp; a better quality of life for as long as possible, (or perhaps delay the worst of the debilitating effects until even a cure) then it should be available ASAP.</td>
</tr>
<tr>
<td>Annaluisa P.</td>
<td>My son would like to be able to take the MOXile, hoping it can slow down AF, pending a possible future definitive therapy.</td>
</tr>
<tr>
<td>Archana P.</td>
<td>Need this medicine for my friend asap</td>
</tr>
<tr>
<td>Arjana P.</td>
<td>Yes that would be a great oppurtunity for my daughter</td>
</tr>
<tr>
<td>Aslian P.</td>
<td>Yes, that would be a great chance for my sister</td>
</tr>
<tr>
<td>Asteria P.</td>
<td>my children would take the drug</td>
</tr>
<tr>
<td>Bert P.</td>
<td>Absolutely! Considering there is no alternative and the proven safety of Omaveloxolone I don’t see any reason for not approving this therapy. If it was only for slowing or stopping the progression it will be worth all the effort to get Omav on the market.</td>
</tr>
<tr>
<td>Brenda P.</td>
<td>?Receive?</td>
</tr>
<tr>
<td>Chamucia P.</td>
<td>Because i believe that the omaveloxolone it’s safe and will minimize daily criticism, will give more self-confidence, will give more freedom of life and will also minimize the consequences of bulling</td>
</tr>
<tr>
<td>Charulata P.</td>
<td>Needs medicines as early as possible</td>
</tr>
<tr>
<td>Christine P.</td>
<td>Yes they would like that option.</td>
</tr>
<tr>
<td>Christos P.</td>
<td>yes because it help the research</td>
</tr>
<tr>
<td>Chrysovalantis P.</td>
<td>I want 5o have the chance to try this medication</td>
</tr>
<tr>
<td>Cindy P.</td>
<td>Absolutely. With a recently diagnosed daughter(11), it’s already progressed. Time is not on our sides, and if this drug can help, even in a small way, it’s a step that FA didn’t have before. Nobody wants to see their child, full of life, deteriorate, be robbed of so much. It’s a pain that I have not found words for. It crushes my soul to the core, to think of what is coming with advanced FA. So please say yes. For K., and everyone else with FA they really have nothing to lose and so much to gain.</td>
</tr>
<tr>
<td>Claire P.</td>
<td>My niece is 22. She has her whole life ahead of her and if this drug made her life a little easier as I feel it could I want her to be able to get access to the drug.</td>
</tr>
<tr>
<td>Clelia P.</td>
<td>I have watched my granddaughter’s mobility, fine motor-skills and diction deteriorate during the four years since investigations leading to her diagnosis began. Her intellect, creativity, sense of humour and love of life have not diminished. Anything that would extend her ability to live her life as freely as possible has my support.</td>
</tr>
<tr>
<td>Cristina P.</td>
<td>Yes I want to take drug</td>
</tr>
<tr>
<td>Dafni P.</td>
<td>It’s her only opportunity at the moment so of course</td>
</tr>
<tr>
<td>Daniela P.</td>
<td>Omaveloxolone is the first drug to show significant improvement of neurological function across several clinical measures in people with Friedreich’s ataxia (FA) and it has proven safe and well tolerated. When afflicted by such a debilitating disease small improvements can make the world of difference to a person’s quality of life.</td>
</tr>
<tr>
<td>Dave P.</td>
<td>He would</td>
</tr>
<tr>
<td>David P.</td>
<td>If my nose was able to receive this medication it could potentially slow it down or even stop it but if she keep on going the way she is now she will probably be dead in ten years or early she does have muck to lose by trailing it</td>
</tr>
<tr>
<td>Name</td>
<td>Comment</td>
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</tr>
<tr>
<td>Davina P.</td>
<td>If the drug was available for our daughter to take we wouldn’t hesitate to have her take it. It’s been 3 years since she was diagnosed, and it’s heartbreaking watching her go from a kid who danced, did gymnastics, participated in junior lifesaving - albeit, slightly clumsily, to an adolescent who has to hang into my arm when we go out, and who is being fitted for her first wheelchair. Managing her day around her fatigue levels, seeing how much independence she's lost, feeling nervous every time she offers to cut up the vegetables for a salad, and catching glimpses of the bruises that dot her legs, the result of bumps and falls is exhausting for us as her parents, and a constant reminder that without a drug that will cure, or at least stall this disease, that it’s only going to get worse. Omaveloxolone is a drug that will buy us time. And time is the most precious gift we can ask for.</td>
</tr>
<tr>
<td>Despoina P.</td>
<td>My family member would like the drug</td>
</tr>
<tr>
<td>Diane P.</td>
<td>Absolutely, it should be available As soon as possible to all patients. The data provided by part one and part two of the study along with the open label extension shows significant statistical improvement when looking at the activities of daily life and measures on the FARS Scale. This is adequate and sound proof of the efficacy of MOXie.</td>
</tr>
<tr>
<td>Dimitris P.</td>
<td>My child would like this option.</td>
</tr>
<tr>
<td>Elane P.</td>
<td>Yes, i would like to take the remedy</td>
</tr>
<tr>
<td>Elena P.</td>
<td>Yes the drugs is need for my daugther, actually She havent any treatment.</td>
</tr>
<tr>
<td>Elisane P.</td>
<td>Omaveloxolone is necessary to improve the patient’s quality of life!</td>
</tr>
<tr>
<td>Eoghan P.</td>
<td>Yes, can improve the quality of life and possibly reverse some of the effects of FA</td>
</tr>
<tr>
<td>Eri P.</td>
<td>I know that my family member would take this drug</td>
</tr>
<tr>
<td>Evert P.</td>
<td>My family member would like to take the drug/medicine</td>
</tr>
<tr>
<td>Fabia P.</td>
<td>Yes, i would like him to take the medecine</td>
</tr>
<tr>
<td>Francesco P.</td>
<td>Yes, I would the option of taking the medicine for my child.</td>
</tr>
<tr>
<td>Freya P.</td>
<td>She wants the option of taking this but it’s not available in our country</td>
</tr>
<tr>
<td>Gatty P.</td>
<td>Yes, of course, we would try it.</td>
</tr>
<tr>
<td>Genevieve P.</td>
<td>yes, it is important to be able to take this drug which is currently the only one that can have an effect on FA</td>
</tr>
<tr>
<td>George P.</td>
<td>I would want to have the option of trying every possible treatment in order to achieve a quality of life improvement.</td>
</tr>
<tr>
<td>George P.</td>
<td>Yes, I’d prefer my family member to take this medicine for a best future.</td>
</tr>
<tr>
<td>Gustavo P.</td>
<td>My cousin is 29. Omaveloxolone is his only chance in life!</td>
</tr>
<tr>
<td>Inge P.</td>
<td>Yes absolutely it’s the only medicine for FA at the moment what have good results and we hope that’s stop our daughter her disease so she feels better and we hope she don’t need a wheelchair always.</td>
</tr>
<tr>
<td>Inis P.</td>
<td>You have to try anything</td>
</tr>
<tr>
<td>Ioannis P.</td>
<td>My child has FA and due to the severity of their condition they would like to take the drug as soon as possible. We are not sure whether the drug would immediately reach our country IMMEDIATELY if it got a rejection from the FDA so we implore them to reconsider.</td>
</tr>
<tr>
<td>Isabel P.</td>
<td>Now</td>
</tr>
<tr>
<td>Ivan P.</td>
<td>I would like my daughter can improve her quality of life. By taking the medicine there are chances to improve her medical condition and her independence. She has not had the opportunity to participate in the MOXie part 1 or neither 2.</td>
</tr>
<tr>
<td>Jaap P.</td>
<td>Yes, I am aware of side effects and have seen the positive results in scores. Want to use it!</td>
</tr>
<tr>
<td>Janet P.</td>
<td>Yes, due to there being no other treatment available and the relatively small numbers of people with FA meaning large studies are difficult todo</td>
</tr>
<tr>
<td>Jim P.</td>
<td>Yes, I’d prefer my family member to take this medicine for a best future.</td>
</tr>
<tr>
<td>Jociane P.</td>
<td>Yes, because she need to have a better quality of life. And she needs to walk again.</td>
</tr>
</tbody>
</table>
Kenny P. Yes absolutely would give the drug to my daughter. There is nothing currently available treatment wise for her and she is deteriorating as the months pass and it is heartbreaking that we have nothing available to help slow down this monster of a disease.

Laurie P. My cousin would benefit from omaveloxolone

Lindsay P. Yes, anything that will help my cousin live out his life with the best quality possible.

Lucia P. Me and my family are forced to sign this letter and share that omaveloxolone can be administered to anyone who constantly fight against symptoms of FA for 10 years, like my dear son. We mustn’t let this disease destroy not only their bodies but overall their minds. So, if this drug is the only way to bring them to live a new and a better life, it is dutiful to introduce this option.

Lucija P. I want him to have something to hope for, something that will at least help a little bit with symptoms

Maja P. Yes, we are willing to take this medicine. We want to help our child whatever we can

Margarita P. Yes, I’m participantes in the MOXie part 1, part 2 or Open label extensión study

Maria P. Of course I would give omaveloxolone to my sister, the results are perfect, we want this treatment

Maria P. Yes. My niece wants to take omaveloxolone. She has been living with symptoms of for >15 years and requires assistance with all activities of daily living.

Maria Carolina P. I don’t know

María P. Yes my daughters souls take it

Mark P. Not enough being done, help ready available.

Maya P. The girl is 20 and needs assistance in daily life. It’s sad.

Maysa P. It decreases the progress of the disease, allowing the individual to be less dependent on people, contributing to a better future for FA

Michelli Cassiana P. Yes, I would like to take moxie medicine.

Millena P. Omaveloxolone is necessary to improve the patient’s quality of life!

Neil P. Yes, little other options

Neima P. Yes, because based on the available information, I believe that omaveloxolone is safe and effective for the treatment of Ataxia, which will result in the improvement of my motor coordination (a symptom of Ataxia). In addition, the treatment will minimize daily criticism and the consequences of bullying, increasing my self-confidence and giving me freedom of life.

Nicky P. Yes, certainly after years of neglect by the powers that be

Patriciana P. I’m sure my Nephew will want to try anything to improve his life.

Paulo Alexandre P. Yes, because of the dependantse of other people to take care of it for almost everything.

Perla P. To maintain a better quality of life. Didn’t take the amoxie

Rex P. Most definitely...due to the fact that we as a family and me as a father believes that anything is worth a try... We are desperate.

Richard P. Yes, would want the option. Have participated in a number of trials over the years but she now appears to be excluded from recent trials because of her age. My niece has lived with FA for 33 years and we are desperate for any help we can get

Saionara P. Yes, because it presents improvements to patients, and it is a hope for those who want to walk again

Sandy P. Yes, we really need to try this.

Shona P. Yes, got nothing to lose

Soledad P. Because I am convinced that it will help my cousin with proven effects and with a low risk

Sonia Regina P. Never participated in any tests, but if possible, would use the medicine
<table>
<thead>
<tr>
<th>Name</th>
<th>Comment</th>
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<tbody>
<tr>
<td>Sotiria P.</td>
<td>My child would like the option of taking the drug, based on the current results.</td>
</tr>
<tr>
<td>Stefania P.</td>
<td>Yes. It seems to be a promising way. Need to go deeper. Moreover better than doing nothing as now.</td>
</tr>
<tr>
<td>Stella P.</td>
<td>Yes, I'd prefer my family member to take this medicine for a best future.</td>
</tr>
<tr>
<td>Stephen P.</td>
<td>Yes. Any improvement in current life would be appreciated.</td>
</tr>
<tr>
<td>Susan P.</td>
<td>Yes, this is such a debilitating disease we must act now to help stop it from ruining the beautiful lives of our loved ones. Our daughter was diagnosed at 12yrs of age and my husband and I have been carers for her for 32 years, to watch her lose all her dependency and also her sight is incredibly hard for all of us. If this can help her and all the others struggling with the effects of this debilitating disease we welcome it with open arms. ❤️</td>
</tr>
<tr>
<td>Tamires P.</td>
<td>Never participated in any tests, but if possible, would use the medicine.</td>
</tr>
<tr>
<td>Teodora P.</td>
<td>Yes, I would.</td>
</tr>
<tr>
<td>Thomai P.</td>
<td>YES, I'D PREFER MY FAMILY MEMBER TO TAKE THIS MEDICINE FOR A BEST FUTURE.</td>
</tr>
<tr>
<td>Valentina P.</td>
<td>Yes, I would like my sister to have the option to take the drug, we feel we have been waiting several years for this drug to be approved and we feel confident and ready that the time has come.</td>
</tr>
<tr>
<td>Wendy P.</td>
<td>Yes, I would like my niece to be able to take this drug ASAP.</td>
</tr>
<tr>
<td>Wieske P.</td>
<td>I want it for my sister she has FA</td>
</tr>
<tr>
<td>Avrhi P.</td>
<td>YES, I'D PREFER MY FAMILY MEMBER TO TAKE THIS MEDICINE FOR A BEST FUTURE.</td>
</tr>
<tr>
<td>Julie Q.</td>
<td>Yes, they need to increase quality of life and this drug will give them a chance.</td>
</tr>
<tr>
<td>Pierre Q.</td>
<td>For my child, I do want the option of taking such drug, omaveloxolone, that eventually help to ease his living.</td>
</tr>
<tr>
<td>Aasiyah R.</td>
<td>Yes. For better self esteem is better well being</td>
</tr>
<tr>
<td>Adriana R.</td>
<td>Yes. It is an opportunity and hope for a better life for my beloved cousin</td>
</tr>
<tr>
<td>Alberto R.</td>
<td>Yes, i Absolutely agree, i would like that my son Will take this medicine as Soon as possible.</td>
</tr>
<tr>
<td>Alesia R.</td>
<td>Yes of course it's life changing</td>
</tr>
<tr>
<td>Alexandra R.</td>
<td>My friend cousin is 11 years old. She was diagnosed with FA when she was 5 years old. Throughout the years she had been getting worst. Right now she needs a walker to walk but it is still hard for her. The medicine will help her a lot physically and emotionally. She will have bigger hopes on walking again!</td>
</tr>
<tr>
<td>Alexandre Wagner Vieira R.</td>
<td>Yes. It's so urgent and important for all with Fara .</td>
</tr>
<tr>
<td>Aliasger R.</td>
<td>If getting this medicine will help my brother than that's a bonus. We can do things more like we use to before.</td>
</tr>
<tr>
<td>Alicia R.</td>
<td>Of course she would take the medicine</td>
</tr>
<tr>
<td>Almeida R.</td>
<td>yes, she wants to take the medicine</td>
</tr>
<tr>
<td>Ana Maria R.</td>
<td>They want to take the drug/medicine</td>
</tr>
<tr>
<td>Andrea R.</td>
<td>Absolutely with result slowing the progression, every extra day is critical for my family.</td>
</tr>
<tr>
<td>Name</td>
<td>Comment</td>
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<tr>
<td>------------------------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Anne R.</td>
<td>Allow Individuals with Friedreich Ataxia Access to Omaveloxolone</td>
</tr>
<tr>
<td>Annette R.</td>
<td>I think she will use the medicine because she asked me to sign this form.</td>
</tr>
<tr>
<td>Antonio R.</td>
<td>Yes, I would like to take the medicine</td>
</tr>
<tr>
<td>Aurélie R.</td>
<td>Yes, I would like my children to have access to this medicine</td>
</tr>
<tr>
<td>Beverley R.</td>
<td>My niece wants to have the option of taking the drug/medicine as she is a young girl of 19. She is bright and caring. She currently is at university with the help of her carer, but has had episodes whilst there. Its very upsetting for the family. I really hope this drug/medicine is made available in the UK soon.</td>
</tr>
<tr>
<td>Bianca R.</td>
<td>We need this petition to be accepted because it will help a lot in the quality of many people who have suffered from this pathology for years, we believe in the evolution of a treatment! And we need it urgently!</td>
</tr>
<tr>
<td>Carolina R.</td>
<td>We need to get it approved as soon as possible because I have 2 boys with FA and it is a rapidly progressive disease, they already use a wheelchair and have hypertrophic cardiomyopathy</td>
</tr>
<tr>
<td>Carolina R.</td>
<td>Yes, I would take it. This is the first promising medicine to stop the progression of this disease</td>
</tr>
<tr>
<td>Carolina R.</td>
<td>Yes she would</td>
</tr>
<tr>
<td>Catalina R.</td>
<td>Yes, of Course. We don’t want to lose Any time more. Se can not wait.</td>
</tr>
<tr>
<td>Catherine R.</td>
<td>Yes time is running out for these two young beautiful adults</td>
</tr>
<tr>
<td>Chloe R.</td>
<td>Yes my sister would take the drug to bring back some independence back into her life</td>
</tr>
<tr>
<td>Ciaran R.</td>
<td>Yes, the results are very encouraging</td>
</tr>
<tr>
<td>Darren R.</td>
<td>Yes he is willing to take it</td>
</tr>
<tr>
<td>Débora R.</td>
<td>Yes, we are already convinced and confident about efficacy of omaveloxone.</td>
</tr>
<tr>
<td>Dex R.</td>
<td>Yes, any glimmer of hope is welcome</td>
</tr>
<tr>
<td>Diego Alejandro R.</td>
<td>Yes they want. As we evidenced in the first testing waves, results are insane! There are no issues with drugs so far. Additional, this drug is focused only in FA. So, make easier distribution processes could help saving too much lives! Please</td>
</tr>
<tr>
<td>Dipika R.</td>
<td>We need to have omav-moxi as soon as possible</td>
</tr>
<tr>
<td>Domenica R.</td>
<td>I agree with the distribution of the drug</td>
</tr>
<tr>
<td>Donna R.</td>
<td>Yes so that independence may return</td>
</tr>
<tr>
<td>Dorival R.</td>
<td>Do not participate, only follow the clinicas trial</td>
</tr>
<tr>
<td>Dorothy R.</td>
<td>Yes so as to have a better quality of life</td>
</tr>
<tr>
<td>Eliane R.</td>
<td>Yes ... at the moment it is our hope!</td>
</tr>
<tr>
<td>Elizabeth R.</td>
<td>Yes as deteriorating fast</td>
</tr>
<tr>
<td>Esther R.</td>
<td>The FDA should approve the release of the drug because there is currently no approved drug that shows that it is capable of having any benefit for the disease. However, omaveloxolone has been shown to slow the disease in their studies, and knowing that AF patients do not have any medication, no matter how little benefit omaveloxolone provides, it should be approved.</td>
</tr>
<tr>
<td>Fabiana R.</td>
<td>Yes. If there is a chance to reverse, stagnate, alleviate or better yet, cure this disease, it is worth the use. I believe in science, in scientists, in God! Please make it available to all interested parties, depending on being from the USA. Appreciate! God bless them!</td>
</tr>
<tr>
<td>Felipe R.</td>
<td>Yes. This is a hope for my mother. She’s 66 yo and has weak bones. Every time she falls we got really concerned if she broke anything. Her mental health is not good. She’s depressed and deserves any hope.</td>
</tr>
<tr>
<td>Fernanda R.</td>
<td>To improve the quality of life of people with ataxia, it would be of great help and something fundamental</td>
</tr>
<tr>
<td>Flavia R.</td>
<td>My cousin had FA and he wants the option of taking the medicine.</td>
</tr>
<tr>
<td>Geovanna R.</td>
<td>Yes, it would be extremely important to bring the medicine to Brazil, making it possible for low-income people to have access to the medicine.</td>
</tr>
</tbody>
</table>
Gotthard R.  Of course she would take the medicine
Guilherme R.  My relative would like to be part of the study with omaveloxolone
Hilde R.  Yes, my niece would be so happy if there is an medication for this horrible disease. She has been bullied, made fun of etc. And I would do anything for her to make her life better.
Ignacio R.  This medicine had shown to produce remarkable improvements on the patients taking it.
J R.  Yes, my family member would like to have the option to take the drug/medicine. There is no other cure yet. This is the only hope for my family. And my family member is such a great, positive and lovely young woman.
Jefferson R.  yes, because it would be the first and only treatment available in the world for AF
Jhon Calisto R.  Yes she wants
Jigesh R.  Need omav as soon as possible
Joel R.  Yes because without omaveloxolone, what other option is there? If there is research to support the effectiveness of the drug, and no other hope, then there is no doubt in my mind, and anyone who would disagree cannot fully grasp the situation many FA sufferers find themselves in.
Jorge R.  Yes, i would
Julio Alberto R.  To improve his current situation !!
Juzer R.  My son was on interferon gamma and we saw improvements with his ability to do things as he didn't fatigue as much it increased his quality of life. Yes we would take Omaveloxolone to help slow this devastating disease.
Karl R.  It’s time to have something against FA and have some hope.
Katherine R.  Yes, my mum would want to try it
Ken R.  Yes.Any chance of help is better than none.
Laura R.  I would like this and other drugs to be available in order to slow down the progression and / or cure the disease.
Leandro R.  Illness going on.
Liz R.  Yes we would 100% want the opportunity to have Omaveloxolone available. It was such a distressing thing to have our then 5 year old diagnosed with FA. The most upsetting part was being told that there was no treatment available for such a serious, progressive and life limiting disease. The results of Omaveloxolone provide a light and hope for our family, in what has been a very bleak time. Omaveloxolone has the ability to give our 6 year old, V., the chance to have a better quality of life. Time is not on our side with this disease. In one year our son has gone from walking unaided, to a walker, to a manual chair and just last month we were told that he will need an electronic wheelchair to enable him to make the journey to school and back. He has started to choke on his food and drink and looks at us helplessly when having one of these episodes. His passion is reading and story telling - he taught himself to read at the age of 3 and a half, but his speech is slowing down and he can’t do all the voices for the different characters like he used to. He watches his friends playing in the playground, longing to join in but his body is too fatigued. Our children are deteriorating day by day and seeing their hopes and dreams for the future becoming less attainable. Knowing there is a medication out there to help is life changing. Our 6 year old asks daily whether anyone has found a way to help his wobbly legs yet and the answer is yes! We are so thankful for all the work that has gone into Omaveloxone and urge the FDA to consider approving it as a treatment for FA, giving children like V. the chance to have a better quality of life.
Lorraine R.  Yes I would want the option of taking the drug. Research progress requires that type of option. Research is the only hope for FA diagnosed. As long as the omaveloxolone gives a hope of improvement against the disease, even little, we have to try.
Luise R.  Yes of course she would take the medicine
Lynn R.  My son would welcome this new drug the sooner the better before he deteriorates even more
Macarena R.  My cousin’s child will take the drug if its available.
Mags R.  I would love for my child to live a normal life. I know she would love to participates
<table>
<thead>
<tr>
<th>Name</th>
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<tbody>
<tr>
<td>Manfred R.</td>
<td>Yes, we would take the medicine. It’s hard to find something for this dissesse.</td>
</tr>
<tr>
<td>Manuel R.</td>
<td>I live far from my family and I am unaware of the specific medications I take</td>
</tr>
<tr>
<td>Manuel R.</td>
<td>Yes, because I’ve got nothing to lose and everything to win</td>
</tr>
<tr>
<td>Mario R.</td>
<td>If we will take the option, it is our only chance. Time moves on and we must do something</td>
</tr>
<tr>
<td>Mark R.</td>
<td>Yes. For all the reasons in the Letter</td>
</tr>
<tr>
<td>Martin R.</td>
<td>My daughter and me as parent want the option of taking Omaveloxolone as soon as possible. We strongly believe that Omaveloxolone can have a real positive impact for people living with FA.</td>
</tr>
<tr>
<td>Mary R.</td>
<td>This would be amazing as it would help my daughter out tremendously.</td>
</tr>
<tr>
<td>Mary R.</td>
<td>Yes. Results look very promising</td>
</tr>
<tr>
<td>Matias R.</td>
<td>Best of the best</td>
</tr>
<tr>
<td>Matthew R.</td>
<td>Would give my mother in law an opportunity to live a normal life</td>
</tr>
<tr>
<td>Maurice R.</td>
<td>Yes (satisfied with the outcome of trials to date)</td>
</tr>
<tr>
<td>Michael R.</td>
<td>This would be a brilliant thing as it would help my daughter enormously.</td>
</tr>
<tr>
<td>Michele R.</td>
<td>Yes i would</td>
</tr>
<tr>
<td>Michel R.</td>
<td>My cousin is a young woman, who has lost her youth and is losing her adult life due to the disease. Very sad.</td>
</tr>
<tr>
<td>Mirko R.</td>
<td>I agree with the distribution of the drug</td>
</tr>
<tr>
<td>Nicolle R.</td>
<td>It is important give a chance with this medicine to all people with Ataxia desease around the world. For this reason Im applying to you this request for my cousin treatment and for her family. Give her a little bit hope to change her life and mobility to do the simple things in the life.</td>
</tr>
<tr>
<td>Oscar R.</td>
<td>My parent need the medicine for a a better style of live in day to day routines.</td>
</tr>
<tr>
<td>Pamela R.</td>
<td>Yes i would</td>
</tr>
<tr>
<td>Patricia R.</td>
<td>Yes, she would want to take the medicine because it will help her dealing with the disease</td>
</tr>
<tr>
<td>Patricia R.</td>
<td>Yes, this would give her a chance</td>
</tr>
<tr>
<td>Paulo R.</td>
<td>J. need to try this new medicine otherwise his situation will be worse and very poor life condition</td>
</tr>
<tr>
<td>Peter R.</td>
<td>My son was first diagnosed at 18 years of age. He is now age 50. He lives at home with me and his mother. He has dutifully followed all the advice provided by medical practitioners but has reached the stage where he now requires assistance in all his daily activities. He has fought against the effects of the illness and even worked part-time. Both his parents are octogenarians. Omaveloxolone is the only drug that has shown significant promise for Friedreich Ataxia patients and the studies relevant to this drug suggest that it can be beneficial, even though it may have only a stabilising effect on some sufferers. Such an effect would provide great relief to elderly carers who hold great fears for the future of a suffering child threatened with further deterioration and left without family support.</td>
</tr>
<tr>
<td>Piero Giovanni R.</td>
<td>Yes I want</td>
</tr>
<tr>
<td>Popescu R.</td>
<td>we are experience a cure with entraverine. we didn t participate at Moxle.</td>
</tr>
<tr>
<td>Priscila R.</td>
<td>No yet. He is trying to take</td>
</tr>
<tr>
<td>Raul R.</td>
<td>For all the patients so they have the opportunity to try a new and possible alternative that helps them improve their quality of life</td>
</tr>
<tr>
<td>Raymund R.</td>
<td>Yes, because time is running out for L. and R.</td>
</tr>
<tr>
<td>Sabine R.</td>
<td>Of course my daughter would take the medicine.</td>
</tr>
<tr>
<td>Sakina R.</td>
<td>Yes, we would still take the medicine as something is better than nothing. Plus long term side effects aren’t as important as quality of life and being able to do more presently.</td>
</tr>
<tr>
<td>Sally R.</td>
<td>yes please, especially as it can slow FA down</td>
</tr>
<tr>
<td>Name</td>
<td>Comments</td>
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</tr>
<tr>
<td>Sâmia R.</td>
<td>My cousin has FA and would like to have the option of taking the medication.</td>
</tr>
<tr>
<td>Sarah R.</td>
<td>It would give my mum a chance to live a normal life/enjoy time with grandchildren.</td>
</tr>
<tr>
<td>Sarah R.</td>
<td>Yes, the results of the trials are very encouraging.</td>
</tr>
<tr>
<td>Sergio R.</td>
<td>Yes, absolutely. 4 members of my direct family has this sickness and one of them has passed away. Please any help to find a cure or relief for this disease. I fully support.</td>
</tr>
<tr>
<td>Shaun R.</td>
<td>I believe that this is an option to give my family member a chance to better their health and living condition, if it could be an answer to that so be it and may god help them to become a solution to this condition.</td>
</tr>
<tr>
<td>Simone R.</td>
<td>Yes we are desperate for my brother to have a quality live to raise his son.</td>
</tr>
<tr>
<td>Stephan R.</td>
<td>This is not necessarily for my child but I am also involved in a Patient Advocacy Group in France comprising of 1000 Members.</td>
</tr>
<tr>
<td>Tanja R.</td>
<td>Yes, my family member would take the drug.</td>
</tr>
<tr>
<td>Teja R.</td>
<td>Yes, it is the only real option available and we deserve the opportunity to trial something which means that our family may get more time, or even time that is of a greater quality, with my husband.</td>
</tr>
<tr>
<td>Teresa R.</td>
<td>Yes, I would love to have this option because I hope it will give results.</td>
</tr>
<tr>
<td>Thomas R.</td>
<td>Of course they would take the medicine</td>
</tr>
<tr>
<td>Valeria R.</td>
<td>Yes. My cousin want to take the medication</td>
</tr>
<tr>
<td>Valeria R.</td>
<td>I am asking that this drug will be available to all people living with FA</td>
</tr>
<tr>
<td>Walter R.</td>
<td>No! Too young to be a Guinea pig!!</td>
</tr>
<tr>
<td>Yerra R.</td>
<td>Yes I would like the drug to be administered</td>
</tr>
<tr>
<td>Yusuf R.</td>
<td>Yes. It will give my nephew a better chance in life to improve his lifestyle and give him opportunity to do things by himself and be able to be more independent. Stop the degeneration and try to get more of a normal life rather then getting worse with overtime. This will be the best thing that would happen to the FA community. I beg FDA to expedite the approval.</td>
</tr>
<tr>
<td>Adriana S.</td>
<td>Everyone deserves the right to have a quality life.</td>
</tr>
<tr>
<td>Alessandra S.</td>
<td>Yes, I would like to have access to this drug</td>
</tr>
<tr>
<td>Alice Maria S.</td>
<td>Yes, I want to take omaveloxolone</td>
</tr>
<tr>
<td>Alina S.</td>
<td>I would want my daughter to take omaveloxolone in order to improve her neurological condition and to help her performing the most daily living activities.</td>
</tr>
<tr>
<td>Alison S.</td>
<td>My daughter would like the option of taking the drug with the hope that this would slow the progression of the disease for her.</td>
</tr>
<tr>
<td>Alison S.</td>
<td>Working</td>
</tr>
<tr>
<td>Amerilda S.</td>
<td>Yes, I would like to use the medicine</td>
</tr>
<tr>
<td>Ana Lucia S.</td>
<td>So that my cousin and others have some treatment against this devastating disease.</td>
</tr>
<tr>
<td>Anabella S.</td>
<td>Yes because we need a treatment to cure</td>
</tr>
</tbody>
</table>
COMMENTS FROM FA COMMUNITY
Parents & Family Members Outside the US

Anderson S. I wish he had the opportunity to use the medication, for a better quality of life.
André S. 2013, my sister have a rare disease, and i know how is difficult
Andrea S. While other kids are growing and enjoying life more and more we have seen that the kid of a good friend of us needs more and more help in her life due to the progression of this ugly disease.
Andrea S. Yes. My family member found the medicine very helpful.
Angelika S. yes wed wish to have the option of medicine
Annet S. Yes, she want to take the drug. If not then she will die.
Anton S. They hope the drug can stop the disease from progressing
Antonia S. Of course we want the medicine even if its doesn’t cure we are reaching one step closer to prevent or even more to find the cure
Antonio S. Definitely
Antonis S. I believe that omaveloxolone has positive effects and is a huge hope for my brother but also for any other patient
Arno S. Yes sure
Arse S. Yes of course, we want to try omaveloxolone
Augusto S. Yes. For my niece’s hope and healing!
Avery S. I believe my dad would want the option of taking the drug to increase his quality of life. Since the drug has been proven to help prevent/slow down symptoms and reduce what he may end up losing, it would be greatly beneficial.
Beatrice S. My cousin has 3 children with FA who would all benefit from omaveloxolone. They all want to be given the option of taking this medicine to relieve serious and persistent symptoms.
Beatrice S. My daughter will take the medicine as she’s seeking solution to enhance her day to day life and extend as a consequence her life expectancy.
Beatriz S. Yes! We need that help and believes that it will help a lot
Bernadette S. Yes. We need access to every opportunity to help manage FA and improve life quality.
Billy S. she be so happy
Britt S. Yes, she would be grateful to take Omav
Carlos S. Yes, I wish to have access
Catia S. Yes, because she needs to take this medication.
Cesar S. Yes. Because it is a hope of improving the quality of life of the affected person
Charlie S. Yes, it is critical patients are given the option of treatment. Who doesn't want a better quality of life and the chance to reverse the illness?
Chloe S. Yes everyone with a family member of FA should be able to take the medicine
Chris S. I would give the omaveloxolone to my son because as i see from the results of the trial it works very good, and i don’t have time fa is getting worse every day
Christelle S. Yes, we would let her take the medicine because so far nothing exists to help people with FA and it’s excruciating to witness your child get worse and worse, so any medicine with some possible efficiency is to be tried, with the hope of a stabilization or even maybe improvement of their everyday life. Please gave them this chance!
Christian S. Would M. the medicijnen approved
Christina S. We have seen that the progression of this ugly deseases has slown down for one participant of the study, which we know in person. Therefore we want to get the medicine for our kid, who is facing more and more challenges and requiers more and more support due to her progression.
<table>
<thead>
<tr>
<th>Name</th>
<th>Comment</th>
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<tbody>
<tr>
<td>Christine S.</td>
<td>It will be the decision of my child, currently treated with interferon Gamma off-label.</td>
</tr>
<tr>
<td>Corinne S.</td>
<td>Yes!! Very much! omav can change their life and slow down the progression. They are so young and have a Full live in front of them!</td>
</tr>
<tr>
<td>Damares Duane S.</td>
<td>I have two uncles with FA and my family has suffered a lot, for many years, if there is have a chance to alleviate the symptoms it will be wonderful.</td>
</tr>
<tr>
<td>Daniela S.</td>
<td>Improve life condition, in the sense of having some autonomy.</td>
</tr>
<tr>
<td>Daniele S.</td>
<td>Yes. It will help a lot.</td>
</tr>
<tr>
<td>David S.</td>
<td>Yes! Her needs are increasing for care and mobility. The sooner this drug is approved in Canada, the sooner FA sufferers may get relief!</td>
</tr>
<tr>
<td>Dawson S.</td>
<td>My mother would like the opportunity to try the medication because it can slow the progression of FA and provide her with better quality of life</td>
</tr>
<tr>
<td>Dionne S.</td>
<td>My family member would definitely want to take Omaveloxolone</td>
</tr>
<tr>
<td>Dylan S.</td>
<td>Yes, he would like the option to take the medicine.</td>
</tr>
<tr>
<td>Eamonn S.</td>
<td>Yes, anything that could improve my daughters quality of life is welcomed</td>
</tr>
<tr>
<td>Edilaine S.</td>
<td>Yes, I want to have access to the medicine</td>
</tr>
<tr>
<td>Elaine S.</td>
<td>This medication inhibits the progression of the disease. Fundamental until a cure is found.</td>
</tr>
<tr>
<td>Eliana Maria Del S.</td>
<td>Yes . I would love to have the option to use.</td>
</tr>
<tr>
<td>Emily S.</td>
<td>Yes, my daughters mobility deteriorating already just 1 year out diagnosis anything that can slow progression will help her have as &quot;normal&quot; a childhood/ adolescence as possible.</td>
</tr>
<tr>
<td>Enzo S.</td>
<td>Yes, because I know people who need it.</td>
</tr>
<tr>
<td>Erica S.</td>
<td>My cousin should have the right to use whatever him and his family feel is the right choice for his situation. If something is shown to work, it should be an option. Thank you</td>
</tr>
<tr>
<td>Erika S.</td>
<td>Yes absolutely!!!</td>
</tr>
<tr>
<td>Esra S.</td>
<td>Yes of course, we want to try omaveloxolone</td>
</tr>
<tr>
<td>Eva S.</td>
<td>To obtain the treatment with this drug that can improve the live of my relative</td>
</tr>
<tr>
<td>Evelyn S.</td>
<td>It would be extremely important to bring the medicine to Brazil, thus making it possible for low-income people to have access to the medicine.</td>
</tr>
<tr>
<td>Farida S.</td>
<td>Yes. She’s been suffering from this disease for years.</td>
</tr>
<tr>
<td>Farouk S.</td>
<td>my mother has Fara</td>
</tr>
<tr>
<td>Firoozeh S.</td>
<td>My nephew with FA participated in part 1 and is currently in the extension study. He has experienced a visible improvement in specific areas, such as balance, while the deterioration rate in another area markedly has decreased.</td>
</tr>
<tr>
<td>Franjo S.</td>
<td>Yes, in any case, to improve the quality of life</td>
</tr>
<tr>
<td>Franz-Josef S.</td>
<td>Yes, in any case, to improve the quality of life</td>
</tr>
<tr>
<td>Gabi S.</td>
<td>My sons W. take omaveloxolone Wien ist avariable in Switzerland</td>
</tr>
<tr>
<td>Gabriela S.</td>
<td>Better quality of life, progress towards recovery, and health.</td>
</tr>
<tr>
<td>Genevieve S.</td>
<td>Yes I would, both for my family member and for research advancement.</td>
</tr>
<tr>
<td>George S.</td>
<td>Yes after reading into the drug I believe it would deeply benefit my brother (H.). A to stop the degeneration of his body and B to give him a better chance in life. It’s a tough thing to go through for a young man having watched him get worse over the years. Any breakthrough in a drug to help FA I would strongly recommend trying to anyone. Let alone someone as close to me as my brother. Hope this helps with your decision. Kind regards</td>
</tr>
<tr>
<td>Gerardo S.</td>
<td>Because I want all people to have access at it and improve their daily lives.</td>
</tr>
</tbody>
</table>
Giovanna S. Yes, I would try the medicine for my child
Gisela S. It’s time to have something against FA and have some hope.
Guilherme S. I wish he could take the medication, to improve his quality of life.
Gustavo S. My family member has FA and want the option of taking the drug/medicine. Thank you
Hildegard S. It is so hard for me as a Grandpa to see my grandchild loosing more and more the controle about her body. Every year it is getting worse. She has no normal life like all the other 14 age old Kids.
Humberto S. Although my mother didn’t participate in the studies, she would want to take the medicine
Ioanna S. Yes they would like the option. No they haven’t participated in any clinical trials.
Irram S. My brother aged 27 suffers Friedrichs Ataxia. He was always an independent & active child with big dreams. Unfortunately this disease has crushed all his dreams and stripped away all his independence. It is extremely painful & difficult to see a family member suffer in this way, every moment of the day. Every single day is a challenge for our entire family, the regular falls, the damage to body, the physical and emotional pain all having a massive impact on the full family. The moxie trial has shown amazing results and the availability of this drug would be life changing for us as a family. There would be nothing more meaningful in this world than to see my brother be able to walk again. I can imagine that there’s many other families suffering in the same way. This drug could be life changing for soo many! This condition most commonly becomes symptomatic in the early teenage years which is when youngsters are growing up and wanting to achieve huge things in life. However this comes as a big punch in the face and takes everything away. Please make Omaveloxolone available immediately. This has come as a huge ray of hope & it would be like a miracle to soo many families! Please don’t hesitate to provide this drug to those affected so that families have the chance to live again! The future of so many people is in your hands, please save thousands of peoples life and make this drug available to them immediately.
Isabel S. ?To have a better quality of life he didn’t take any life attitude he didn’t take MOXIe
Isabelle S. I would like my son to be able to take this medication before his condition really deteriorates; he is still autonomous and I would like this autonomy to remain even if we can’t get back to the life we had before.
Ivoneide S. May MOXIe be approved to help fighting this terrible disease
Jaciara S. Yes. I wish she had the opportunity to improve.
Jacinta S. I think they should chose for themself they have already lost so much
Janete S. Yes. He wants it
Jean-Marc S. Yes, for taking the treatment
Jean-Michael S. Based on the data which describe that omaveloxone 160mg has been well-tolerated by patients, this give me insurance and safety for my family member. All help will be welcomed.
Jeannine S. Don’t know
Joanne S. We would like to have the option to choose this drug. Any hope of improvement or stopping the disease progressing is better than none.
Jody S. Yes they should be included
Jonas S. Yes, cause i think this immediately changes the FA symptoms and the expansion of FA in your body
José Gustavo S. “Because my family and I are convinced that the results demonstrate meaningful benefit and low risk and would like our family member to have access to this medication. We believe that the studies completed to date provide sufficient evidence to support the approval of Oma
Josinaldo S. Yes, I do
Juçara S. Yes, I would use it right away.
Kailane S. Yes because my friend and I believe that this medicine might be the actual cure of AF. And she’d be very glad to experiment it.
Karl-Ernst S. Seeing our grandson from being a healthy active boy to now struggling to walk a few steps is cruel and absolutely devastating and heartbreaking. Please allow the access to the drug now
<table>
<thead>
<tr>
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<tbody>
<tr>
<td>Kim S.</td>
<td>Yes we want the option to take the drug so we can slink the symptoms</td>
</tr>
<tr>
<td>Kirsten S.</td>
<td>We need this drug for the boy with FA ASAP so not more valuable time is lost.</td>
</tr>
<tr>
<td>Laura S.</td>
<td>Yeah. I would love to see my aunt, who has FA, taking this medication and getting better results.</td>
</tr>
<tr>
<td>Laura S.</td>
<td>Yes, based on the output from the trials, these are very encouraging.</td>
</tr>
<tr>
<td>Liduina S.</td>
<td>For my nephews to be entitled to treatment against this disease so devastating that is FA</td>
</tr>
<tr>
<td>Lily S.</td>
<td>My sister has FA. She’s 15. When I was 15 and since the I’ve been lucky enough to of lived an normal, active teen experience. The delaying of this drug means the delaying of my sisters ability to slow down her disease and steals away years of her adolescence that are so precious and already abundant with their own challenges. I would give anything to trade places with her, to let the aches and pains be mine so that she can live more freely. Of course I don’t have the choice but this drug is a chance to let her share in the life experience we should all be entitled too, and to reduce the pain and degeneration it already breaks our heart to see her struggle with. Please don’t delay the release of this drug a year is too long for someone who’s life feels harder and hurts more with each passing day.</td>
</tr>
<tr>
<td>Lise S.</td>
<td>Yes, my sister would like to try the medicine for all its worth. She has lost så much coused by fa, and we/she is willing to try everything.</td>
</tr>
<tr>
<td>Livia S.</td>
<td>Yes. Anything you can try to mitigate the effects of this disease should be tried</td>
</tr>
<tr>
<td>Lorraine S.</td>
<td>Yes my Mother would try it</td>
</tr>
<tr>
<td>Luciane S.</td>
<td>Gradually I see that the disease stabilizes. Yesterday some improvements.</td>
</tr>
<tr>
<td>Lucidelma S.</td>
<td>Need the medicine to improve A. health</td>
</tr>
<tr>
<td>Lucy S.</td>
<td>Yes they would love the opportunity to take it.</td>
</tr>
<tr>
<td>Luis S.</td>
<td>Ir helps to improve her life style</td>
</tr>
<tr>
<td>Luiz S.</td>
<td>Yes, I would definitely buy the medicine.</td>
</tr>
<tr>
<td>Luiz Vitor S.</td>
<td>She wants the option of taking the drug</td>
</tr>
<tr>
<td>Manolis S.</td>
<td>Yes of course I would having the hope my it Will help son as it is the only and First drug for FA. It is hope for my son and family. Thankyou.</td>
</tr>
<tr>
<td>Maria S.</td>
<td>D. wants to take this medicine</td>
</tr>
<tr>
<td>Maria Aparecida S.</td>
<td>Yes, she would like to take the medication</td>
</tr>
<tr>
<td>Maria Del Carmen S.</td>
<td>I imagine he epileptico administrate it</td>
</tr>
<tr>
<td>Maria Ivonete S.</td>
<td>I have two nephews with FA. I wish them much improvement</td>
</tr>
<tr>
<td>Maria Lucia S.</td>
<td>So that my nephews have the right to treatment against this debilitating disease</td>
</tr>
<tr>
<td>Marianne S.</td>
<td>Yes, we want the option. We want J. to have a chance to live.</td>
</tr>
<tr>
<td>Marily S.</td>
<td>yes my husband wants to take the drug as quickly as possible</td>
</tr>
<tr>
<td>Marit S.</td>
<td>Both my family members have been living with FA for years, and need assistance with more and more of their everyday needs. They both claim that they want the option of taking the medicine, given the facts they know about it.</td>
</tr>
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</table>
## Comments from FA Community

### Parents & Family Members Outside the US

<table>
<thead>
<tr>
<th>Name</th>
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<tbody>
<tr>
<td>Mary Christine S.</td>
<td>Yes. It is a hopeful sight if progress.</td>
</tr>
<tr>
<td>Max S.</td>
<td>Yes, stage 2 clinical trials looked promising and I want that to be an option.</td>
</tr>
<tr>
<td>Michaela S.</td>
<td>The debilitating effect of FA on my cousins daughter and the emotional turmoil it causes his family leaves them wanting the option if taking the drug to provide their daughter with the best opportunities in life.</td>
</tr>
<tr>
<td>Michele S.</td>
<td>Yes I want that my daughter take omaveloxolone.</td>
</tr>
<tr>
<td>Milorad S.</td>
<td>Yes, I believe it would improve the quality of life dramatically.</td>
</tr>
<tr>
<td>Moises S.</td>
<td>Yes. He wants it</td>
</tr>
<tr>
<td>Muhamad S.</td>
<td>I would like my family member to take it if the medicine.</td>
</tr>
<tr>
<td>Nagela S.</td>
<td>Yes. I wish my husband could take the medicine</td>
</tr>
<tr>
<td>Nicholas S.</td>
<td>Yes. Unfortunately the FDA did not approve it because the trial (around 100 people) apparently was too small. This was a surprise to Reata, FARA and Ataxia UK, and a great disappointment to the entire FA community. It is incredibly expensive and of course time consuming to organise larger trials, and it is also difficult to find enough FA patients who have not already been trialling various other drugs or therapies to take part in a new trial. The FDA could legally approve the drug based on the results of the trials so far if they choose to, and we would like to encourage Reata to re-apply and for the FDA to reconsider.</td>
</tr>
<tr>
<td>Nycole S.</td>
<td>for help someone a like</td>
</tr>
<tr>
<td>Oezlem S.</td>
<td>my sister is 16 years old and i found her at this sudie is located</td>
</tr>
<tr>
<td>Øivind S.</td>
<td>Yes - I would definately want my son to take this medicine.</td>
</tr>
<tr>
<td>Ove S.</td>
<td>Yes, she would be very grateful to take Omav</td>
</tr>
<tr>
<td>Pam S.</td>
<td>Anything that is going to help my daughter we are wanting to try ..</td>
</tr>
<tr>
<td>Paola S.</td>
<td>Yes i would</td>
</tr>
<tr>
<td>Patricia S.</td>
<td>My family member would definitely take the drug! She is deserving of the chance and the sooner the better! Speed it up and help these people!</td>
</tr>
<tr>
<td>Patrick S.</td>
<td>Yes we would do anything or try anything and this stage, please we beg of you allow this.</td>
</tr>
<tr>
<td>Paul S.</td>
<td>It would allow people with less severely developed fa to be able to live a normal life as it would stop the progression, it might not be as useful for the fully progressed but it would be life changing for those just diagnosed</td>
</tr>
<tr>
<td>Paula S.</td>
<td>I think they should have the right to choose it for themself</td>
</tr>
<tr>
<td>Peter S.</td>
<td>Yes...absolutely! Safety is of course important but time is something we just don’t have. Please let us take such a small risk for the chance to preserve life and dignity.</td>
</tr>
<tr>
<td>Philinear S.</td>
<td>My family member would like the possibility to improve his chances of a normal life with the medicine.</td>
</tr>
<tr>
<td>Priscila S.</td>
<td>For sure. A promising drug will help us slow the progression of AF and maintain quality of life while we wait for definitive treatment.</td>
</tr>
<tr>
<td>Priscila S.</td>
<td>Yes. The results are promising, it’s a hope that we have to deal with this disease.</td>
</tr>
<tr>
<td>Richard S.</td>
<td>Yes we would like the option to take the drug which will slow down the progression of this heartbreaking disease and provide opportunity for a longer healthier quality of life.</td>
</tr>
<tr>
<td>Ricor S.</td>
<td>Yes. My family member wants to have the option to take omaveloxolone!!! She is 29 years old and we see this drug as the only viable means for her stability and eventual recovery.</td>
</tr>
<tr>
<td>Ridwan S.</td>
<td>Yes, because i believe that omaveloxolone is safe and it may help with the treatment of AF</td>
</tr>
<tr>
<td>Robert J S.</td>
<td>My 71 year old wife, G. was diagnosed with FA in 1968 and would greatly appreciate a treatment that could possibly help alleviate her suffering from this cruel debilitating disease which she has bravely fought for a very long time.</td>
</tr>
<tr>
<td>Roberta S.</td>
<td>She wants to take the Moxie just she hope it can help her to live better, she doesn’t want any opinion.</td>
</tr>
</tbody>
</table>
it is the first hope for our children so that they can live a little better their youth and also avoid these physical and psychological tortures.

Yes! It will help J. a lot!

yes want the option

Yes, my son would take omav today if he could. Regarding the safety of the drug, adverse effects seem to be minimal. We understand that the number of patients in the trial was small and that less frequent issues might appear when a larger population is treated. But this will always be the case with FA trials. The risk of adverse effects must be balanced against the impact of FA if left untreated, as is currently the case. The damages of FA on children during their development are huge, and therefore patients and their parents are willing to accept a higher level of risk and potential side effects. Because of their condition, young FA patients are in frequent contact with health care practitioners, and negative drug effects could easily be monitored and addressed. As far as we are concerned, the risk a drug or treatment might present is largely outweighed by the certainty of the debilitating effects of FA progression. Regarding drug efficiency, we feel that any positive effect, even if it was only a reduction in the speed of progression of the disease, would highly benefit our son. Delaying the age at which a kid is wheelchair-bound, or reducing the severity of symptoms like dysarthria or fatigue, would give children a better chance to succeed in school and socially. This would improve the odds of them becoming independent adults, to the extend that their condition allows. More generally, the healthier patients are, the higher the possibility of recovering from FA if a more effective treatment becomes available. Therefore, even if Omaveloxolone ended up having only a limited efficiency for our son, it would still be a vast improvement as compared to the current absence of treatment.

Yes, My family member would take the medicine to help in the research to this disease. Maybe she won’t take it for herself, but definetly to help other people with FA.

Yes, I do

Would want the option of taking the drug /medicine.

Yes. As there is proof that it is helpful to reduce symptoms. I have spoken to the 3 members of family that have FA and they would all be willing to take the drug/medicine.

Please hurry! We are talking about lives here! Our children deserve a better life! You can make a difference and approve MOXIe to save our children! Thank you 🙏

Yes, I want

Please we would like MOXIe to get approved! Thanks to you our children can live a better life! Please hurry!

My daughter suffers from FA and it's absolutely necessary to have this drug.

With Omaveloxolone we have a hope! think about all persons who suffer from this terrible disease, my son suffers from FA, he is 16 years old, he waits for medicines desesperately!!! Let us try this omaveloxolone, please think about the sicks …

Yes we need help

I support my family as they are feeling desperate to try this drug to see if it is effective to benefit the quality of this young lad’s life.

Yes, Quality of life

My cousin has not yet taken the medicine, but I would like him to have access

3 of my children’s cousins, all in one family, have FA. They would very willingly take the drug/medicine. I am American living in Belgium, these cousins reside in the UK.

Yes - although at this point in the progression of her condition the drug would offer little help for my mother (aged 53), the genetic component of Friedreich’s Ataxia has been a major factor in my decision to not have children and the availability of an effective treatment would possibly change this decision.

Yes if it can help to slow the condition I believe it would be beneficial

Yes, he wants too take the medicin

Yes I would like my family member to take the drug/medicine.

We want MOXIe please to stop the progression of this awful disease. My nephew has Friedrich Ataxia.
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<thead>
<tr>
<th>Name</th>
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<tbody>
<tr>
<td>Thomas S.</td>
<td>We have seen that the progression of this ugly disease has slowed down for one participant of the study, which we know in person. Therefore we want to get the medicine for our kid, which is facing more and more challenges and requires more and more support due to her progression.</td>
</tr>
<tr>
<td>Thomas S.</td>
<td>Yes. At present, we can only see our family members getting worse and neither we nor the healthcare system can do anything to stop or even slow down the process. I lost my oldest son when he was 15 because of FA. My second son is getting worse and needs help with everything practical. My partner also has the disease, as does her sister. Their brother died when he was 35 due to the disease.</td>
</tr>
<tr>
<td>Thorsten S.</td>
<td>If it is well tolerated, we would take every chance to slow down the progression of FA.</td>
</tr>
<tr>
<td>Ute S.</td>
<td>We want to be able to see our grandson enjoy life as he should. Please give access to the drug now.</td>
</tr>
<tr>
<td>Vanessa S.</td>
<td>Yes, I would like to take MOXiLe</td>
</tr>
<tr>
<td>Varlli S.</td>
<td>My sister (43) and brother (34) have FA. As a family we have been living with the devastating effects of FA for 29 years, since 1991 when my sister was diagnosed as a 14 year old. We have lived through the years of relentless progression and debilitation without any approved treatments. As a family we have remained confident that a treatment would eventuate once the clinical trial research conclusively provided the evidence of safety and benefit. We have long been supportive of this clinical research and one of my siblings even participated in a clinical trial that was discontinued due to worsening of symptoms. Throughout, we have been confident that the clinical research framework was there to safeguard against doing harm and we were very grateful for that. In the case of Omaveloxolone, I believe the safety and efficacy data currently available to be solid, and I believe that it is finally, after 29 years, the first time the research data has conclusively provided evidence of benefit. I believe that to now deny patients access to this proven treatment is to do further harm to those living with FA. As my siblings age, we as a family are no longer desperate for a cure, as we were many years ago. For us, a treatment that slows or even stops progression is our dream. Based on the data currently available on safety and efficacy of Omaveloxolone, I believe Omaveloxolone is that treatment, and that everyone living with FA deserves the option of deciding for themselves if they wish to take this now proven treatment. We thank the FDA for their careful consideration and safeguarding of patients' welfare and implore the FDA to now allow FA patients the option to access this proven treatment before more devastating debilitation and death occurs in the FA community.</td>
</tr>
<tr>
<td>Victor S.</td>
<td>Yes, I would like to take MOXiLe</td>
</tr>
<tr>
<td>Vikram S.</td>
<td>Yes, definitely. This is a game changer and we would definitely want my sister to get the drug/medicine as quickly as possible.</td>
</tr>
<tr>
<td>Vilma S.</td>
<td>Yes, I want to take omaveloxolone</td>
</tr>
<tr>
<td>William S.</td>
<td>We are waiting for a treatment with lots of hope</td>
</tr>
<tr>
<td>Wolfgang S.</td>
<td>It is so hard for me as a Grandpa to see my grandchild losing more and more the control of her body. Every year it is getting worse. She has no normal life like all the other 14 age old Kids.</td>
</tr>
<tr>
<td>Xavier S.</td>
<td>Of course! She would take the medicine. Any minor chance to fight this situation must be taken, whatever it would cause. This is the only way to brighten their daily life, or at least trying to know what must be improved in the formula for future attempts. Whatever the “price” to pay. When life is at stake, ones must consider every opportunity.</td>
</tr>
<tr>
<td>Yaritza S.</td>
<td>Currently there is no treatment, this drug effectively stops the course of the disease, there is evidence to support it. Thus I ask you please to solicitate the FDA to help us in making the criteria more flexible so that all patients with FA can have this drug.</td>
</tr>
<tr>
<td>Yeker S.</td>
<td>No current available treatment. Has participated in FRAMES clinical trial</td>
</tr>
<tr>
<td>Yudmila S.</td>
<td>Yes, my family member want the option of taking the omaveloxolone medicine so she can have more control of her body parts, and finally stops suffering with bullying! Thank you</td>
</tr>
<tr>
<td>Zvornicanin S.</td>
<td>My sister has FA and she would take the drug</td>
</tr>
<tr>
<td>Aaron T.</td>
<td>Yes, we want to get urgent access to omaveloxolone as it has clearly demonstrated in the clinical trials that it is beneficial for the neurological function of FA patients, which will help slow/stop this relentlessly progressive disease which has no effective treatments. Due to the progressive deterioration of this disease, our daughter simply does not have the time to wait for more trials which will be further delayed by the pandemic, so it is critically imperative that this drug therapy is approved now for immediately use to treat patients of this devastating condition. This treatment would in turn provide our daughter with precious time in the hope of the development and approval of future gene therapies. We call on you both, Reata &amp; FDA to please work together now to bring omaveloxolone as a therapy to our daughter and the FA community.</td>
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COMMENTS FROM FA COMMUNITY
Parents & Family Members Outside the US

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<tr>
<th>Name</th>
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<tbody>
<tr>
<td>Alana T.</td>
<td>I would like to have access</td>
</tr>
<tr>
<td>Andrea T.</td>
<td>It hemos to improve her life style</td>
</tr>
<tr>
<td>Angela T.</td>
<td>Yes definitely! Say YES. FA has seriously affected R. life and the symptoms have worsened very quickly. We all want her to have the best life possible and would be keen for her to take it to make her life better.</td>
</tr>
<tr>
<td>Anna T.</td>
<td>Don’t know as it’s my nephew</td>
</tr>
<tr>
<td>Aoife T.</td>
<td>Don’t know as it’s my cousin</td>
</tr>
<tr>
<td>Beth T.</td>
<td>Yes - anything that could possibly help him would be incredible</td>
</tr>
<tr>
<td>Claire T.</td>
<td>Definitely, without a doubt, I would want my daughter to take the drug omaveloxolone. The results from the trial are what everyone with FA and everyone connected to FA have been waiting and praying for everyday. FA is a cruel disease, a disease that takes away so much on an individual. Your ability to walk, talk and so much more. My 13 year old daughter, is still able to walk but is very unbalanced, and has many falls. Time is something with FA that we DO NOT HAVE. The results from the Moxie trial have shown to Slow down and possibly stop this awful disease. There is absolutely no other treatment available for FA patients. Another trial for omaveloxolone is just not an option, it could take years. We need omaveloxolone to be approved urgently.</td>
</tr>
<tr>
<td>Claudia T.</td>
<td>Yes! They want to take the medicines to try to feel better</td>
</tr>
<tr>
<td>Claudine T.</td>
<td>No thank you</td>
</tr>
<tr>
<td>Coralie T.</td>
<td>Yes we would take the drug</td>
</tr>
<tr>
<td>Eunice T.</td>
<td>We opt to take medicine</td>
</tr>
<tr>
<td>George T.</td>
<td>We believe Omav can help the patients. Please approve it as soon as possible! My niece has this awful disease. Please help her to live a better life! Thank you very much</td>
</tr>
<tr>
<td>Georgia T.</td>
<td>Yes we do</td>
</tr>
<tr>
<td>Georgios T.</td>
<td>Yes we do</td>
</tr>
<tr>
<td>Hakan T.</td>
<td>For now, I can only get vitamin support with my kwndi facilities. However, I would like to participate if I have a chance. I want to be treated too</td>
</tr>
<tr>
<td>Ines T.</td>
<td>Yes definitely would want the option for taking the omaveloxolone.</td>
</tr>
<tr>
<td>Isabelle T.</td>
<td>I am hopeful that my daughter can get access to this drug</td>
</tr>
<tr>
<td>John T.</td>
<td>Yes we would like the option to at least try to slow or negate the effects of FA &amp; to be denied this option when it could mean so much does not seem the least bit fair.</td>
</tr>
<tr>
<td>Karen T.</td>
<td>I am responding on behalf of my Goddaughter / niece (my brothers daughter) who is suffering with FA. Please release this drug urgently to help her before it’s too late. Thank you and kindest regards</td>
</tr>
<tr>
<td>Katerina T.</td>
<td>Yes. My family member with FA would want to take the drug/medicine.</td>
</tr>
<tr>
<td>Katherine T.</td>
<td>Of course we want to take the drug as soon as possible! We have been waiting for so long and time is running against all the patients suffering with FA! Please hurry up and approve omaveloxolone!!!!!!!!!</td>
</tr>
<tr>
<td>Lorraine T.</td>
<td>Yes, if there is a chance to slow progression or even reverse some of the symptoms why not give the drug/medicine to give our family/friends a better quality of life.</td>
</tr>
</tbody>
</table>
COMMENTS FROM FA COMMUNITY
Parents & Family Members Outside the US

Maria T. My daughter did not participate in the Moxie extension trial and would like to take the drug
Maria T. Yes, i would like him to take the medecine
Mario T. YES, as soon as possible; Omaveloxolone today is the only chance to counteract the disease
Marnie T. Yes I believe my siblings 100% would want the option of trying this new treatment if it was made available to them. They both had to stop taking their main medication after over 10 years of use due to it causing severe osteoporosis, leaving them with no main treatment since. Their condition has significantly deteriorated since ceasing their previous medication and a new treatment would be welcomed even if it comes with a risk.
Mervyn T. Yes, as the clinical trials have been safe and have shown statistically significant improvements. As you know there are no other approved treatments available to stop or slow the progression of this devastating disease, therefore, we are calling on Reata & FDA to provide immediate access to Omaveloxolone as patients simply do not have the time to wait for more clinical trials.
Michelle T. Yes definitely
Patricia T. My mom has FA, she really wants and needs a solution for this disease. It is killing my mom and us, her children.
Renata T. Yes, my family member would take the medicine.
Robert T. Yes. Every effort should be made to examine all therapeutic possibilities.
Roxanne T. Yes we do
Sebastiano T. My daughter would be willing to take the drug, she has not been part of any trials
Sheila T. Yes, my son with FA is very eager to start taking the drug and I want him to have the opportunity of this drug to hopefully improve his rapidly declining condition. To have the chance of stopping the progression and start to give him some independence is important in so many ways. We feel time is running out for sufferers like my son and knowing a drug is out there that can potentially save his life it is so vital it should be approved as soon as possible. I have already lost my elder son to FA in 2019 aged 30. His health declined rapidly in the last 2 years of his life and I cannot bear to lose my only other child to this cruel disease knowing we are so close to having a life changing/saving drug available. Please allow this drug to be approved as quickly as possible to give all sufferers a chance. Thank you so much for reading this.
Sophie T. I want my son to be cured. He has not participated in clinical trials. He is followed up in Marseille. We are in a hurry because he is desperate.
Stavroula T. Absolutely, it should be available as soon as possible to all patients. The data provided by part one and part two of the study along with the open label extension shows significant statistical improvement when looking at the activities of daily life and measures on the FARS Scale. This is adequate and sound proof of the efficacy of MOXie.
Sunil T. Family member with FA. (Niece) Yes would like the right medication.
Valérie T. Yes. I would like my daughter to benefit from this drug to get better both physically and psychologically. I would like her health to stop degrading or to even improve.
Vasilis T. Yes we do
Wanda T. Yes, that is what he wants.
Aalok U. Need this medicine for my brother in law as soon as possible
Aytül U. She require assistance with all activities of daily living. And her brain power is full there. But she loses her ability to speak. Every day more... she is kidnapped in her body. She will taking the medicine. And her brother has either FA....
Deloris U. Yes please consider my daughter for this medication as she has been turned down her whole life from trying anything, always told she is too old. She is very strong and will try anything if she is given the chance. She is loosing hope of ever being chosen to try anything. So please, please give her a chance to try this drug.
Karoline Tomren U. Yes! We got nothing to loose...
Mahmut Memduh U. Yes he wants and I want.
Nazir U. This should be an option, at least is a try to have more mobility and self confidence.
COMMENTS FROM FA COMMUNITY
Parents & Family Members Outside the US

Andrr V. Yes absolutely! Showing more significant improvement from Moxie is too strict a standard. FA is a degenerative condition, slowing the progression is a choice every teenager should have at their disposal.

Anne-Wouke V. Yes. Most tools are not preventive and as a family member I would like to see something make a difference. The disadvantages of the medicine are always going to be less than nothing.

Cécile V. Yes. No other available treatment.

Chantal V. My family members want to take the option of taking the drug.

Claudio V. Yes of course

Danny V. Yes she would take the drug without any doubt. There’s literally nothing that’s out there to fix this devastating, life-shortening disease.

Edgar V. We have no experience, we did not participate in any part of MOXIe, but we would like to take any chance to improve our daughter’s health condition.

Emma V. Yea absolutely. Anything that could help him as he is losing his ability to talk which is the most heartbreaking. Also his vision is terribly impaired. Without his body to use it is devastating watching him lose speech and vision. Please help.

Emma V. YES, EVERYTHING IS WORTH A TRY WHEN TIME IS THE ESSENCE

Esra V. Yes of course, we want to try omaveloxolone

Eveline V. If it is safe, and if the medicine is easy to swallow for an 8 year old, we would definitely consider giving our child the omaveloxolone. But we also find it very difficult to understand all the medical information.

Fernanda V. My friend cousin is 11 years old. She was diagnosed with FA when she was 5 years old. Throughout the years she had been getting worse. Right now she needs a walker to walk but it is still hard for her. The medicine will help her a lot physically and emotionally. She will have bigger hopes on walking again!

Gaëtan V. Yes, we want to be able to choose

Gerwald V. Terms of living making better and longer

Gilia V. Nu familie menner want the option of taking medicine

Guilherme V. Yes, she would do it. We have the time and resources to go wherever we need to go in order to improve her quality of life.

Hassen V. Since there is no other solution and this drug works and will help thousands around the world, we would take the drug.

Helene V. Yes! If there is any chance for getting better from this cruel disease I know for sure my family will try it! This disease is slowly killing their joy of life!

Herma V. Child of someone I know

Inge V. To live longer

Ismael V. Yes! My family member wants to take the medicine since she sees it as the best option left for her to get better

Jesus V. To help T. to get the treatment for his disease

Jitske V. Yes, she would definitely want the option of taking the medicine. Her swallowing function and her speech is getting worse. The last years her arms/hands/legs are getting worse and she’s having more pain. The perspective of a new medicine would definitely give her more hope on a better quality of life.

Jouwke V. I don’t know

Jovo V. YES. It’s heartbreaking to watch my granddaughter struggle. I pray everyday that she will get the help she needs to live a better life. I love her will all my heart.

Karla V. Yes. But we live in Chile, Southamerica. Would it be accessible for us too?

Kristel V. Yes. As a parent I find myself in this nightmare of watching my child slowly die in front of me and there’s nothing I can do about it. So now there’s a chance that this medication will help. It’s a chance, a glimmer of hope and it’s better than nothing. Let us be the ones to decide.

Kristi V. We do want to participate and give the medication to my niece. She is only 9 years old.
<table>
<thead>
<tr>
<th>Name</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Laurent V.</td>
<td>I want my daughter having a decent life and be more independent by improving her health.</td>
</tr>
<tr>
<td>Luis V.</td>
<td>I have a friend who has the opportunity to take the drug.</td>
</tr>
<tr>
<td>Luiz Aurélio V.</td>
<td>Yes because we believe in this research</td>
</tr>
<tr>
<td>Lutz V.</td>
<td>Yes, because there is no Other chance and the illness otherwise is just continuing</td>
</tr>
<tr>
<td>Manuel V.</td>
<td>Yes .</td>
</tr>
<tr>
<td>Marcos V. V.</td>
<td>YES I WISH TO HAVE ACCESS TO THIS MEDICINE</td>
</tr>
<tr>
<td>Martijn V.</td>
<td>Yes, she is definitely willing to take the medicine.</td>
</tr>
<tr>
<td>Megi V.</td>
<td>Yes. That would be a great chance for my cousin. I hope this medicine will be on market soon</td>
</tr>
<tr>
<td>Metty V.</td>
<td>I hope that this medicine will be available for my grand daughter soon. It will make her very happy and it would be a huge blessing for our family.</td>
</tr>
<tr>
<td>Micheli V.</td>
<td>I would like my cousin to have the opportunity to use this medicine to improve her motor coordination, which has already lost a lot due to the disease, it would be an opportunity for her to improve, as we live in the heart of palmitos / SC Brazil and there is nothing to help in treatment, we are desperate and we need all possible help</td>
</tr>
<tr>
<td>Milan V.</td>
<td>Yes, the drug is proven to help people in this situation, this would drastically change my cousins life</td>
</tr>
<tr>
<td>Mylène V.</td>
<td>Yes! She hopes to be able to walk normal again..</td>
</tr>
<tr>
<td>Pallavi V.</td>
<td>Looks a ray of hope</td>
</tr>
<tr>
<td>Prakash V.</td>
<td>Will participate</td>
</tr>
<tr>
<td>Retha V.</td>
<td>Yes my daughters would like to take the medicine.</td>
</tr>
<tr>
<td>Rob V.</td>
<td>It regards my niece, she would like to have this option</td>
</tr>
<tr>
<td>Samantha V.</td>
<td>Yes, Honestly at this point my family would love to try anything that will/may help my brother!</td>
</tr>
<tr>
<td>Sigrid V.</td>
<td>Yes i have 2 children with FA and all we (my husband and me) want is for the disease to stabilize of even be cured. I often think about the fact that I am not going to survive my children and that is not right: they have to survive us!</td>
</tr>
<tr>
<td>Tawnya V.</td>
<td>Absolutely I have twin boys who both have FA and the progression in the last year is devastating. They really need this now!</td>
</tr>
<tr>
<td>Valerie V.</td>
<td>YES we would like to take the option of taking the medicine. Our daughter was a sportive person until 17 years old.Today she is not able to walk by herself.So if this drug can give her the chance to walk again it will be wonderful.</td>
</tr>
<tr>
<td>Villa V.</td>
<td>I know that my family member would want the drug</td>
</tr>
<tr>
<td>Vivek V.</td>
<td>Am unable to help my niec</td>
</tr>
<tr>
<td>Yann V.</td>
<td>I would love to see my sister be able to do more activities with us, even if she can bike, sitski and even if she's happy and living it well, i would love to see her being able to do more family activities with us.</td>
</tr>
<tr>
<td>Adam W.</td>
<td>Absolutely, Omav has been demonstrated to be well tolerated and has a proportionally small risk factor when considering the devastating impact FA has on patients health, lifestyle and overall enjoyment of life</td>
</tr>
<tr>
<td>Armand W.</td>
<td>Yes we would want for our granddaughter to have the option of taking Omaveloxolone, because so far it is the only medicine known which can help people with FA by improving their quality of life . We pray for her to have this opportunity , because something is better than nothing. Because living with FA when you are a teenager is not living the life one should be entitled to have at 14. Because after being deprived of their ability to walk, to move, to take care of themselves, to speak correctly, now there is this slight chance of gaining again some quality of life with Omaveloxolone . So yes, please, give FA patients this hope for a better life!</td>
</tr>
<tr>
<td>Aron W.</td>
<td>Every new promising treatment should, I firmly believe, be an option to the patient. Seeing my signifcat other rise up from this terrible affliction is something very much worth pursuing, and if this drug displays efficacy, then we would want to try it.</td>
</tr>
<tr>
<td>Aukje W.</td>
<td>The Mother of the child(My Niece) asked me to sign this letter for her daughter, so Yes i trust this medicine.</td>
</tr>
</tbody>
</table>
COMMENTS FROM FA COMMUNITY
Parents & Family Members Outside the US

Bobbie W.  Yes she would. She has late onset and being able to trial something when new into the journey may have massive benefits
Carolyn W.  Yes. To enable the person with FA to live as normal a life as possible.
Chris W.  To give longer life expectancy
Cora W.  Yes would be interested for my grandsons in the hope this drug gives, would need Health Canada approval for it though. Maybe we could have compassionate access through Heskth Canada. It’s been horrible watching the progression of FA in my grandsons
Cristina W.  YES, he want the option of taking the drug/medicine
Dhruv W.  Living with FA is difficult for my sister and our family. After reading about the current status(safety and efficacy) of the vaccine I am confident in saying that having the option to take the vaccine will definitely be better for a FA patient such as my sister.
Dominic W.  The answer is yes. I have three relatives with FA, and they would all be keen and willing to take this drug. The United States Food and Drug Administration (US-FDA) defines Fast Track as a process designed to facilitate the development and expedite the review of drugs to treat serious diseases and fill an unmet medical need. Filling an unmet medical need is further defined as providing a therapy where none exists or providing a therapy which may be potentially superior to existing therapy. This was introduced to curtail the duration in drug regulation and approval process, and to facilitate the discovery and marketing of drugs targeted for serious or rare diseases and to accelerate the approval of molecules showing superior efficacy than the existing one. Let’s go!!
Eileen W.  My niece is 15 and needs help now not in years to come
Esther W.  It is currently the only hope there is...
Farzana Jessica W.  She wants the option of taking the medicine
Graham W.  We feel empathy with all FAers and especially young people facing a life with a worsening debilitating disease, so would love to see a hastening of potential treatments and Omav appears to be worth pursuing for expediting its availability to the market. In my wife’s case, due to her age, an outcome taking several years may not be of much benefit but even a couple of points improvement in her dexterity would not go astray even in the next couple of years.
Jacqueline W.  My granddaughter is only 13 years old. She is a very intelligent, outgoing, friendly girl who loves sport, going out with friends and taking part in many school activities. She also had many aspirations of taking on responsibility for caring for others and making a difference to her community. Unfortunately, in the last year she has had to stop playing sport and many school activities owing to balance issues associated with FA. She is also very depressed to think that her aspirations and future are likely to be very limited as her disease progresses. The family is trying to encourage her of a much brighter future should a new drug omaveloxolone be available.
Jean W.  My daughter in law wants to participate
Jmh W.  Yes, will take omaveloxolone
Jörg W.  She wants it to get a better quality of life again
Katerina W.  MOXie medicine can help the Fa patients. Please approve it soon! Thank you ❤️
<table>
<thead>
<tr>
<th>Name</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Laurel W.</td>
<td>Yes - my boyfriend's brother has FA and would be open to taking any medication that would help slow or stop the progression of the disease.</td>
</tr>
<tr>
<td>Lisa W.</td>
<td>Please give my daughter chance of this drug. We have no other choice</td>
</tr>
<tr>
<td>Mark W.</td>
<td>Unknown</td>
</tr>
<tr>
<td>Nicola W.</td>
<td>Yes because their mother, my niece, wants it for her 3 children with FA</td>
</tr>
<tr>
<td>Pam W.</td>
<td>Yes - we are very interested in having this available to reduce the progression of FA!!</td>
</tr>
<tr>
<td>Patrick W.</td>
<td>Yes as quickly as possible</td>
</tr>
<tr>
<td>Pauline W.</td>
<td>M. is our grandson and has been slowly deteriorating for the last 8 years</td>
</tr>
<tr>
<td>Peter W.</td>
<td>My grandson has FA and is 24 and we see the change monthly for the worst</td>
</tr>
<tr>
<td>Robert W.</td>
<td>Yes, to hopefully help my brothers disease get better if possible!</td>
</tr>
<tr>
<td>Ron W.</td>
<td>Yes. We support participation in duly controlled clinical trials and development of new treatments.</td>
</tr>
<tr>
<td>Sharon W.</td>
<td>My niece and husband have two sons with this disease! Normal everyday living is difficult.</td>
</tr>
<tr>
<td>Stephane W.</td>
<td>She certainly would like to take this drug.</td>
</tr>
<tr>
<td>Stephen W.</td>
<td>Yes I would want my son to take the new drug, anything that can enhance and extend his quality of life has to be a positive step.</td>
</tr>
<tr>
<td>Steve W.</td>
<td>Yes, my daughter in law is mother to a one year old who will become more demanding as she develops over the coming years. Any improvement to the symptoms of FA will be beneficial to them both and facilitate a richer life together</td>
</tr>
<tr>
<td>Tamara W.</td>
<td>Yes, they want to live as long as possible.</td>
</tr>
<tr>
<td>Toni W.</td>
<td>Would love any kind of hope for my son</td>
</tr>
<tr>
<td>Tracy W.</td>
<td>Yes they would like to be able to take the drug. If there is a possibility of recovery or even just better quality of life it should be made available</td>
</tr>
<tr>
<td>Trevor W.</td>
<td>The data is significant enough to confidently take the drug and as a parent I would have no issue with the drug being administered to my child.</td>
</tr>
<tr>
<td>Virginia W.</td>
<td>Definitely, the outcome for their rapid decline is without hope, at least this drug would give them that.</td>
</tr>
<tr>
<td>Willie W.</td>
<td>Want the option to take the medicine. Everything try to have a better life.</td>
</tr>
<tr>
<td>Athena X.</td>
<td>My son S. and his family and friends are wishing for treatment for FA. S. is willing to try any medicine that may improve his debilitating disability.</td>
</tr>
<tr>
<td>Ali Y.</td>
<td>My wife has FA and I want her cure and I want this drug to be approved</td>
</tr>
<tr>
<td>Brad Y.</td>
<td>Yes my daughter would take Omaveloxolone. It could slow her progression and even reverse some of FA's effects for the past two years.</td>
</tr>
<tr>
<td>Carianne Y.</td>
<td>Yes my daughter would definitely take omaveloxolone if it were available.</td>
</tr>
<tr>
<td>Emmanuel Y.</td>
<td>My sister of age 65 has been diagnosed FA since 15 years old. I did not participate in any study but would be interested in knowing more and may use any medicine that could help.</td>
</tr>
<tr>
<td>Gültén Y.</td>
<td>Yes, I want</td>
</tr>
<tr>
<td>Hacer Y.</td>
<td>My brother has never used the drug. he has friends who have seen it very useful in phase trials.</td>
</tr>
<tr>
<td>Philip Y.</td>
<td>Yes - given the nature of the condition and watching their slowly declining physical health, anything which offers a chance of a cure or an improvement of their condition would be amazing. Appreciate drugs need to be tested safely, but a) this is an incredibly rare condition, so understandably hard to find enough volunteers, b) the trial results are promising, and c) the alternative to treatment is a slow lingering death, so withholding this treatment for bureaucratic reasons seems incredibly cruel.</td>
</tr>
<tr>
<td>Rahul Y.</td>
<td>He is willing to take the medicine. He hasn’t participated in any clinical trial because there were no clinical trial centres in India.</td>
</tr>
</tbody>
</table>
### Comments from FA Community

**Parents & Family Members Outside the US**

<table>
<thead>
<tr>
<th>Name</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Amaro Z.</td>
<td>To improve everyone's life, especially my aunt</td>
</tr>
<tr>
<td>Elena Z.</td>
<td>Yes. For his improvement, because it is terrible to see how it is getting worse and it is terrible not to have a medicine to help him, do everything possible to get it approved for my son there and for all people who require it to move on with their life... For them we hope that the drug will be approved.</td>
</tr>
<tr>
<td>Eleni Z.</td>
<td>Yes I want, because there is no more time for her</td>
</tr>
<tr>
<td>Filio Z.</td>
<td>Yes I want my child take the medicine because there is no more time</td>
</tr>
<tr>
<td>Jetmira Z.</td>
<td>I wish that my brother get a drug for the most ugly illness. I feel sad for all the ill people</td>
</tr>
<tr>
<td>Karla Z.</td>
<td>Yes, I would want the option</td>
</tr>
<tr>
<td>Katerina Z.</td>
<td>Please approve the Omav for our children!</td>
</tr>
<tr>
<td>Marius Z.</td>
<td>Yes. It's finally a chance to get better</td>
</tr>
<tr>
<td>Nilza Z.</td>
<td>Yes, my parent can take this medicine. It is our chance to see any changes</td>
</tr>
<tr>
<td>Pavlos Z.</td>
<td>If the medicine is checked and approved from the world organization of medicines yes.</td>
</tr>
<tr>
<td>Spyros Z.</td>
<td>Yes I want my child take the medicine, because there is no more time</td>
</tr>
<tr>
<td>Stamatis Z.</td>
<td>Yes I want</td>
</tr>
<tr>
<td>Zacharias Z.</td>
<td>Yes I want my wife to take the medicine</td>
</tr>
<tr>
<td>Πιάνης B.</td>
<td>Want the option of drug/medicine</td>
</tr>
</tbody>
</table>

Footnote 1 - 998 signers commented - “Yes” or “Of Course” Footnote 2 - 797 signers commented - “To have a better quality of life. Haven’t taken MOXie yet.” Footnote 3 - 99 signers commented - “Yes, we want to have access to this medicine.” Footnote 4 - 87 signers commented - “She wants to take the moxie just she hope it can help here to live better she doesent want any opinion.” Footnote 5 - 31 signers commented either - “N/A”, “No”, “Nothing”, or “No Experience.” Footnote 6 - 29 signers commented - “Yes to taking this medicine” Footnote 7 - 5 signers commented - “OK”
SIGNATURES - INDIVIDUALS LIVING WITH FA IN THE US

To maintain the privacy of signers, they are represented by their first names and the first initial of their last names.
SIGNATURES - INDIVIDUALS LIVING WITH FA OUTSIDE OF THE US

To maintain the privacy of signers, they are represented by their first names and the first initial of their last names.

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SIGNATURES - INDIVIDUALS LIVING WITH FA OUTSIDE OF THE US

Titi P.  
Valentina P.  
Vasilios P.  
Veronica P.  
Vicente P.  
William P.  
Xhesika P.  
Erica Q.  
Gabriel Q.  
Montserrat Q.  
Adriana R.  
Ali R.  
Ana R.  
Barry R.  
Ben R.  
Benjamin R.  
Bruna De Conz R.  
Cathy R.  
Claudia R.  
Dominique R.  
Elena R.  
Flavio Candido R.  
Fontaine R.  
Francineide R.  
Franklin R.  
George R.  
Giorgia R.  
Gonzalo R.  
Guido R.  
Guy R.  
Helena R.  
Henar R.  
Henrique R.  
Igor Diego R.  
Julia R.  
Karina R.  
Karla R.  
Karoline R.  
Katie R.  
Leonie R.  
Liam R.  
Luciana Andrade R.  
Luciane R.  
Mª Ángeles R.  
Maria R.  
Marianne R.  
Marie R.  
Mane R.  
Marius R.  
Monica R.  
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Tori T.  
Zehra U.  
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Agnikta V.  
Carmela V.  
Chene V.  
Débora V.  
Diego V.  
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Chrysanthis Z.  
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Dominik Z.  
Marirosa Z.  
Paola Z.  
Pia Z.  
Samir Z.  
Γιώργος Μ.  
Κατερίνα Μ. 
Σοφια Μ.
To maintain the privacy of signers, they are represented by their first names and the initial of their last names.

Aida A.
Al A.
Alejandro A.
Alex A.
Alexa A.
Alexis A.
Alison A.
Aluna A.
Alyssa A.
Amanda A.
Amanda A.
Amber A.
Amy A.
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SIGNATURES - PARENTS & FAMILY MEMBERS IN THE US

Luis R. Rusty R. Ashley S. Dan S. Jan S. Kelly S. Kelly S.
Luiz R. Sabrina S. Aubrey S. Dana S. Janie S. Kenda S.
Luke R. Sally R. Barbara S. Danielle S. Janine S. Kendee S.
Lyle R. Sam R. Barbara S. Danita S. Jenny S. Kendell S.
Lyndsey R. Sam R. Barbara S. Danny S. Kevin S. Kendyl S.
Mackenzie R. Sarah R. Barry S. Danish S. Kevin S. Kent S.
Maddy R. Sarah R. Beater S. Dave S. Kevin S. Kent S.
Marco R. Shannon R. Beverley S. Dawn S. Kevin S. Keza S.
Maria R. Sharad R. Bonni S. Dawn S. Kevin S. Krishna S.
Marielle R. Shelby R. Brad S. Dawn S. Keziah S. Krystal S.
Mark R. Sheila R. Brad S. Daeanne S. Kyle S. Kyle S.
Mark R. Sherra R. Brandi S. Brent S. Debra S. Kyle S.
Renee R. Anuhash S. Brill S. Brianna S. Debra S. Kyle S.
Royce R. Ashleigh S. Dalton S. Brandy S. Debby S. Kyra S.

Signatures - Parents & Family Members in the US
SIGNATURES - PARENTS & FAMILY MEMBERS OUTSIDE THE US

Clara B. Emma B.
Clari B. Erina B.
Claudia B. Erica B.
Claudie B. Erin B.
Claudinei B. Esteban B.
Cled B. Ethan B.
Clovis B. Euffauzia B.
Clowis B. Iva Johannes B.
Colleen B. Evano B.
Conor B. Everald B.
Corey B. Evie B.
Courtney B. Fariba B.
Cristiana B. Fazila B.
Cristina B. Federica B.
Cristine B. Federico B.
Dagmar B. Fernando B.
Dahlia B. Friket B.
Daiele Aline B. Finna B.
Dalia B. Florence B.
Darnian B. Fourus B.
Dan B. Fran B.
Dan B. Franca B.
Daniel B. Francis B.
Daniel B. Francisco B.
Daniel B. Francisco B.
Daniel B. Javier De B.
Daniele B. Donna B.
Daniele B. Don B.
Dario B. Fran B.
Darla B. Gabriel B.
David B. Gabriel B.
David B. Gabrielle B.
David B. Gabriel B.
David B. Gabriele B.
Dayna B. Gabe B.
Deanna B. Garth B.
De-Anne B. Gaston B.
Deb B. Geneveive B.
Deborah B. Geoff B.
Deirdre B. Geraldine B.
Denise B. Gerard B.
Denise B. Gerardo B.
Dianne B. Getalinde B.
Diana B. Giang B.
Didier B. Gigi B.
Didier B. Gilbert B.
Dimitrios B. Grineva B.
Don B. Giovanna B.
Donna B. Giuse B.
Doree B. Giulia B.
Doreen B. Giuliano B.
Doug B. Ginezela B.
Duncan B. Glenda B.
Dylan B. Gloria B.
Edvan B. Graciela B.
Edson B. Graham B.
Edvarri B. Han B.
Elaine B. Hanna B.
Elia B. Heith B.
Eliea B. Heidi B.
Elia B. Helene B.
Elisabeth B. Hélène B.
Elisabeta B. Hemavate B.
Ellen Francine B. Hilad B.
Emanuel B. Iago B.
Tarcisio B. Ian B.
Emiliane B. Igor Daniel B.
Emilien B. Imran B.
Emily B. Ingunn B.
Emina B. Isabelle B.
Isabelle B. Isadora Luci B.
Ismael B. Isobel B.
Ivana B. Ivone B.
Iz B. Jacobin B.
Jaco B. Jade B.
Jagriti B. Koen B.
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SIGNATURES - PARENTS & FAMILY MEMBERS OUTSIDE THE US

David C.
David C.
Deborah C.
Deborah C.
Darren C.
Decima C.
Declan C.
Denise C.
Denise C.
Denise C.
Derek C.
Derek C.
Diana C.
Diara C.
Diego C.
Diego C.
Dirk C.
Divanete C.
Djairina C.
Djetto C.
Dju C.
Dominique C.
Donal C.
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Doris C.
Douglas C.
Dulcineia C.
Duli C.
Ece C.
Edna C.
Eduardo C.
Eduardo C.
Eduardo C.
Eddard C.
Effe C.
Ege Su C.
Eli C.
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Enriqueta C.
Emmanuel C.
Emmanuela C.
Enzo C.
Eridania C.
Erik C.
Erika C.
Esteban C.
Estela C.
Ester C.
Euster C.
Euzenio C.
Euzebio C.
Evertont C.
Evie C.
Ewandro C.
Fabiana C.
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Faye C.
Federico C.
Felipe C.
Felix C.
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Fritz C.
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SIGNATURES - PARENTS & FAMILY MEMBERS OUTSIDE THE US

Neima P.
Niall P.
Nick P.
Nicky P.
Nicolas P.
Nicole P.
Norma P.
Nureen P.
Oddvait Sigurd P.
Odo P.
Oliva P.
Odivio P.
Cett C.

Phuong Thuy P.
Petrus P.
Patricio P.
Nicolas P.
Richard P.
Patricia P.
Patrice P.
Pamela P.

Oda P.
Rozaine P.
Robin P.
Robert P.
Vinicios P.

Ruben Oscar P.
Rubens P.
Salomara P.
Sally P.
Sam P.
Sandra P.
Sandy P.
Santiago P.

Sara P.
Sara P.
Sarah P.
Saul P.
Sarah P.
Sébastien P.
Sépia P.
Sérgio P.
Shawley P.
Sheena P.
Sheila P.
Shona P.
Shevan P.
Shiela P.
Sillon P.
Sinalena P.
Simone P.
Simons P.
Solange P.
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Laura S.
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Sara L.
Rafael S.
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SIGNATURES - PARENTS & FAMILY MEMBERS OUTSIDE THE US

Mauro T.
Meryn T.
Metaxas T.
Michaela T.
Michelle T.
Miguel T.
Miguel T.
Mireille T.
Musante S.
Narendra T.
Neyma T.
Nicolas T.
Oliver T.
Ophelie T.
Ori T.
Pafsanias T.
Pamela A.
Pao T.
Patricia A.
Patricia A.
Paul T.
Perihan T.
Quentin T.
Regina Terse T.
Reinaldo T.
Renata A.
Rizzato T.
Robert T.
Robert T.
Ropart T.
Rosanne T.
Russell T.
Ruy T.
Sara T.
Sasha T.
Sebastiano T.
Sema T.
Sheila T.
Sibel T.
Sigurd Reynir T.
Simone T.
Soﬁa T.
Sophie T.
Soraya T.
Starnata T.
Stavroula T.
Steven T.
Sunil T.
Suzanne T.
Sylvie T.
Taki T.
Tanis T.
Tanya T.
Tanya T.
Thomas T.
Tracey T.
Valerie T.
Vasile T.
Vassili T.
Versavel T.
Vijay T.
Walther T.
Wanda T.
Kyra T.
Yasemin T.
Zahra T.
Zoe T.
Aalok U.
Alexandra U.
Aytul U.
Delouis U.

James U.
José Luis U.
Karoline T.
Tomven U.
Mahmut T.
Memduh U.
Mevlut U.
Mistafa U.
Naaz U.
Nicola U.
Sigrid U.
Stephane U.
Vaide U.
Nicolas U.
Sevcan U.
Vedat U.
Agilede G.
Agustin V.
Aldo V.
Aline V.
Alice V.
Alice V.
Alicia V.
Alison V.
Ana Beatrix V.
Anders V.
Andrea V.
Andr V.
Annette V.
André V.
Anne V.
Anne V.
Annalies V.
Anne-Wouke V.
Arianna V.
Aris V.
Astrid V.
Franz-Josef V.
Gabriel V.
Gabriela V.
Gabriele V.
Gabrielle V.
Gael V.
Gaetan V.
Garth V.
Garnier V.
Georgine V.
Gerd V.
Gerwald V.
Gilia V.
Ginette V.
Gomar V.
Gordana V.
Gretchen V.
Ghilmer V.
Hafna V.
Hassen V.
Helene V.
Henri V.
Henrique V.
Herm V.
Herman V.
Hilde V.
Hilfrud V.
Ingrid V.
Ines V.
Inês V.
Irge V.
Irka V.
Izabella V.
Jackson V.
Javier V.
Jennifer V.
Jesus V.
Jitske V.
Joël V.
José Miguel V.
Jouweke V.
Jovo V.
Jug Angelov V.
Julia V.
Karim V.
Karim V.
Karta V.
Kim V.
Krista V.
Krysa V.
Laure V.
Laurent V.
Lena V.
Lena V.
Lorena V.
Louise V.
Luis V.
Luiz Aurélio V.
Lutz V.
Luiz Del Carmen V.
Madore V.
Mahomed V.
Maik V.
Manon V.
Manuel V.
Marc V.
Marcel V.
Marcel V.
Marcos V.
Marcos V.
Marius V.
Maria V.
Maria de Florencia V.
Maria Sol V.
Marian V.
Marianne V.
Marichen V.
Marie V.
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Marina V.
Mariluz V.
Marcilu V.
Martin V.
Martine V.
Maruza V.
Mateus V.
Mathieu V.
Matielo V.
Mauro V.
Mega V.
Metzy V.
Michel V.
Mathieu V.
Milan V.
Mina V.
Mireille V.
Morana V.
Muriel V.
Mylène V.
Nadia V.
Najma V.
Nancy V.
Nayara V.
Neazana V.

Nevio V.
Nelson V.
Nicolas V.
Padraig V.
Pallavi V.
Patricia V.
Pedro V.
Peter V.
Petra V.
Philippe V.
Pilar V.
Prakash V.
Rafaela V.
Rene V.
Retha V.
Rita V.
Rob V.
Rob V.
Robert V.
Roger V.
Rohan V.
Romey V.
Sabine V.
Samantha V.
Santigio V.
Sara V.
Sara V.
Sara V.
Shelly V.
Sigrid V.
Solène V.
Stephen V.
Suelen V.
Sushama V.
Sylviane V.
Tawnya V.
Terezinha V.
Vilarranho V.
Thomas V.
Tiaan V.
Timoteo V.
Tifaine V.
Valerie V.
Vanessa V.
Vanessa V.
Vanon V.
Villa V.
Vision V.
Vivek V.
Wayne V.
Willem V.
Yann V.
Yolanda V.
Adam W.
Adina W.
Aileen W.
Alex W.
Alina W.
Andrews W.
Andrew W.
Anisha W.
Anna W.
Anne W.
Armand W.
Aron W.
Aukje W.
Bart W.
Bobbie W.
Brian W.
Caroline W.
Carolyn W.

Charlotte W.
Chelsee W.
Chris W.
Christophe W.
Claartje W.
Connie W.
Cora W.
Cristina W.
Cuen W.
Dan W.
Danielle W.
Dave W.
David W.
Dhruv W.
Dominic W.
Donna W.
Edel W.
Eduardo W.
Eileen W.
Elnaie W.
Eleanor W.
Ellen W.
Emma W.
Emma W.
Erin W.
Esther W.
Fabianna W.
Fazanza Jessica W.
Floriano W.
Frances W.
Franch W.
Franziska W.
Glenn W.
Grace W.
Graham W.
Guy W.
Hayley W.
Heleen W.
Herta W.
Holly W.
Jacqueline W.
Jan W.
Jane W.
Janelle W.
Jason W.
Jean W.
Jenny W.
Jmh W.
Joan W.
Jon W.
Jorg W.
Jule W.
Julia W.
Justin W.
Katerina W.
Kelly W.
Kenny W.
Korridor W.
Kyle W.
Laerte W.
Laura W.
Laurel W.
Lee W.
Lena W.
Lesley W.
Liam W.
Lindsay W.
Lisa W.
Lori W.
Louise W.
Louise W.
Lydia W.
Lynn W.
Marcel W.
Maria W.
Mark W.
Martin W.
Martin W.
Matt W.
Melissa W.
Michelle W.
Muzna W.
Myra W.
Nadia W.
Natalie W.
Nathan W.
Neal W.
Nick W.
Nicola W.
Nigel W.
Pam W.
Pat W.
Patricia W.
Patrick W.
Patrice W.
Pauline W.
Peter W.
Ron W.
Ron W.
Rudy W.
Sam W.
Sanne W.
Sany W.
Sarah W.
Sharon W.
Sheila W.
Sherrise W.
Stanley W.
Stephanie W.
Stephen W.
Steve W.
Tamar W.
Thomas W.
Tomi W.
Tori W.
Tracy W.
Trevor W.
Tyll W.
Vanessa W.
Victoria W.
Victoria W.
Virginia W.
Vladimir W.
Willie W.
Ana Carolina W.
Athena X.
Enrico X.
Jax X.
Maria X.
Abida Y.
Ali Y.
Assane Y.
Beyza Y.
Billault Y.
Brad Y.
Carianne Y.
Cecilia Y.
Chanavat Y.
Emmanuel Y.

Federico Y.
Gulsam Y.
Gültén Y.
Hacer Y.
Le Priol Y.
Lynn Y.
Maria Nidia Y.
Marlene Y.
Mesnilday Y.
Mustafa Y.
Negro Y.
Nesilhan Y.
Philip Y.
Poitiers Y.
Rahul Y.
Suel Y.
Tanya Y.
Adriana Cassia Z.
Amaro Z.
Andrés Z.
Anton Z.
António Carlos Z.
Bautista Z.
Christiane Z.
Christina Z.
Christina Z.
Damiar Z.
Dena Z.
Eduardo Z.
Elena Z.
Eleni Z.
Emilio Gabriel Z.
Filio Z.
Jemira Z.
Kamila Z.
Kara Z.
Katerina Z.
Lennard Z.
Leonardo Z.
Lori Z.
Lorraine Z.
Luciana Z.
Mahomed Z.
Maria Z.
Marius Z.
Meaghan Z.
Milena Z.
Mirel Z.
Nada Z.
Nildomar Z.
Nilza Z.
Oanali Z.
Pavlos Z.
Robin Z.
Roland Z.
Salman Z.
Santino Z.
Shaik Z.
Sidneia Z.
Sigmoid Z.
Silver X.
Silvia Z.
Spyros Z.
Stamatis Z.
Virginia Z.
Zacharias Z.

Γιάννης B.
Πέννιν B.
Σαμμίρι B.
Σαββάνι Δ.
Σαολίνα τού
Σκιτρούς Κ.
Σιοδρίου Κ.
Παναθέλια Κ.
Προίτζα Κ.
Σιντέλα Ν.
Ελίνιν Ν.
Ελιν Ν.
SIGNATURES - FRIENDS, ADVOCATES & VOLUNTEERS

Francisco A.
Florencia A.
Fernando A.
Fernanda A.
Fabiola A.
Felipe A.
Fay A.
Fernanda A.
Fabiola A.
Fabio A.
Fabiola A.
Fabre A.
Fabiola A.
Fabrizio A.
Fady A.
Fani A.
Farah A.
Fatima A.
Fátima A.
FAU A.
Fauzan A.
Fay A.
Fazaeli A.
Federica A.
Federico A.
Fegli A.
Felli A.
Felix A.
Fernando A.
Fernanda A.
Fermin A.
Fernando A.
Fernando A.
Feyza A.
Flavia A.
Florence A.
Florencio A.
Florencia A.
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Florencia A.
Florencia A.
Florencia A.
France A.
Guilherme A.
Ingrid A.
Gonzalo A.
Gordon A.
Frederic A.
Federico A.
Fernanda A.
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Fernanda A.
Giancia A.
Giorgio A.
Giorgina A.
Gioia A.
Gloria A.
Glenda A.
Glauber A.
Francisco A.
Fernando A.
Fernando A.
Fernando A.
Gisella A.
Giuseppe A.
Gianluca A.
Giliano A.
Giancarlo A.
Gianluigi A.
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SIGNATURES - FRIENDS, ADVOCATES & VOLUNTEERS
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SIGNATURES - FRIENDS, ADVOCATES & VOLUNTEERS
SIGNATURES - FRIENDS, ADVOCATES & VOLUNTEERS

Anne G
A. G.
Annie G.

Anne G
Anita G.
Anthea G.

Ana G
Anastasia G.

Anders G.
Ananda G.
Andrea G.

Andreia G.
Andrea G.

Andreas G.
Andrea G.

Andrei G.
Andrea G.

Antoni G.
Antonia G.

Antonella G.
Antonio G.

Andera G.
Antonio G.

Anton G.
Antonio G.

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SIGNATURES - FRIENDS, ADVOCATES & VOLUNTEERS

 Evan G.  Yerimen G.  Gabriella G.  Gabriela G.  Gabrielle G.  Gabrielle G.
 F.G.  Gabriella G.  Gabrielle G.  Gabrielle G.  Gabrielle G.  Gabrielle G.
 Fabiana G.  Gabriella G.  Gabrielle G.  Gabrielle G.  Gabrielle G.  Gabrielle G.
 Fabio G.  Gabriella G.  Gabrielle G.  Gabrielle G.  Gabrielle G.  Gabrielle G.
 Fabiola G.  Gabriella G.  Gabrielle G.  Gabrielle G.  Gabrielle G.  Gabrielle G.
 Fabrizio G.  Gabriella G.  Gabrielle G.  Gabrielle G.  Gabrielle G.  Gabrielle G.
 Faizal G.  Gabriele G.  Gabriel G.  Gabriel G.  Gabrielle G.  Gabrielle G.
 Fanny G.  Gabriel G.  Gabriel G.  Gabriel G.  Gabrielle G.  Gabrielle G.
 Federica G.  Gaila G.  Galia G.  Galyon Mae G.  Galyn G.  Galyn G.
 Federico G.  Gary G.  Gary G.  Gary G.  Gary G.  Gary G.
 Federico G.  Gavan G.  Gavino G.  Gavino G.  Gavino G.  Gavino G.
 Felicia G.  Gaye G.  Gaye G.  Gaye G.  Gaye G.  Gaye G.
 Felicitas G.  Gemma G.  Gena G.  Gena G.  Gena G.  Gena G.
 Felipe G.  Gergana G.  Gergana G.  Gergana G.  Gergana G.  Gergana G.
 Felix G.  George G.  George G.  George G.  George G.  George G.
 Filipe G.  Georgia G.  Georgia G.  Georgia G.  Georgia G.  Georgia G.
 Filigot G.  Georgina G.  Georgina G.  Georgina G.  Georgina G.  Georgina G.
 Filomena G.  Georgina G.  Georgina G.  Georgina G.  Georgina G.  Georgina G.
 Fiona G.  Georgina G.  Georgina G.  Georgina G.  Georgina G.  Georgina G.
 Florin G.  Gerardo G.  Gerardo G.  Gerardo G.  Gerardo G.  Gerardo G.
 Florian G.  Gerardus G.  Gerardus G.  Gerardus G.  Gerardus G.  Gerardus G.
 Fotini G.  Gertruda G.  Gianni G.  Gianni G.  Gianni G.  Gianni G.
 Fran G.  Gianni G.  Gianni G.  Gianni G.  Gianni G.  Gianni G.
 Francesca G.  Giannina G.  Giannina G.  Giannina G.  Giannina G.  Giannina G.
 Frances G.  Giannina G.  Giannina G.  Giannina G.  Giannina G.  Giannina G.
 Francesca G.  Giannina G.  Giannina G.  Giannina G.  Giannina G.  Giannina G.
 francesca G.  Giannina G.  Giannina G.  Giannina G.  Giannina G.  Giannina G.
 Francisco G.  Gillian G.  Gillian G.  Gillian G.  Gillian G.  Gillian G.
 Francisco G.  Gina G.  Gina G.  Gina G.  Gina G.  Gina G.
 Francesco G.  Gina G.  Gina G.  Gina G.  Gina G.  Gina G.
 Françoise G.  Gina G.  Gina G.  Gina G.  Gina G.  Gina G.
 Frank G.  Giorgia G.  Giorgio G.  Giorgio G.  Giorgio G.  Giorgio G.
 Frank G.  Giorgio G.  Giorgio G.  Giorgio G.  Giorgio G.  Giorgio G.
 Franziska G.  Giorgos G.  Giorgos G.  Giorgos G.  Giorgos G.  Giorgos G.
 Fred G.  Giuseppe G.  Giuseppe G.  Giuseppe G.  Giuseppe G.  Giuseppe G.
 Freddie G.  Giselle G.  Giselle G.  Giselle G.  Giselle G.  Giselle G.
 Freddie G.  Gil Clérico G.  Clérico G.  Clérico G.  Clérico G.  Clérico G.
 Friedrik G.  Gloria G.  Gloria G.  Gloria G.  Gloria G.  Gloria G.
 Freyga G.  Gloria G.  Gloria G.  Gloria G.  Gloria G.  Gloria G.
 Fynn G.  Godoy G.  Godoy G.  Godoy G.  Godoy G.  Godoy G.
 Gabriel G.  Gonzalo G.  Gonzalo G.  Gonzalo G.  Gonzalo G.  Gonzalo G.
 Gabriela G.  Grace G.  Grace G.  Grace G.  Grace G.  Grace G.
 Gabriela G.  Gracie G.  Gracie G.  Gracie G.  Gracie G.  Gracie G.
 Gabriela G.  Graciele G.  Graciele G.  Graciele G.  Graciele G.  Graciele G.
SIGNATURES - FRIENDS, ADVOCATES & VOLUNTEERS

Aaron H.
Abbey H.
Aby H.
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Aby H.
Ally H.
Adalade H.
Adam H.
Adam H.
Adam H.
Adrienne H.
Adron H.
Agnes H.
Aida H.
Aid H.
Aid H.
Aid H.
Aime H.
Aimee H.
Aina H.
Alan H.
Alanda H.
Alberta H.
Alberto H.
Ali H.
Allena H.
Albera H.
Alex H.
Alex H.
Alexander H.
Alexander H.
Alexandra H.
Alexandra H.
Alexis H.
Alyna H.
Alfred H.
Alice H.
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Alicia H.
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Alina H.
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Alisa H.
Alisia H.
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Alissa H.
Alla H.
Allan H.
Allah H.
Andrea H.
Andres H.
Annessia H.
Annette H.
Annika H.
Anthea H.
Anthony H.
Anthony H.
Arly H.
Armin H.
Arnest H.
Arnold H.
Arpaha H.
Art H.
Asad H.
Ashlee H.
Ashley H.
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Ashe H.
Aud H.
Aubrey H.
Audrey H.
Audy H.
Aurelia H.
Aurelie H.
Austin H.
Autumn H.
Avery H.
Avery H.
Avery H.
Alyline H.
Balilee H.
Barb H.
Barbara H.
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Beatrich H.
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Elliott P.
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Elspeth P.
Elvira P.
Emilia P.
Emilie P.
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Enrique P.
Enzo P.
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Estefania P.
Estela P.
Estelle P.
Eugene P.
Eugene P.
Eugenie P.
Eugenie P.
Evangelia P.
Evangelia P.
Evangelos P.
Evdokia P.
Eve P.
Evelinle P.
Evgeni P.
Eytel P.
Ezequiel P.
Ezequiel P.
Erdan P.
Fabiana P.
Facundo P.
Facundo P.
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Faithe P.
Faiser P.
Fai P.
Falcone P.
Federico P.
Felicia P.
Felipe P.
Felipe P.
Felix José P.
Ginger P.
Ginny P.
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Giovanna P.
Gisela P.
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SIGNATURES - FRIENDS, ADVOCATES & VOLUNTEERS

Pauline P. Renata P.
Paulo P. Renato P.
Paulo P. Renato P.
Paulo P. Renato P.
Payton P. Renato P.
Paz P. Renato P.
Pedro P. Renato P.
Pedro P. Renato P.
Peggy P. Renee P.
Penelope P. Renee P.
Penny P. Renee P.
Peter P. Renee P.
Peter P. Renee P.
Petra P. Rebecca P.
Petrina P. Rebecca P.
Phil P. Rhionna P.
Philipp P. Rhonda P.
Philippa P. Ricardo P.
Phyllis P. Richard P.
Phyllis P. Richard P.
Phyllis P. Richard P.
Pla Andrea P. Richard P.
Pierre P. Richard P.
Pierre P. Richard P.
Poilyanne P. Rick P.
Polly P. Rick P.
Pramod P. Rina P.
Prashant P. Rinaldi P.
Prathyusha P. Riss P.
Preston P. Rita P.
Priscilla P. Rob P.
Prue P. Robbi P.
Rachel P. Robert P.
Rachel P. Robert P.
Rachel P. Robert P.
Rachel P. Robert P.
Rachel L. Robert P.
Rachelle P. Robert P.
Raeanne P. Robert P.
Rafaela P. Roberta P.
Rafaela P. Roberta P.
Rafaela P. Roberta P.
Rafaela P. Roberta P.
Raff P. Robin P.
Raffaelle P. Robin P.
Rajesh P. Robson P.
Ralph P. Robyn P.
Ralph P. Robyn P.
Buchanan P. Rocio P.
Bum P. Rocio P.
Ram P. Rocio P.
Ram Bahadur P. Rocio P.
Ramiro P. Rodrigo P.
Ramiro P. Rodrigo P.
Ramiro P. Rodrigo P.
Randy P. Rodrigo P.
Randy P. Rodrigo P.
Ray P. Rodrigo P.
Reba P. Rodrigues P.
Rebeca P. Roisin P.
Rebecca P. Romina P.
Rebecca P. Romina P.
Rebecca P. Romina P.
Rebecca P. Ron P.
Rebecca P. Ronald P.
Rebecca P. Ron P.
Regina P. Ronna P.
Regina P. Ronna P.
Relinda P. Rosalia P.
Rémi P. Rosalia P.
Nersya R.  Pamela R.
Nevada R.  Pamela R.
Niamh R.  Pamela R.
Nic R.  Pandon R.
Nic R.  Paola R.
Nicholas R.  Rafa R.
Nicholas R.  Rafael R.
Nicholas R.  Ralston R.
Nichole R.  Ralf R.
Nichole R.  Ralf R.
Nichole R.  Ralph R.
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SIGNATURES - FRIENDS, ADVOCATES & VOLUNTEERS

Drayan S. Elieete Riodoff S. Emily S. Eugene S. Florencio S. Gaby S. Grace S. Hannah S. Holly S.
Drury S. Eilomar S. Elis S. Eva S. Florencio S. Gabi S. Grace S. Hannah S.
Drew S. Elis S. Elisabeth S. Ev S. Florencio S. Gabi S. Grace S. Harald S.
Drew S. Elisabeth S. Ev S. Eva S. Florene S. Gabi S. Grace S. Harry S.
Drew S. Elisabeth S. Ev S. Eva S. Florent S. Gabi S. Grace S. Harry S.
Drew S. Eliza S. Ev S. Eva S. Florien S. Galant S. Graciela S. Grace S. Harry S.
Drew S. Eliza S. Ev S. Eva S. Florian S. Galant S. Gracielle S. Grace S. Harry S.
Drew S. Eliza S. Ev S. Evangeline S. Florin S. Galante S. Gracielle S. Grace S. Harry S.
Drew S. Eliza S. Ev S. Eve S. Fohna S. Garrett S. Greg S. Greg S.
Dyngma S. Elizabeth S. Emily S. Evelin S. Forest S. Gary S. Gary S.
ECHO S. Elizabeth S. Emily S. Evelyn S. Fran S. Gary S. Gary S.
Eckart S. Elizabeth S. Emily S. Everton S. Fran S. Frances S. Gary S.
Ed S. Elizabeth S. Emma S. Evindar S. Ewald S. Frances S. Gary S.
Ed S. Elizabeth S. Emma S. Zeequeil S. Ezequeil S. Francesca S. Gary S.
Edel S. Elizabeth S. Emma S. Zeequeil S. Ezequeil S. Francesca S. Gary S.
Edi Liene S. Elizabeth S. Emma S. Zeequeil S. Ezequeil S. Francesca S. Gary S.
Edina Regina S. Elizabeth S. Emma S. Zeequeil S. Ezequeil S. Francesca S. Gary S.
Edith S. Elizabeth S. Emma S. Zeequeil S. Ezequeil S. Francesca S. Gary S.
Edna S. Elizabeth S. Emma S. Zeequeil S. Ezequeil S. Francesca S. Gary S.
Edna S. Elizabeth S. Emma S. Zeequeil S. Ezequeil S. Francesca S. Gary S.
Edward S. Elizabeth S. Emma S. Zeequeil S. Ezequeil S. Francesca S. Gary S.
Edward S. Elizabeth S. Emma S. Zeequeil S. Ezequeil S. Francesca S. Gary S.
Eddy S. Elizabeth S. Emma S. Zeequeil S. Ezequeil S. Francesca S. Gary S.
Edson S. Elizabeth S. Emma S. Zeequeil S. Ezequeil S. Francesca S. Gary S.
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Ed S. Elizabeth S. Emma S. Zeequeil S. Ezequeil S. Francesca S. Gary S.
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Edward S. Elizabeth S. Emma S. Zeequeil S. Ezequeil S. Francesca S. Gary S.
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Edward S. Elizabeth S. Emma S. Zeequeil S. Ezequeil S. Francesca S. Gary S.
SIGNATURES - FRIENDS, ADVOCATES & VOLUNTEERS

Lea U.
Leigh(Ux  
Lia U.
Linda U.
Lisa U.
Louis U.
Lucia U.
Luciana U.
Luísa U.
Luz U.
Magdalena U.
Mara U.
Maria U.
Maria Cecilia U.
Maria Laura U.
Mariane U.
Mat U.
Maureen U.
Max U.
Melina U.
Misty U.
Mollie U.
Nadine U.
Natacha U.
Neil U.
Nicole U.
Niklas U.
Nora U.
Norma U.
Diego U.
Diego U.
Rogério
Dione U.
Romina U.
Ron U.
Ronda U.
Rúbia U.
Sara U.
Sarah U.
Serene U.
Mariana U.
Simone U.
Sophia U.
Sophia U.
Stefania U.
Svitlana U.
Suzana U.
Tatjana U.
Tatiana U.
Talitha U.
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SIGNATURES - FRIENDS, ADVOCATES & VOLUNTEERS
         Samiran W.        Sharon W.       Stephen W.       Tori W.          Wendy W.         Betty Y.          Jair Y.          Abby Z.
         Samiran W.        Sharon W.       Stephen W.       Torsten W.        Wendy W.         Brandi Y.         Jean Y.          Abigail Z.
         Samiran W.        Sharon W.       Stephen W.       Tracey W.         Wendy W.         Brandi Y.         Jeff Y.          Ac.Z.
         Samiran W.        Sharon W.       Stephen W.       Tracey W.         Wesley Y.         Brandi Y.         Jeff Y.          Addilyn Z.
         San San W.       Sandra W.       Steven W.        Tracy W.         Whitney W.        Brandi Y.         Jen Y.          Adrienne Z.
         San San W.       Sandra W.       Steven W.        Tracy W.         Whitney W.        Bruno Y.          Jen Y.          Nicolene Y.
         San San W.       Sandra W.       Steven W.        Tracy W.         Whitney W.        Bruno Y.          Jenna Y.          Adriana Z.
         San San W.       Sandra W.       Steven W.        Trent W.          William W.        Carla Y.          Omar Y.          Agustina Z.
         Sandra W.       Sarrah W.       Steven W.        Trent W.          William W.        Carmen Y.          Oziem Y.          Alana Z.
         Sandra W.       Sarah W.        Steven W.        Trad W.           William W.        Cath Y.          Patty Y.        Alessio Z.
         Sandra W.       Sarah W.        Steven W.        Trina W.          William W.        Charles Y.        Peggy Y.        Alicia Z.
         Sandra W.       Sarah W.        Steven W.        Trinity W.         William W.        Cher Y.          Phyllis Y.        Alivio Z.
         Sandra W.       Sarah W.        Steven W.        Trish W.          William W.        Chris Y.          Pier Angel Y.        Alyssa Z.
         Sandra W.       Sarah W.        Steven W.        Tristan W.        William W.        Christine Y.       Praveen Y.        Amanda Z.
         Sandra W.       Sarah W.        Steven W.        Troy W.           William W.        Katie Y.          Ray Y.          Ara Z.
         Sandra W.       Sarah W.        Steven W.        Tyler W.          William W.        Claudia Y.        Rebecca Y.        Ana Z.
         Sandra W.       Sarah W.        Steven W.        Tyler W.          William W.        Clifford Y.        Rebecca Y.        Ana Paula Z.
         Sandra W.       Sarah W.        Steven W.        Tyler W.          William W.        Corey Y.          Reita Y.        Anaabela Z.
         Sandra W.       Sarah W.        Steven W.        Tyler W.          William W.        Danielle Y.       Ride Y.          Andrea Z.
         Sandra W.       Sarah W.        Steven W.        Tyler W.          William W.        Debra Y.          Rosetta Y.        Andres Z.
         Sandra W.       Sarah W.        Steven W.        Tyler W.          William W.        Debra Y.          Rosilyn Y.        Andrew Z.
         Sandra W.       Sarah W.        Steven W.        Tyler W.          William W.        Debra Y.          Sadie Y.        Angela Z.
         Sandra W.       Sarah W.        Steven W.        Tyler W.          William W.        Debra Y.          Sam Y.        Angela Z.
         Sandra W.       Sarah W.        Steven W.        Tyler W.          William W.        Debra Y.          Scott Y.        Angela Z.
         Sandra W.       Sarah W.        Steven W.        Tyler W.          William W.        Debra Y.          Selvi Y.        Anila Z.
         Sandra W.       Sarah W.        Steven W.        Tyler W.          William W.        Debra Y.          Sema Y.        Anna Z.
         Sandra W.       Sarah W.        Steven W.        Tyler W.          William W.        Debra Y.          Sena Y.        Anne Z.
         Sandra W.       Sarah W.        Steven W.        Tyler W.          William W.        Debra Y.          Seray Y.        Anne Z.
         Sandra W.       Sarah W.        Steven W.        Tyler W.          William W.        Debra Y.          Sevi Y.        Annika Z.
         Sandra W.       Sarah W.        Steven W.        Tyler W.          William W.        Debra Y.          Shanhtal Y.        Ariadne Z.
         Sandra W.       Sarah W.        Steven W.        Tyler W.          William W.        Debra Y.          Sherry Y.        Ariella Z.
         Sandra W.       Sarah W.        Steven W.        Tyler W.          William W.        Debra Y.          Shirley Y.        Artur Z.
         Sandra W.       Sarah W.        Steven W.        Tyler W.          William W.        Debra Y.          Sofia Y.        Ashley Z.
         Sandra W.       Sarah W.        Steven W.        Tyler W.          William W.        Debra Y.          Austin Y.        Beate Z.
         Sandra W.       Sarah W.        Steven W.        Tyler W.          William W.        Debra Y.          Beatrix Z.        Beien Z.
         Sandra W.       Sarah W.        Steven W.        Tyler W.          William W.        Debra Y.          Ben Z.        Bianc Z.
         Sandra W.       Sarah W.        Steven W.        Tyler W.          William W.        Debra Y.          Blair Z.        Bia Z.
         Sandra W.       Sarah W.        Steven W.        Tyler W.          William W.        Debra Y.          Bob Z.        Bindi Z.
         Sandra W.       Sarah W.        Steven W.        Tyler W.          William W.        Debra Y.          Bonnie Z.        Brian Z.
         Sandra W.       Sarah W.        Steven W.        Tyler W.          William W.        Debra Y.          Britney Z.        Caitlin Z.
         Sandra W.       Sarah W.        Steven W.        Tyler W.          William W.        Debra Y.          Caitlin Z.        Carolina Z.
         Sandra W.       Sarah W.        Steven W.        Tyler W.          William W.        Debra Y.          Valerie Y.        Caroline Z.
         Sandra W.       Sarah W.        Steven W.        Tyler W.          William W.        Debra Y.          Abril Y.        Britto Z.
         Sandra W.       Sarah W.        Steven W.        Tyler W.          William W.        Debra Y.          Virginia Y.        Carrie Z.
         Sandra W.       Sarah W.        Steven W.        Tyler W.          William W.        Debra Y.          Cathy Z.        Celeste Z.
         Sandra W.       Sarah W.        Steven W.        Tyler W.          William W.        Debra Y.          Michael Y.        Charles Z.

SIGNATURES - FRIENDS, ADVOCATES & VOLUNTEERS
Cheryl Z.
Chris Z.
Christa Z.
Christina Z.
Chistine Z.
Christodoulos Z.
Christoph Z.
Christy Z.
Christy Z.
Chrysovali Z.
Cindi Z.
Cindy Z.
Clarita Z.
Claudia Z.
Connie Z.
Corie Z.
Dan Z.
Dan Z.
Dan Z.
Danai Z.
Daniela Z.
Daniele Z.
David Z.
David Z.
David Z.
David Z.
Delaney Z.
Delaney Z.
Dharti Z.
Dimitra Z.
Efelia Z.
Efthelia Z.
Eleni Z.
Elisavet Z.
Elizabeth Z.
Elizabeth Z.
Emilia Z.
Enrico Z.
Eric Z.
Erietta Z.
Erika Z.
Esra Z.
Estefani Z.
Eunice Z.
Evanghelini Z.
Evyenia Z.
Fabien Z.
Fady Z.
Famke Z.
Fayçal Z.
Federico Z.
Finn Luca Z.
Fiorella Z.
Florencea Z.
Frank Z.
Francis Z.
Francisco Z.
Frank Z.
Fynn Z.
Gabriella Z.
Gail Z.
Gerda Z.
German Z.
Gertrud Z.
Giancarlo Z.
Gisela Z.
Gioele Z.
Gloria Z.
Graciela Z.
Grant Z.
Greg Z.
Guido Z.
Hannah Z.
Hannah Z.
Hayley Z.
Heather Z.
Heidi Z.
Helen Z.
Henry Z.
Hugo Arturo Z.
Iara Z.
Ignacio Z.
Ignacio Alberto Z.
Iljah Z.
Ilia Z.
Irem Z.
Ivana Z.
Ivonne Z.
Jaime Z.
Jaimie Z.
James Z.
James Z.
Jan Z.
Janaina Z.
Jane Z.
Janice Z.
Jen Z.
Jennie Z.
Jennifer Z.
Jennifer Z.
Jessalyún Z.
Jessica Z.
Jessica Z.
Jill Z.
Jinni Z.
Joanna Z.
Joaquín Z.
Johan Z.
Jola Z.
Jose Z.
Jose Luis Z.
Josefine Z.
Juan Andrés Z.
Juan Jesús Z.
Judy Z.
Jukian Z.
Julia Z.
Julio César Z.
Justin Jia Z.
Kacey Z.
Kalliopi Z.
Karen Z.
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Karen Z.
Kathleen Z.
Kathy Z.
Kathy Z.
Keli Z.
Kelly Z.
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Kerneth Z.
Kerry Z.
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Kevin Z.
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Kim Z.
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Kirsten Z.
Kostas Z.
Kossete Z.
Lars Z.
Laura Z.
Lauren Z.
Lia Z.
Lilia Yanneth Z.
Linda Z.
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Lisa Z.
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Loic Z.
Lorella Z.
Lorena Z.
Lorenzo Z.
Lourdes Z.
Luan Z.
Lucia Z.
Lucia Z.
Lujan Z.
Luz Z.
Luynae Z.
Macaúl Z.
Maeghan Z.
Magalie Z.
Maira Z.
Maren Z.
Maria Z.
Maria Z.
Maria Z.
Maria Z.
Maria Claudia Z.
Maria De Los Angeles Z.
Maria Soledad Z.
Mariana Z.
Mariel Z.
Marina Z.
Mark Z.
María Z.
María Z.
Marile Z.
Marta Z.
Marta Z.
Marta Z.
Martin Z.
Mary Z.
Mary Ann Z.
Mary Ellen Z.
Matias Z.
Matina Z.
Matthew Z.
Matthias Z.
Mattison Z.
Megan Z.
Melanie Z.
Melanie Z.
Melissa Z.
Merissa Z.
Michael Z.
Michelle Z.
Michelle Z.
Michelle Z.
Mike Z.
Mike Z.
Mina Z.
Monica Z.
Monica Z.
Nancy Z.
Nancy Z.
Natalia Z.
Nefeli Stamatia Z.
Nelly Z.
Nestlhan Z.
Nevar Z.
Never Z.
Newton Z.
Nicholas Z.
Nicolas Z.
Nicole Z.
Nicole Z.
Nikos Z.
Nikos Z.
Nina Z.
Noel Z.
Noelle Z.
Nury Z.
Olga Z.
Omer Z.
Orí Z.
Pablo Nicolas Z.
Pat Z.
Paul Z.
Pauline Z.
Peter Z.
Pinelopi Z.
Rachei Z.
Ramiro Z.
Rebecca Z.
Regina Z.
Regina Z.
Rich Z.
Richa Z.
Rob Z.
Rocky Z.
Romaina Z.
Roscha Z.
Sabinra Z.
Salina Z.
Salvina Z.
Samarth Z.
Sandra Z.
Santiago Z.
Sara Z.
Sarah Z.
Savan Z.
Sebastian Z.
Selina Z.
Shabbir Z.
Shameem Z.
Shawn Z.
Shayne Z.
Shela Z.
Shirley Z.
Sian Z.
Silvia Z.
Sophie Z.
Sooraya Z.
Stephanie Z.
Stephanie Z.
Steve Z.
Susan Z.
Susan Z.
Susan Z.
Susan Z.
Suzie Z.
Tammy Z.
Tereza Z.
Thaio Z.
Theresa Z.
Tim Z.
Tomás Z.
Tracy Z.
Trisha Z.
Ulríke Z.
Ute Z.
Vaggelis Z.
Valentina Z.
Vasiléios Z.
Vasilis Z.
Vernon Z.
Veronica Natalia Z.
Victor Z.
Victor Z.
Vince Z.
Vucic Z.
Zacharoula Z.
Zachary Z.
Zenios Z.
Zoe Z.
Zoe Z.
Dana Z.
Iva Z.
Jaroslav Z.
Jason Z.

Ελιάσσατα Α.
Κωστούμια Α.
Πευκο Α.
Πηνέλοπη Α.
Φωτείνη Α.
Κωνσταντίνος Β.
Δημήτρης Γ.
Ελένη Γ.
Παναγιώτης Γ.
Ραντί Γ.
Βελέτσα Ζ.
Ιωάννης Ω.
Καρπ 1.
Αρετή Κ.
Γεωργιάκ Κ.
Γεωργιάκ Κ.
Ευρήκη Κ.
Ελένη Κ.
Ελευθερία Κ.
Εύα Κ.
Θεόλογος Κ.
Κατερίνα Κ.
Μαρία Κ.
Μαρία Κ.
Μαρία Κ.
Ιωάννης Κ.
Σταύρος Κ.
Δημήτρης Ε.
Ελένη Ε.
Ελένη Ε.
Αντώνιο/Αντίγον Μ.
Βασίλικος Μ.
Βασίλικος Μ.
Γιώργος Μ.
Ιωσέφ Μ.
Ευαγγέλιο Μ.
Θεόδωρος Μ.
Θεοφίλος Μ.
Τερέζα Μ.
Άγια Ν.
Κατέρινα Ν.
Πέτρος Ο.
Αικατερίνη Π.
Θανάση Π.
SIGNATURES - HEALTHCARE PROVIDERS

To maintain the privacy of signers, they are represented by their first names and the first initial of their last names.
SIGNATURES - CAREGivers

To maintain the privacy of signers, they are represented by their first names and the first initial of their last names.

Cinthia C.
Claire C.
Danielle C.
Diego C.
Dylan C.
Elise C.
Evelyn C.
Fiona C.
Giane Mari C.
Iona C.
Jackie C.
James C.
Julian C.
Julie C.
Karine C.
Karissa C.
Kayla C.
Kierstin C.
Lautaro C.
Le Strat C.
Linda C.
Lisa C.
Luisa C.
Lydia C.
Madison C.
Maggie C.
Maria Eugenia C.
Max C.
Mel C.
Melinda C.
Nadja C.
Nathan C.
Nico C.
Padma C.
Prestley C.
Raf C.
Robin C.
Román C.
Sabrina C.
Sabrina C.
Serrin C.
Tima C.
Tina C.
Tony C.
Tricia C.
Vanessa D.
Alexis D.
Ben D.
Brianne D.
Camille D.
Charles D.
Clair D.
Dayna D.
Dimitriss D.
Dimitrid C.
Dena D.
Emma D.
Jannik D.
Josefi D.
Jules D.
Laura D.
Lieselotte D.
Loretta D.
Maart D.
Magali D.
Maria D.
Marianne D.
Marin D.
Mary D.
Nayara D.
Nicolas D.
Romand D.
Ruy Patrick D.
Salome D.
Sharon D.
Sinnad D.
Soja D.
Softs D.
Stef D.
Suaine D.
Tamara D.
Telma D.
Tone D.
Vindar D.
Walter D.
Anne E.
Bente Karine E.
Edwina E.
Else E.
Frank E.
Helga E.
Herman E.
Kai E.
Lena E.
Renate E.
Sadullah E.
Sarah E.
Sharnee E.
Thomas E.
Antoinette F.
Cassandra F.
Chantelle F.
Charly F.
Chrisanthi F.
Daniel F.
Daniel F.
Daniel F.
Dawn F.
Deirdre F.
Dinar F.
Dylan D.
Evangelos F.
Faree F.
Fareesa F.
Felipe F.
Frank F.
Georges F.
Giada F.
Gianni F.
Jane F.
Jessica F.
Juliana F.
Karen F.
Laura F.
Lisa F.
Lorena F.
Martina F.
Melanie F.
Mia F.
Morgan F.
Nathan F.
Sabine F.
Tara F.
Anon F.
Todd F.
Uljana F.
Alessa G.
Alexa G.
Andre G.
Angeles G.
Bruno G.
Delfina G.
Faith G.
Florian G.
Anon G.
Jasper G.
Jessica G.
Jonas G.
Katerina G.
Katiane G.
Kijana G.
Lara G.
Lena G.
Lyra G.
Manuela G.
Margaux G.
Maria G.
Martha G.
Max G.
Melanie G.
Mikayla G.
Niels G.
Paul G.
Prisy G.
Renato G.
Romane G.
S. G.
Sandra G.
Sarah G.
Sian G.
Simone G.
Taylor G.
Teresa G.
Yannis G.
Aigge H.
Anégelique H.
Anthony H.
Ashlid H.
Carl H.
Celine H.
Colin H.
Friederike H.
Galina H.
Henri H.
Hilfe Gunna H.
Ingrid H.
Inka H.
Joshua H.
Julien H.
Juliette H.
K H.
Keyshauna H.
Lotomy H.
Leonardo H.
Lorna H.
Madeleine H.
Mai Ida H.
Max H.
Nick H.
Philip H.
Remy H.
Rochelle H.
Rochelle H.
Sarah H.
Sineadconnaughton H.
Stephanie H.
Thomas H.
Tobias H.
Tory H.
Zareen H.
Bart I.
Emma I.
Muhammad I.
Nicolas I.
Rado I.
Aie J.
Arya J.
Austin J.
Branka J.
Elli J.
Emile J.
Eric J.
Evans J.
Fulgéncia J.
Gachet J.
Iada-Eline J.
Iise J.
Joshua J.
Maria Riise J.
Neena J.
Stefanija J.
Thomas J.
Adriana K.
Alfred K.
Ana K.
Andreas K.
Ashley K.
Barbara K.
Bill K.
Birgit K.
Caroline K.
Carsten K.
Cheryl K.
Christina K.
Eletheria K.
Emma K.
Graham K.
Hani K.
Jaane K.
Jacqueline K.
Jean-Louis K.
John K.
Julie K.
Karim K.
Katrín K.
Kira K.
Kristallia K.
Laura K.
Layla K.
Lennart K.
Lorraine K.
Malia K.
Mandep K.
Natalie K.
Naureen K.
Nelke K.
Nepomuk K.
Nikhil K.
Noreen K.
Paolo K.
Pia K.
Renate K.
Sebastian K.
Simon K.
Sinead K.
Stefanie K.
Taffy K.
Thomas K.
Vanda K.
Vandana K.
Agostina L.
Alf L.
Alyssa L.
Anna L.
Ann-Malin L.
Antonio L.
Aslaug L.
Audrey L.
Austin L.
Bekah L.
Boris L.
Brooke L.
Carmel L.
Chloé L.
Christian L.
Claudie L.
Daphnæ L.
David L.
Denis L.
Elena-Kim L.
Estévão L.
Gabriela L.
Gro L.

Agnes A.
Agustin A.
Ameera A.
Ángela A.
Annika A.
Annoha A.
Ayoté A.
Arian A.
Bashar A.
Carolina A.
Charleen A.
Chris A.
Christina A.
Dimitra A.
Farah A.
Heather A.
João Victor A.
John Victor A.
Juan A.
Lautaro A.
Lisa A.
Luzie A.
Luciana A.
Mariana A.
Merve A.
Momed A.
Naline A.
Nora A.
Ruth A.
Santiago A.
Sasha Gonzalez A.
Sebrena A.
Sema A.
Sheilla A.
Sherize A.
Swantje A.
Verhelst A.
Zahra A.
Ziyad A.
Agustina B.
Alexis B.
Alexia B.
Andrea B.
Anna B.
Anik B.
Annika B.
Atlanticya B.
Bennet B.
Beth B.
Bjorn B.
Caroline B.
Carsten B.
Chris B.
Christiane B.
Claire B.
Daniël B.
Edwin B.
Elizabeth B.
Emma B.
Esme B.
Etienne B.
Eva B.
Faraaz B.
Harman B.
Iain B.
Iran B.
Jessica B.
Jochen B.
Jodi B.
Jonathann B.
Julie B.
Kai B.
Kevin B.
Kim B.
Kimball B.
Kirsten B.
Kristina B.
Lars B.
Laura B.
Leendert B.
Lianne B.
Lorraine B.
Louis B.
Lucas B.
Luis B.
Maya Berta B.
Mari B.
Marita B.
Misti B.
Nina B.
Nora B.
Oliver B.
Paola B.
Patricia B.
Pierre-Louis B.
Rezo B.
Ricarda B.
Richard B.
Sara B.
Saska B.
Sem B.
Shaday B.
Sheena B.
Sibylle B.
Sofie B.
Sofie B.
Sohanie B.
Sophia B.
Syed B.
Theresa B.
Thibaud B.
Wibke B.
Yorick B.
Alexis C.
Amos C.
Anastasia C.
Andrew C.
Aylin C.
Berrodier C.
Brigitte C.
Caroline C.
Charmaine C.
Eliana B.
To maintain the privacy of signers, they are represented by their first names and the first initial of their last names.

Rebekah L.
Ronaldo L.
Sarah L.
Valentina L.
Andre M.
Andreas M.
Anna M.
Anna M.
Ashutosh M.
Bree M.
Chloe M.
Christa M.
Dave M.
Dolores M.
Dupuy M.
Emma M.
Ferarese M.
Francisca M.
George M.
Giovanni M.
Jost M.
Kathleen M.
Kristy M.
Leticia M.
Loan M.
Lucien M.
Luiz M.
Mark M.
Martin Miguel M.
Martine M.
Mercedes M.
Natasha M.
Pablo M.
Paola M.
Patrick M.
Renato Carvalho M.
Sara M.
Sophia M.
Vilte M.
Zila M.
Zilvia M.
Ioulia N.
Jay N.
Jill N.
John N.
Marek N.
Oliver N.
Quang N.
Scott N.
Styliani N.
Tricia N.
Danyella O.
Debora O.
Florian O.
Harry T. O.
Luna O.
Tyler O.
Yagmur Ö.
Alexandra P.
Alexandra P.
Alexys P.
Andreas P.
Andres P.
Beatrice P.
Benilde P.
Christoph P.
David P.
Eleni P.
Eric P.
Irene P.
Isabel P.
Jasminka P.
Linda P.
Lou P.
Mariana P.
Mark P.
Maxime P.
Natalie P.
Rahuy P.
Rebekah P.
Scott P.
Soﬁa P.
Uda P.
Anne Q.
Cristina Cecilia Q.
Loane Q.
Alberto R.
Amber R.
Brenda R.
Claudia R.
Fernando R.
Geeta R.
James R.
Layne R.
Lewis R.
Maddie R.
Marcela R.
Maria R.
Marion R.
Moritz R.
Remi R.
Rodrigo R.
Roland R.
Tatiana R.
Alberto S.
Antonia S.
Antonio S.
Brose S.
Cecilia S.
Charlotte S.
Chloe S.
Chris S.
Consuelo S.
Diego S.
Eike S.
Erin S.
Evlyn S.
Heidi S.
Javier S.
Jomar S.
Jose Carlos Barbosa S.
Lea S.
Leonardo S.
Lisa S.
Luciano S.
Maya S.
Montoya S.
Nell S.
Pete S.
Rania S.
Rucha S.
Sandeep S.
Sara S.
Sebastián S.
Shailesh S.
Steven S.
Susan S.
Sushmita S.
Tamm S.
Tiana S.
Ana Carolina T.
Barbara T.
Darby T.
George T.
Marc T.
Vasileios Panagiotis T.
Anaíla U.
Alec V.
Alice V.
Aly V.
Andrew V.
Arthur V.
Charlotte V.
Dorianmarie V.
Enrique V.
Julieta V.
Kasie V.
Nicolás V.
Oskar V.
Victor V.
Yurika V.
Aubie W.
Allie W.
Jason W.
Matte W.
Marisa W.
Mckenzie W.
Megan W.
Michael W.
Stefan W.
Taffeta W.
Ursula W.
Verónica W.
Victoria W.
Eleni X.
Linus Z.
Lily Z.
Tilo Z.
SIGNATURES - OTHER

To maintain the privacy of signers, they are represented by their first names and the first initial of their last names.

Angela A.
Antônio A.
Cinzia A.
Eunilson A.
Ewan A.
Natália A.
Nish A.
Raja Rajeswari A.
Ravapé A.
Sakurako A.
Alexandre B.
Arthur B.
Carolina B.
Gaurav B.
Joanna B.
John B.
Jonah B.
Julia B.
Julie B.
Justina B.
Lisa B.
Luiz B.
Myro B.
Nina B.
Nora B.
Olive B.
Andres C.
Faustine C.
Guilherme C.
Maria C.
Maria Josefin C.
Matthieu C.
Rambeloson C.
Sergi C.
Sergio C.
Shauna C.
Gabriella D.
Kevin D.
Melanie D.
Sniram D.
Theo D.
Walter D.
Edson E.
Karádag E.
Ollie E.
Samuel E.
Vinicius E.
Agustin F.
Cathy F.
Hank F.
J F.
Matias F.
Moniquis F.
Nathan F.
Parker F.
Pierre F.
Andrea G.
Andreas G.
Carol G.
David G.
Dean G.
Julieta G.
Karen G.
Katie G.
Lilian G.
Loura G.
Lucia G.
Maiara Cristina G.
Marco G.
Vanessa G.
Alicia H.
Ana H.
Christine H.
Haylie H.
Joanne H.
Karen H.
Russell H.
Simon H.
Constanza I.
Kieran I.
Aibino J.
Calantzopoulos J.
Ircel J.
Loeka J.
Rachel J.
Silvio J.
Amanda K.
Ashish K.
Ester K.
Jim K.
Marvin K.
Narelle K.
Natasa K.
Nele K.
Renata K.
Diana Estela L.
Judy L.
Maira L.
Alice M.
Camila M.
Carol M.
Cathy M.
Denise M.
Eliana M.
Joerg M.
Jomar M.
Juliea M.
Laura M.
Marcus M.
Marina M.
Marius M.
Pierre M.
Roshan M.
Yuri M.
Maryann N.
Christian O.
Danielle O.
Finola O.
Karyna O.
Mariano O.
Viry O.
Archana P.
Doris P.
Jose P.
Lea P.
Lola P.
Maria Flavia P.
Mauricio Fernando P.
Paul P.
Raul P.
Vanessa P.
Alba R.
Barbara R.
David R.
Khalil R.
Laurine R.
S R.
Stuey R.
Américo Paulo Paim S.
Amie S.
Andrea S.
Anu S.
Christopher S.
Fernando S.
Giulia S.
Gloria S.
Hana S.
Igor S.
Janet S.
Kevin S.
Kim S.
Kimberly S.
Lily S.
Luz S.
Maria S.
Maria S.
Marisol S.
Mark S.
Nicolas S.
Romeyer S.
Sarah S.
Shanu S.
Vai S.
Anais T.
Jassiel T.
Jordan T.
Laura T.
Lucy T.
Norma Cristina T.
Palley T.
Shaun T.
Shruti T.
Mayra U.
Carlos V.
Lucrecia V.
Monica V.
Sarah V.
Thomas V.
Antonio W.
Cassandra W.
Charlotte W.
George W.
Jeff W.
Mckenna W.
Rick W.
Lakisha Y.
SIGNATURES - ADVOCACY ORGANIZATIONS

Acapi Asociación Civil
ADCA/ Ataxie- Gabrielle Donne- Op Den Kelder
‘Agigma Zois Ngo’ - Cancercare- Christina Nomikou
Anti-Cancer ATH- Maria Chinari
Asso Alatax
Ataxia Awareness Society- Swasti Wagh
Ataxia de Friedreich Brasil- Amalia Maranhao
Ataxia UK- Richard Brown, Mbe
Care Plus NJ- Jeremy Levy
Donna Gray
FamiliesSCN2A Foundation- Jennifer Burke
Friedreich Ataxia Lebanese Association- Marianne Hakim
Friedreich Ataxia Research Association- Sherelle Fyfe
Friedreich’s Ataxia Research Alliance Ireland- Mary Kearney
Greek Patients’ Association Greek Patients’ Association
Hellenic Friedreich Ataxia Association
MDA Hellas- Evgenia Oikonomidou & Georgia Moraiti
National Ataxia Foundation- Lori Shogren & Stephanie Lucas
Rare Alliance Greece
Remember the Girls- Taylor Kane
“Samarytanin” Foundation- Barbara Niepsuj
Team Telomere- Katie Stevens
The Hepatitis Hilfe Österreich - Platform for Healthy Liver (HHÖ)- Angelika Widhalm
The Lion Project- Zak Ferry
Uplifting Athletes
VHL Greece - Athina Alexandridou

Σύλλογος Γονέων Και Παιδιών Με Συμπτώματα Σευτομάτια “Η Αγία Σοφία” Association of Parents and Guardians of Children with Congenital Heart Diseases “Agia Sofia”
Σύλλογος Υποστήριξης Ρευματοπαθών Δικτύου Αιτωλίας Ιταλίας- Association for the Support of Rheumatologists of West Attica Jesus
Dr. Billy Dunn, Director  
Office of Neuroscience,  
Center for Drug Evaluation and Research,  
Food and Drug Administration,  
10903 New Hampshire Avenue,  
Silver Spring, MD 20993-0002  

Dear Dr. Dunn,  

We, the undersigned, are specialists knowledgeable about the care of Friedreich Ataxia (FA), a rare genetic disease that affects less than 5,000 individuals in the United States. Many of us are clinician researchers and trialists who have studied the natural history of FA, developed outcome measures and conducted clinical trials. Given the multisystem impact of FA, we are neurologists, medical geneticists, cardiologists, endocrinologists and doctors in physical therapy. All individuals with FA suffer neurological symptoms that are progressive and lead to loss of ambulation and independence with all activities of daily living over two to three decades. The neurological symptoms together with cardiac dysfunction lead to early mortality with the average life expectancy being 35 years. There are no approved disease modifying treatments for FA.  

We are writing with regard to the drug Omaveloxolone (Omav) which has completed clinical trials as a potential treatment for FA sponsored by Reata. In support of the Friedreich’s Ataxia Research Alliance (FARA) leadership, scientific advisory board, clinical investigators and the individuals with FA in the United States and their families, we write to support FARA’s request to Reata to submit a New Drug Application (NDA) on an urgent basis and FDA to exercise the flexibility granted by law and contained in FDA guidance in considering approval of an NDA for Omav in FA based on the existing evidence from clinical trials.  

We would like to provide our independent views of the results of MOXIE Part 1 (Phase 2a) and Part 2 (Phase 2b) and why we believe they are persuasive and clinically meaningful by demonstrating that:  
- Nrf2 has been validated as a therapeutic target in FA  
- Omav has a defined dose-response relationship on both pharmacodynamics markers and clinical benefit (MOXle Part 1)  
- Clinical efficacy in a double blind placebo controlled trial (MOXle Part 2) has been established  
- Additional evidence of clinical benefit is observed in MOXle Part 2 from the Baseline-Controlled study and  
- Omav is generally safe and well-tolerated (MOXle Part 1 and 2)
Nrf2 has been validated as a therapeutic target in FA. In multiple academic laboratories it has been demonstrated that a consequence of frataxin deficiency is a maladaptive response that decreases levels and activity of Nrf2. Nrf2 suppression leads to excess oxidative stress, mitochondrial dysfunction and reduced ATP production. In both in vitro and in vivo studies of FA models, Omav rescues these features and increases cell viability and other phenotypes.

We are first impressed by the pharmacodynamic data from both the MOXIe Part 1 and 2 studies. Omav alters a series of Nrf2 targets such as ferritin and GGT and indirectly AST and CK which were measured in both studies. The data from Part 1 and Part 2 not only demonstrate activation of the Nrf2 pathway in a dose-dependent manner but also demonstrate favorable biological effect of the drug in vivo. Of note, individuals with FA have low ferritin levels as a component of the pathophysiology of the disease; in both studies, treatment significantly elevated ferritin levels toward normal levels, consistent with a reversal of the pathophysiology of FA. Another important pharmacodynamic finding is that sub-clinical abnormalities in renal function reversed in the treatment group while the placebo group experienced further decline in function over the 48-week Part 2 study. We believe these biomarkers demonstrate biological evidence that, when considered alongside the clinical data on neurological function, strongly support disease-relevant target engagement by Omav.

MOXIe Part 2 was a randomized, placebo-controlled, double-blind, parallel-group study to evaluate the safety and efficacy of 150 mg Omav in FA patients. The primary endpoint was the change from baseline in the modified Friedreich Ataxia Rating Scale (mFARS) at Week 48. 103 individuals with FA, ages 16-40 years, enrolled and randomized 1 to 1 (drug and placebo) and studied for 48 weeks. Individuals with FA treated with Omav (150 mg/day) demonstrated a statistically significant, placebo-corrected 2.40 point improvement in mFARS after 48 weeks of treatment (p=0.014). The mFARS is a physician-assessed neurological rating scale used to measure FA disease progression. Improvements were observed in all prespecified subgroups and populations. All subsections of mFARS favored Omav. The data on the secondary endpoints provide evidence of internal consistency and support that what was observed in clinical function as measured by the mFARS was reflected in how patients felt as measured by the PGIC and FA-ADL.

Omav also significantly improved activities of daily living and other efficacy measures in some analysis populations. Finally, the change in mFARS scores on Omav was more than 2.5 times the yearly change in placebo or matched natural history groups, suggesting that the drug provides an improvement of more than 2.5 years of progression in the study. These values are certainly meaningful in the daily lives of patients.
LETTER FROM HEALTHCARE PROVIDERS

A baseline-controlled study was designed to help assess the strength and certainty of the positive primary endpoint findings in MOXie Part 2 from MOXie Part 3, the Open Label Extension (OLE). Patients considered treatment-naïve prior to initiation of Omav treatment in MOXie Part 3 OLE (i.e., MOXie Part 1 patients and MOXie Part 2 placebo patients) served as their own controls. The primary efficacy endpoint of the baseline-controlled study was the paired difference in annualized mFARS slope in the treatment period relative to the pre-treatment period (48 weeks). All treated populations reversed their disease course and improved. The p-value for primary analysis was 0.0022. Multiple sensitivity and other analyses confirmed the robustness of the results. Of note, the baseline-controlled study maintained operational and analytical rigor given that mFARS assessments were conducted in a systematic manner, and investigators and patients remained blinded to prior treatment assignments in Part 1 and 2. Furthermore, the quantitative level of improvement has been consistent in magnitude across all of the studies, even before accounting for subtle differences in subject cohorts. This provides evidence of the reproducibility of treatment effect.

Omav has been generally safe and well-tolerated in FA in three clinical studies with few discontinuations or serious adverse events.

FARA has supported a prospective, longitudinal natural history and outcome-measure study conducted by the Collaborative Clinical Research Network in FA (CCRN) since 2003 which has enrolled more than 1,000 FA patients. There have been more than 15 publications generated from this study including several providing rationale and evidence for clinically relevant outcome measures that are sufficiently sensitive for conducting FA clinical trials in a practical manner. In addition, we have worked with FDA to identify the modified version of the FARS neurological scale (mFARS) to be an acceptable primary endpoint clinical trials. This approach has been acceptable to sponsors and several FA trials have been or are being conducted using the mFARS as the primary end point.

We believe that the mFARS data along with the FA-ADL data (which was nominally statistically significant despite being underpowered in MOXie) from MOXIE Part 2, supported by the pharmacodynamic effect and the baseline-controlled study, provide strong evidence of the treatment effect of Omav in slowing disease progression and possibly improving neurological function. Our experience from the natural history study and other clinical trials, in which we have demonstrated mFARS to be a sensitive and predictive measure of neurological progression and clinical function and have observed that individuals with FA consistently progress as measured by the mFARS, informs the strength of our conviction that, in this well-controlled study over 48 weeks, improvement in mFARS is clinically meaningful and likely predictive of longer-term benefit. In addition, as we have now had patients taking Omav in an open label extension study for about 2 years, we have observed and heard from patients that they “have not worsened or progressed” since initiating Omav, an outcome that is of the highest priority to patients given relentless progression of FA.
LETTER FROM HEALTHCARE PROVIDERS

Our community understands that it may take many years to show unequivocal long-term benefits on disease progression. In the meantime, with no available treatment, patients and physicians know they will only continue to lose function, ability to do activities, their independence, and ultimately their lives. Therefore, the small uncertainty of an ultimate positive treatment effect can be tolerated. What would devastate this community is if a safe treatment that showed an impact on those earlier indicators was not permitted to go forward in an accelerated fashion while the long-term benefits are confirmed.

Further, we don’t believe it is feasible to conduct additional placebo-controlled trials of Omav in the United States due to complications of the current pandemic and the limited number of patients available as there are multiple trials ongoing. We are eager to work with Reata to conduct an ex-US, controlled, post-marketing, confirmatory study to evaluate longer-term clinical benefit.

In conclusion, as healthcare professionals, familiar with and in many cases actively treating patients with FA, relying upon our best ability and medical judgment of the clinical and basic science data collected to date, we want the option to prescribe Omav as a treatment for our patients with FA. We therefore ask you to encourage the sponsor to submit a new drug application for Omav for the treatment of Friedreich ataxia, and that you undertake to promptly review that application.

We also want to take this opportunity to whole-heartedly thank you and your colleagues at the FDA for all the work you are doing through the current crisis to respond to the urgent demands the pandemic has imposed. We admire and thank you for your continued commitment to the patients affected by Friedreich ataxia, even as you battle a broader public health crisis.

Sincerely,

David R Lynch, MD, PhD
Children’s Hospital of Philadelphia & University of Pennsylvania
LETTER FROM HEALTHCARE PROVIDERS

Additional Omav Clinical Trial Investigator Signatures

Sylvia Boesch, MD, MSc
Medical University Innsbruck

Martin Delatycki, MD, PhD
Bruce Lefroy Centre for Genetic Health Research &
Murdoch Children’s Research Institute

Paola Giunti, MD, PhD
University College of London

Chad Hoyle, MD
Ohio State University

Caterina Mariotti, MD
IRCCS-Neurological Institute Carlo Besta, Milan

Katherine Mathews, MD
University of Iowa Carver College of Medicine

Susan Perlman, MD
University of California Los Angeles Ataxia Center &
HD Center of Excellence

Sub Subramony, MD
University of Florida College of Medicine

George Wilmot, MD, PhD
Emory University School of Medicine

Theresa Zesiewicz, MD
University of South Florida Ataxia Research Center
LETTER FROM HEALTHCARE PROVIDERS

Additional Healthcare Provider Signatures

Nehman Abouazar, MD  
Centre Hospitalier de Mouscron - Belgium

Nicholas Allen, MD  
Galway University Hospital, Ireland

Tetsuo Ashizawa, MD  
Houston Methodist Research Institute

Lauren Baldelli, Registered Nurse  
Ottawa Public Health, Almonte General Hospital, Arnprior General Hospital

Guy Benarrouch, MD  
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Marissa Bunch, PhD APRN  
UT Chattanooga

Anne Connolly, MD  
Nationwide Children’s Hospital, Columbus Ohio

Linda Cripe, MD  
Nationwide Children’s Hospital

Antoine Duquette, MD, MSc, FRCP(C)  
Centre hospitalier de l’Universite de Montreal

Anne Fournier, MD  
CHU mère-enfant Sainte-Justine

Christopher Gomez, MD, PhD  
The University of Chicago

Alan Johnson, PT  
St Peter’s Healthcare Partners

Alan Johnson, PT  
St Peter’s Healthcare Partners

Katherine Julian, MD  
University of California, San Francisco

Karl Klamar, MD  
Nationwide Children’s Hospital, Ohio State University Wexner Medical Center

Albert La Spada, MD, PhD, FACMGG  
University of California, Irvine

Timothy Landers, PhD APRN-CNP FAAN  
Nationwide Childrens Hospital

Charlie Lewis, RN  
INOVA fair oaks

Kimberly Lin, MD  
Children’s Hospital of Philadelphia

Jennifer Lundine, PhD  
The Ohio State University

Querida Masters, PTA  
Heywood Hospital

Shana McCormack, MD, MTR  
Children’s Hospital of Philadelphia; Perelman School of Medicine at the University of Pennsylvania

Wolfgang Merx, Dr.Med.  
Gemeinschaftspraxis Uckerath

Martina Minnerop, MD  
Institute of Neuroscience and Medicine (INM-1), Research Center Juelich, Juelich, Germany, and Department of Neurology, Center for Movement Disorders and Neuromodulation, Heinrich Heine University, Düsseldorf, Germany
LETTER FROM HEALTHCARE PROVIDERS

Additional Healthcare Provider Signatures

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Kathrin Reetz, MD  
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Philip Schmidt, MD  
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Philipp Tresohlavy, MD  
Landeskranchenhaus Steyr, Austria

Chris Urban, MD  
SurgCenter Development
We, the Belgian Association for Friedreich’s Ataxia and Other Hereditary Ataxias (ABAF), are active in Belgium since 2001. Under the direction of its scientific council, our Association continuously raises funds to finance research projects, collaborates in medical studies, aims to promote information about FA. We also are member of Euro-ataxia, and we partner with FARA as well as other large French and European rare disease organizations.

It is important for drug and biologic sponsors and the FDA as well as the EMA, to hear the voices of rare disease communities and to know that these patients and their family members do engage in understanding the data from clinical trials in making decisions about safety and efficacy. Patients and caregivers provide elucidative insight on the level of uncertainty and risk they are willing to bear, as they live with their disease every day.

The ABAF has had the opportunity to review the results of the MOXIe studies and as our stakeholders are individuals living with FA we, like FARA, believe it is important to facilitate opportunities for direct patient engagement and incorporate the patient experience in the interpretation of results and decision making. It is based on these understandings and beliefs that ABAF supports the efforts of the Friedreich’s Ataxia Research Alliance and FA Community Call to Action requesting Reata to submit a New Drug Application (NDA) on an urgent basis and FDA to exercise the flexibility granted by law and contained in FDA guidance in considering approval of an NDA for Omaveloxolone in FA based on the existing evidence from clinical trials.
While we respect the FDA’s processes in approving drugs and biologics, it important for the FDA to appreciate that time is imperative in their evaluations of data for rare diseases. Each day that passes for these patients is a day for additional functional losses to occur. For all diseases, and for rare diseases in particular, law and regulation allow for a collaborative process for review where patients and caregivers have an equal seat at the table to describe their lived experiences with their disease and with taking the drug or biologic under review.

We believe that we are at an important inflection point in FA drug development with a positive clinical result and believe that we need to achieve clarity on guidance regarding what level of evidence is necessary for approving new drugs for FA. This guidance could help inform similar decisions for related rare diseases, especially other inherited ataxias, and/or could influence similar decisions by other regulatory bodies, ex-US, where there are individuals with FA are living.

We thank Reata and the FDA for their urgent review of the present letter, and we respectfully request that both organizations work together to provide access to Omaveloxolone for people with FA as soon as possible.

Caroline Decarpentrie, présidente
CALL TO ACTION

to REATA and the U.S.FDA (Food and Drug Administration)

We, the Association Française de l'Ataxie de Friedreich (AFAF), active in France since 1980, bring together more than 1000 members, including Friedreich's Ataxia (FA) patients and their parents and families. Under guidance of its scientific board, our Association continuously raises funds in order to finance research projects, collaborates to medical studies, aims to promote information about FA and its medical surveillance to health care providers, and brings social and psychological support to patients and their family. We also are member of Eurordis, Euro-ataxia, Orphanet, the French Rare Disease Alliance, and we partner with FARA as well as other large French and European Rare Disease Organizations.

It is important for drug and biologic sponsors, the FDA as well as the European Medical Agency (EMA), to hear the voices of rare disease communities and to know that these patients and their family members do engage in understanding the data from clinical trials and in making decisions about safety and efficacy. Patients and caregivers provide elucidative insight on the level of uncertainty and risk they are willing to bear, as they live with their disease every day.

The AFAF has had the opportunity to review the results of the MOXIE studies and as our stakeholders are individuals living with FA we, like FARA, believe it is important to facilitate opportunities for direct patient engagement and incorporate the patient experience in the interpretation of results and decision making. It is based on these understandings and beliefs that AFAF supports the efforts of the Friedreich's Ataxia Research Alliance and FA Community Call to Action.

This call to Action therefore requests Reata to submit a New Drug Application (NDA) on an urgent basis and the FDA to exercise the flexibility granted by law, and contained in FDA guidance, in considering approval of the NDA for Omaveloxolone in FA, based on the existing evidence from clinical trials.

While we respect the FDA's processes in approving drugs and biologics, it is important for the FDA to appreciate that time is imperative in their evaluations.

E-mail : contact@afaf.asso.fr / Tel : 03 23 58 61 65
Site : www.afaf.asso.fr
Siège Social : 12 Place Brisset – 02500 Hirson- France
of data for rare diseases. Each day that passes for these patients is a day for additional functional losses to occur. For all diseases, and for rare diseases in particular, law and regulation allow for a collaborative process for review where patients and caregivers have an equal seat at the table to describe their lived experiences with their disease and with taking the drug or biologic under review.

We believe that we are at an important inflection point in FA drug development with a positive clinical result and that we need to achieve clarity on guidance regarding what level of evidence is necessary for approving new drugs for FA. This guidance could also help inform similar decisions for related rare diseases, especially other inherited ataxias, and/or could influence similar decisions by other regulatory bodies, outside the US, where individuals with FA are living. Specifically, we believe that FDA decisions will strongly influence the arbitrage of the European Medical Agency, which granted orphan designation to Omaveloxolone in 2018.

We thank Reata and the FDA for their urgent review of the present letter, and we respectfully request that both organizations work together to provide access to Omaveloxolone for people with FA as soon as possible.

January 15th 2021

Dr. Juliette DIEUSAERT, présidente
Reata Pharmaceuticals
U.S. Food and Drug Administration

I write on behalf of the AISA Association that I represent and of the patients who refer to us.

A.I.S.A. is a Volunteer Organization and operates in the social and health field to encourage and promote research on all types of Ataxia, and strives to support ataxia patients and their families, by helping them in solving the problems arising from the onset of the disease.

AISA is an ONLUS association, registered in Registro del Terzo Settore (formerly Registri del Volontariato), it is part of EUROATAXIA which brings together the organizations that deal with Ataxia in Europe, of F.I.S.H. (Federazione Italiana per il Superamento dell’Handicap - Italian federation for overcoming disability) of FAND (Federazione Associazioni Nazionali Disabili – national federation of associations for people with disabilities), of Consulta Malattie Rare dell’ISS (Rare Diseases Consultation of ISS) and belongs and collaborates with associations linked to Telethon.

Patients and their caregivers inform us about the level of uncertainty and risk they face living with ataxia. AISA had the opportunity to review the results of the MOXIe studies, a multicenter MOXI-1 trial also conducted at the Besta Neurological Institute of Milan, that has proven effective in treating Friedreich’s ataxia. Since our stakeholders are individuals living with FA, we believe it is important to facilitate opportunities for direct patient involvement and to incorporate their experience in the interpretation of results and decision making.

AISA supports FARA’s efforts and the FA Community Call to Action and asks REATA to urgently submit a new drug application (NDA) to exercise the flexibility granted by law and contained in the FDA guidelines, in considering the approval of an NDA for Omaveloxolone in FA, based on existing evidence from clinical trials.

While we adhere to the FDA’s processes in approving drugs and biologics, it is important that the FDA appreciates that time is of the essence in their data assessments for rare diseases. Each passing day for these patients is a day of further functional loss. For all diseases, and in particular rare diseases, laws and regulations allow for a collaborative review process in which patients and health care professionals have an equal seat at the table to describe their experiences with the disease and with taking the drug or biologics.

We believe we are at an important inflection point in the development of drugs for FA with positive clinical outcomes and we believe we need to gain clarity on the guidelines for the level of evidence needed to approve new drugs for FA. This guidance could help inform similar decisions for related rare diseases, particularly other inherited ataxias, and/or could influence similar decisions by other regulatory bodies where people with Ataxia live.

AISA thanks Reata and the FDA and asks to work together to provide access to OMAV to people living with FA as soon as possible.

With Best Regards,

Maria Litani

President of AISA National ODV

Sestri Levante Ge/ January 17, 2021
We at Ataxia Canada represent over 800 Friedreich’s Ataxia patient and families affected and our mission is to improve the well-being of people with familial ataxia and support research. We have been funding research into FA since 1972 with the works of Dr. Barbeau.

It is important for drug and biologic sponsors and the FDA to hear the voices of rare disease communities and to know that these patients and their family members do engage in understanding the data from clinical trials in making decisions about safety and efficacy. Patients and caregivers provide elucidative insight on the level of uncertainty and risk they are willing to bear, as they live with their disease every day.

Ataxia Canada has had the opportunity to review the results of the MOXIe studies and as our stakeholders are individuals living with FA we, like FARA, believe it is important to facilitate opportunities for direct patient engagement and incorporate the patient experience in the interpretation of results and decision making. It is based on these understandings and beliefs that we supports the efforts of the Friedreich’s Ataxia Research Alliance and FA Community Call to Action requesting Reata to submit a New Drug Application (NDA) on an urgent basis and FDA to exercise the flexibility granted by law and contained in FDA guidance in considering approval of an NDA for Omaveloxolone in FA based on the existing evidence from clinical trials.

While we always respect the FDA’s processes in approving drugs and biologics, it important for the FDA to appreciate that time is imperative in their evaluations of data for rare diseases. Each day that passes for these patients is a day for additional functional losses to occur. For all diseases, and for rare diseases in particular, law and regulation allow for a collaborative process for review where patients and caregivers have an equal seat at the table to describe their lived experiences with their disease and with taking the drug or biologic under review.

We believe that we are at an important inflection point in FA drug development with a positive clinical results and believe that we need to achieve clarity on guidance regarding what level of evidence is necessary for approving new drugs for FA. This guidance could help inform similar decisions for related rare diseases, especially other inherited ataxias, and/or could influence similar decisions by other regulatory bodies, ex-US, where there are individuals with FA are living.

We thank Reata and FDA for their urgent review of the letter, especially the patient testimonies and request that they work together to provide access to omav for people with FA as soon as possible.

Francois-Olivier Théberge
General Manager
RE: Letter in support of campaign to approve Omaveloxolone

Ataxia UK is the leading patient organisation supporting those affected with ataxia in the UK. The charity was established over fifty years ago as the Friedreich’s ataxia group, and has a membership consisting of people with a range of ataxias including Friedreich’s ataxia (FA). Ataxia UK provides support and information to families, and importantly actively engages in research activities by funding projects, facilitating and promoting research to find treatments for this group of rare conditions.

As one of the sites for the MOXIe study was in the UK (at the London Ataxia Centre accredited by Ataxia UK) we have been supporting the dissemination of information about the study to our community and assisted in the recruitment process. There has been much interest in the UK in this trial at the various stages, and in particular, when the topline results were first announced just over a year ago.

We are submitting this letter to give a voice to FA patients and carers in the UK and we are aware that the FDA and the sponsor recognise the importance of this input. FA is a progressive condition with no current approved treatment and consequently the availability of interventions that have the ability to slow progression is urgent. Patients and caregivers provide important insight on the level of risk and uncertainty that they are willing to take, as they live with the condition daily.

Ataxia UK agrees with the Friedreich’s Ataxia Research Alliance that Omaveloxolone has the potential to benefit Friedreich’s ataxia patients as demonstrated by clinical trials to date, and that these trials could be considered sufficient to allow the drug to be used by neurologists for their patients. Although the MOXIe trial did not include a very large number of participants, it is important to consider the rarity of the condition. We would support the continued data collection in order to determine the long-term effects of the drug in patients, whilst not stopping patients from access to a drug that has shown efficacy in the trials to date. We therefore support the efforts of the Friedreich’s Ataxia Research Alliance and the global FA Community Call to Action requesting Reata to submit a New Drug Application (NDA) on an urgent basis and FDA to exercise the flexibility granted by law and contained in FDA guidance in considering approval of an NDA for Omaveloxolone in FA based on the existing evidence from clinical trials.
The FDA’s decision has important implications for decisions to be made in the future by regulators outside the US and we are keen for the decision for approval of this drug be also extended to the UK, Europe etc. in due course.

We thank you for your consideration of this important issue.

Yours sincerely,

Julie Greenfield, PhD. 
Head of Research

Sue Millman 
CEO

Professor Barry Hunt 
Trustee

William Littleboy. 
Co-Chair of Trustees

Richard Brown 
Co-Chair of Trustees
To:
U.S. Food and Drug Administration

Dear Leadership Team,

I am the head of the Brazilian community of FA patients and have been able to identify and register more than 540 patients in my country since my younger son was diagnosed with the same syndrome. We currently are the second largest FA population in the world.

Having an FAer in the family and interacting daily with at least 250 patients and parents bonded in an online group gave me enough personal experience to feel the impact of this devastating disease and raise the hope for a medication that can bring relief to such great pain. I have my experience as a mother and as a community leader but I am also a witness to the benefits omaveloxolone (omav) can bring to our children.

My son is one of the two Brazilian patients who had the opportunity to be part of the MOXIe Part 2 clinical trial and continues to get his medication in the current open label extension. I can confidently say that the evidence of his improvement is clear and without question. His gait and motor coordination improved, his fatigue was dramatically reduced, and his speech is much more clear. The benefits omav brought to him are unquestionable, visible and measurable.

My son was fortunate to have had this great opportunity, but there are literally thousands of FAers scattered around the world, many in the Third World, who didn’t have the same good fortune and may never if the FDA doesn’t give them this opportunity. I am from that part of the world and can guarantee that these patients have almost no access to the minimum care that could bring them more comfort and better quality of life. The FDA’s approval of rare disease medications has the magical power of shortening approval time in the regulatory agencies in many countries throughout the world.

The disease has no boundaries, and the lack of any treatment makes the need for omav approval even more urgent by the simple fact that most FApatients cannot wait for another two years for a second full clinical trial to be planned and completed. Their needs should be addressed now because every minute of their shortened timeline counts. I absolutely trust the numbers behind the MOXIe trial because I can see them reflected in my son’s progress. I hope my testimony will be taken into consideration and that you make the best decision on behalf of the FA community of the world.

Amalia Maranhao

Coordinator of the social movement Ataxia de Friedreich Brasil, chairwoman and president of Abahe - Brazilian Association of Hereditary Ataxias
We the Friedreich Ataxia Lebanese Association (FALA) are the first NGO in Lebanon and the region to support people afflicted with Friedreich Ataxia.

Due to the lack of public awareness in Lebanon as well as absence of service provision to FA patients, FALA’s aim is to address their needs and those of their caregivers and to ensure their social integration.

In Lebanon, there are currently 243 cases of FA registered with the Ministry of Social Affairs (MoSA).

It is important for drug and biologic sponsors and the FDA to hear the voices of rare disease communities, especially underserved ones and to know that these patients and their family members do engage in understanding the data from clinical trials in making decisions about safety and efficacy. As a result of needs assessments conducted for the FA patients and their caregivers, FALA was able to determine a wide spectrum of challenges including financial, medical, psychosocial support, ergonomic, and others. Therefore the FDA approval for the 1st ever treatment of this disease, would obviously affect Lebanese patients’ lives on many aspects.

Patients and caregivers provide elucidative insight on the level of uncertainty and risk they are willing to bear, as they live with their disease every day.

FALA has had the opportunity to review the results of the MOXie studies and as our stakeholders are individuals living with FA we, like FARA, believe it is important to facilitate opportunities for direct patient engagement and incorporate the patient experience in the interpretation of results and decision making.

It is based on these understandings and beliefs that FALA supports the efforts of the Friedreich’s Ataxia Research Alliance and FA Community Call to Action requesting Reata to
submit a New Drug Application (NDA) on an urgent basis and FDA to exercise the flexibility granted by law and contained in FDA guidance in considering approval of an NDA for Omaveloxolone in FA based on the existing evidence from clinical trials.

While we always respect the FDA’s processes in approving drugs and biologics, it important for the FDA to appreciate that time is imperative in their evaluations of data for rare diseases. Each day that passes for these patients is a day for additional functional losses to occur. For all diseases, and for rare diseases in particular, law and regulation allow for a collaborative process for review where patients and caregivers have an equal seat at the table to describe their lived experiences with their disease and with taking the drug or biologic under review.

We believe that we are at an important inflection point in FA drug development with apositive clinical results and believe that we need to achieve clarity on guidance regarding what level of evidence is necessary for approving new drugs for FA. This guidance could help inform similar decisions for related rare diseases, especially other inherited ataxias, and/or could influence similar decisions by other regulatory bodies, ex-US, where there are individuals with FA are living.

Closing statement – thank Reata and FDA for their urgent review of the letter, especially the patient testimonies and request that they work together to provide access to omav for people with FA as soon as possible.

Beirut, Lebanon 19-01-2021

Marianne Hakim
FALA- Friedreich Ataxia Lebanese Association
Co-founder & Executive director
We, in Friedreich’s Ataxia Research Alliance Ireland (FARA Ireland), represent people with Friedreich’s Ataxia having been founded by parents or friends of those with FA. Our aim has been to develop a strong connection with those who carry out research in FA, raise funds for research and increase awareness of FA.

It is important for drug companies, biologic sponsors, the Food and Drugs Administration (FDA) and the European Medicines Agency (EMA) to hear the voices of rare disease communities and to know that these patients and their family members do understand the data from clinical trials which eventually will make decisions about safety and efficacy of drugs that those with FA will need. Patients and caregivers have to educate themselves about their rare disease as so many doctors know so little about their particular disease. Those with FA live with uncertainty as their disease progresses on a daily basis.

FARA Ireland has had the opportunity to review the results of the MOXIe studies and like Friedreich’s Ataxia Research Alliance (FARA) in USA believe it is important to facilitate opportunities for direct patient engagement and incorporate the patient experience in the interpretation of results and decision making going forward. It is based on these understandings and beliefs that FARA Ireland supports the efforts of the FARA and FA Community Call to Action requesting Reata to submit a New Drug Application (NDA) on an urgent basis and FDA exercise the flexibility granted by law and contained in FDA guidance in considering approval of an NDA for Omaveloxolone in FA based on the existing evidence from clinical trials.

While we always respect the FDA’s processes in approving drugs and biologics, it important for the FDA to appreciate that time is imperative in their evaluations of data for rare diseases. Each day that passes for these patients is a day for additional functional losses to occur. For all diseases, and for rare diseases in particular, law and regulation allow for a collaborative process for review where patients and caregivers have an equal seat at the table to describe their lived experiences with their disease and with taking the drug or biologic under review.
We believe that we are at an important point in FA drug development with these positive clinical results and believe that we need to achieve clarity on guidance regarding what level of evidence is necessary for approving new drugs for FA a rare disease. This guidance could help inform similar decisions for related rare diseases, especially other inherited ataxias, and/or could influence similar decisions by other regulatory bodies, outside of the USA, including Europe and Ireland.

We wish to thank Reata and FDA for their urgent review of the letter, thank the patients who shared their story and request that Reata & FDA work together to provide access to Omaveloxolone for people with FA as soon as possible.

Sincerely

Mary Kearney Secretary FARA Ireland
General Practitioner
Tutor at Irish College of General Practitioners
Member of Cochrane Collaboration
17th January 2021

Reata Pharmaceuticals

To Whom It May Concern

We, FARA New Zealand (NZ) represent New Zealanders diagnosed with Friedreich’s Ataxia as well as their families and support network. FARA NZ’s mission “United, Positive and Strong, advocating and supporting people with Friedreich Ataxia to have the best care, treatment and quality of life. Our Vision is a cure for Friedreich Ataxia. Our organization provides support, information and fundraising to support scientific research into the condition and treatments. We have organized family information days and worked in partnership with clinician-researchers to develop the Centre for Brain Research (CBR) Neurogenetics Research Clinic at Auckland University and continue to support this initiative.

It is important for drug and biologic sponsors and the FDA to hear the voices of rare disease communities not only in the US, but worldwide and to know that these patients and their family members do engage in understanding the data from clinical trials in making decisions about safety and efficacy. Patients and caregivers no matter where they live, provide elucidative insight on the level of uncertainty and risk they are willing to bear, as they live with their disease every day.

While it is fully understood the FDA’s interests lie in supporting patients in the US, it is a fact that patients and their families across the world share exactly the same views as their colleagues in the US. Importantly, the equivalent regulatory Body in each country involved pays close attention to the work, processes and conclusions of the US FDA as they go about their own processes in approving emerging drugs for use in their jurisdictions. There are impacts beyond the US in the steps taken, or not taken by drug and biologic sponsors and the FDA.

FARA NZ has had the opportunity to review the results of the MOXiE studies and as our stakeholders are individuals living with FA we, like FARA USA, believe it is important to facilitate opportunities for direct patient engagement and incorporate the patient experience in the interpretation of results and decision making. It is based on these understandings and beliefs that FARA NZ and our members fully support the efforts of the Friedreich’s Ataxia Research Alliance and FA Community Call to Action requesting Reata to submit a New Drug Application (NDA) on an urgent basis and for the US FDA to exercise the flexibility granted by US law and contained in FDA guidance in considering approval of an NDA for Omaveloxolone in FA based on the existing evidence from clinical trials.
While we always respect the FDA’s processes and those of their sister organisations in other countries in approving drugs and biologics, it important for the FDA to appreciate that time is imperative in their evaluations of data for rare diseases. Each day that passes for these patients is a day for additional functional losses to occur. For all diseases, and for rare diseases in particular, law and regulation in most jurisdictions allow for a collaborative process for review where patients and caregivers have an equal seat at the table to describe their lived experiences with their disease and with taking the drug or biologic under review.

We, like everyone everywhere living with FA, believe that we are at an important inflection point in FA drug development with a positive clinical result and believe that we now need to achieve clarity on guidance regarding what level of evidence is necessary for approving new drugs for FA. This guidance could help inform similar decisions for related rare diseases, especially other inherited ataxias, and/or it will influence similar decisions by other regulatory bodies, ex-US, where there are individuals with FA are living.

FARA NZ, on behalf of all our members, especially those suffering with FA, congratulate Reata on their work in developing what we see as a very plausible treatment of this devastating disease. We also acknowledge and can see that the advice and guidance provided by the FDA and others has been a critical part of the Reata journey so far. Now, we thank Reata and FDA for receiving our letter, and point out that it has been deliberately submitted jointly with our FARA partner organisations in the US and Australia in the hope of strengthening an appeal by the global FA community in what we all view as a ‘nothing to lose and everything to gain situation’ created by the latest Reata studies, and work together to provide access to Omav for everyone with FA as soon as possible. Every day, every single day, counts in the race against this disease.

Yours faithfully,
FARA NZ

Dianne Boon
Chairperson
Thursday, 14 January 2021

Dear Reata Pharmaceuticals and U.S. Food and Drug Administration leadership,

The Friedreich Ataxia Research Association (fara Australia) represents Australians living every day with the degenerative neuro-muscular condition Friedreich Ataxia (FA). fara Australia’s mission is to fund research to find treatments and ultimately a cure for FA. We have approximately 180 FA patients, living in all areas of Australia. Many FA patients live in our major cities, however some of our FA patients live in remote and rural areas, where it is very difficult to access assistance and allied health services.

It is important for drug and biologic sponsors and the FDA, as well as the Therapeutic Goods Administration (TGA) here in Australia, to hear the voices of rare disease communities and to know that these patients and their family members do engage in understanding the data from clinical trials in making decisions about safety and efficacy. Patients and caregivers provide elucidative insight on the level of uncertainty and risk they are willing to bear, as they live with their disease every day.

fara Australia has had the opportunity to review the results of the MOXIe studies and as our stakeholders are individuals living with FA we, like FARA, believe it is important to facilitate opportunities for direct patient engagement and incorporate the patient experience in the interpretation of results and decision making. We also had Australian FA patients participate in the MOXIe trial as Melbourne was a study site for the Reata clinical trials. It is based on these understandings and beliefs that fara Australia supports the efforts of the Friedreich’s Ataxia Research Alliance and FA Community Call to Action requesting Reata to submit a New Drug Application (NDA) on an urgent basis and FDA to exercise the flexibility granted by law and contained in FDA guidance in considering approval of an NDA for Omaveloxolone in FA based on the existing evidence from clinical trials.
While we always respect the FDA’s processes in approving drugs and biologics, it important for the FDA to appreciate that time is imperative in their evaluations of data for rare diseases. Each day that passes for these patients is a day for additional functional losses to occur. For all diseases, and for rare diseases in particular, law and regulation allow for a collaborative process for review where patients and caregivers have an equal seat at the table to describe their lived experiences with their disease and with taking the drug or biologic under review.

We believe that we are at an important inflection point in FA drug development with a positive clinical result and believe that we need to achieve clarity on guidance regarding what level of evidence is necessary for approving new drugs for FA. This guidance could help inform similar decisions for related rare diseases, especially other inherited ataxias, and/or could influence similar decisions by other regulatory bodies, ex-US, where individuals with FA are living. The TGA places a great deal of importance on decisions made by the FDA. An approval by the FDA of an NDA for Omaveloxolone in FA would have a great influence on decisions made in Australia.

We are grateful to Reata and the FDA for your urgent review of this important letter. The patient testimonies and personal experiences of our FA community highlight how important and necessary Omaveloxolone is for our patients living with FA. Every day their disease progresses, and Omaveloxolone provides hope that we can slow that rate of function loss. We encourage you to work together to provide access to Omaveloxolone for people living with FA as soon as possible.

Kind regards,

Sherelle Fyfe
CEO, fara Australia
We the "Federación de Ataxias de España" (FEDAES), a non-profit organization that, encompassing various Regional Associations of Ataxia and forming part of other national and European federations, has as its main objective to promote the study and scientific research in the field of ataxias. FEDAES works actively to ensure that health care takes into account all citizens equally, and that it protects and supports the needs of minorities.

It is important for drug and biologic sponsors and the FDA as well as the European Medical Agency (EMA) to hear the voices of rare disease communities and to know that these patients and their family members do engage in understanding the data from clinical trials in making decisions about safety and efficacy. Patients and caregivers provide elucidative insight on the level of uncertainty and risk they are willing to bear, as they live with their disease every day.

The FEDAES has had the opportunity to review the results of the MOXIe studies and as our members are individuals living with ataxia we, like FARA, believe it is important to facilitate opportunities for direct patient engagement and incorporate the patient experience in the interpretation of results and decision making. It is
based on these understandings and beliefs that FEDAES supports the efforts of the Friedreich's Ataxia Research Alliance and FA Community Call to Action requesting Reata to submit a New Drug Application (NDA) on an urgent basis and FDA to exercise the flexibility granted by law and contained in FDA guidance in considering approval of an NDA for Omaveloxolone in FA based on the existing evidence from clinical trials.

While we always respect the FDA’s processes in approving drugs and biologics, it important for the FDA to appreciate that time is imperative in their evaluations of data for rare diseases. Each day that passes for these patients is a day for additional functional losses to occur. For all diseases, and for rare diseases in particular, law and regulation allow for a collaborative process for review where patients and caregivers have an equal seat at the table to describe their lived experiences with their disease and with taking the drug or biologic under review.

We believe that we are at an important inflection point in FA drug development with a positive clinical results and believe that we need to achieve clarity on guidance regarding what level of evidence is necessary for approving new drugs for
FA. This guidance could help inform similar decisions for related rare diseases, especially other inherited ataxias, and/or could influence similar decisions by other regulatory bodies, ex-US, where there are individuals with FA are living.

Specifically, we believe that FDA decisions will strongly influence the arbitrage of the European Medical Agency, which granted orphan designation to Omaveloxolone in 2018.

We thank Reata and the FDA for their urgent review of the present letter, and we respectfully request that both organizations work together to provide access to Omaveloxolone for people with FA as soon as possible.
To:  
a) U.S. Food and Drug Administration  
10903 New Hampshire Ave  
Silver Spring, MD 20993-0002  

b) REATA Pharmaceuticals  
5320 Legacy Drive  
Plano, TX 75024  

Subject:  Request for Omaveloxelone to be evaluated as the first treatment for Friedreich Ataxia  

Sir/Lady,  

We, the Hellenic Friedreich’s Ataxia Association (hereinafter HEFAA), represent the Greek patients and their families affected by Friedreich’s Ataxia (FA) with a mission to support the patients, the researchers, the pharmaceutical companies and the regulatory authorities towards finding a cure for FA. HEFAA is the sole association in Greece advocating for Friedreich’s Ataxia and represents the patients and the families in the whole country, including greek-american patients in the US.  

The Hellenic Friedreich’s Ataxia Association has had the opportunity to review the results of the MOXile studies and as our stakeholders are individuals living with FA we, like FARA, believe it is important to facilitate opportunities for direct patient engagement and incorporate the patient experience in the interpretation of results and decision making.  

For us, as patient advocates, the regulatory authorities constitute our security net and safeguard the safety of future approved compounds. While we always respect the FDA’s processes in approving drugs and biologics, it important for the FDA to appreciate that time is imperative in their evaluations of data for rare diseases. One thing that our patients don’t have is time. Each day that passes for these patients is a day for additional functional losses to occur.  

For all diseases, and for rare diseases in particular, law and regulation allow for a collaborative process for review where patients and caregivers have an equal seat at the table to describe their lived experiences with their disease and with taking the drug or biologic under review.  

We understand that according to legislative framework one of the statutory requirements for drug marketing approval is “substantial evidence” that the drug will have its claimed effect. This requirement is the same for all drugs regardless of whether they are for common or rare diseases.
Substantial evidence is based on the results of adequate and well-controlled investigations. It is of note, and highly important in this case of Omaveloxelone, that the regulatory framework provides the necessary flexibility in some circumstances, the data from one adequate and well-controlled clinical investigation and confirmatory evidence to be considered sufficient\(^1\).

HEFAA believes that we are at an important inflection point in FA drug development with positive clinical results and believe that we need to achieve clarity on guidance regarding what level of evidence is necessary for approving new drugs for FA. This guidance could help inform similar decisions for related rare diseases, especially other inherited ataxias, and/or could influence similar decisions by other regulatory bodies.

It is based on these understandings and beliefs that HEFAA supports the efforts of the Friedreich’s Ataxia Research Alliance and FA Community Call to Action requesting Reata to submit a New Drug Application (NDA) on an urgent basis and FDA to exercise the flexibility granted by law and contained in FDA guidance in considering approval of an NDA for Omaveloxolone in FA based on the existing evidence from clinical trials.

We thank you in advance both REATA Pharma and the FDA for urgently reviewing the present letter which should be read in conjunction with FARA’s and similar letters of FA patient advocates globally, and we request that all the stakeholders to work together to provide access to Omav for people with FA as soon as possible.

With the highest of respect

Vasileios KARATZIAS
Hellenic Friedreich’s Ataxia Association
President of the Board

\(^1\) See 21 CFR 314.126(a). See section 505(d) of the FD&C Act. See also the guidance for industry Providing Clinical Evidence of Effectiveness for Human Drug and Biological Products (May 1998).
Since our founding in 1957, the National Ataxia Foundation (NAF) has represented people affected by all forms of Ataxia. Our membership of almost 6,000 includes more than 700 people who either have Friedreich’s Ataxia (FA) or are those who support them.

It is important for drug and biologic sponsors and the FDA to hear the voices of rare disease communities and to know that these patients and their family members do engage in understanding the data from clinical trials in making decisions about safety and efficacy. Patients and caregivers provide elucidative insight on the level of uncertainty and risk they are willing to bear, as they live with their disease every day. NAF was a partner of the Friedreich’s Ataxia Research Alliance (FARA) in 2017 for the Externally-Led Patient Focused Drug Development Meeting (EL-PFDD) for FA. The Voice of the Patient Report that came from that meeting is a powerful summary of the devastating impact of FA. NAF held its own EL-PFDD meeting in 2020 for Polyglutamine Ataxias.

NAF has had the opportunity to review the results of the MOXIE studies, and as many of our stakeholders are individuals living with FA, we, like FARA, believe it is important to facilitate opportunities for direct patient engagement and incorporate the patient experience in the interpretation of results and decision making. It is based on these understandings and beliefs that NAF strongly supports the efforts of the Friedreich’s Ataxia Research Alliance and FA Community Call to Action requesting Reata to submit a New Drug Application (NDA) on an urgent basis and FDA to exercise the flexibility granted by law and contained in FDA guidance in considering approval of an NDA for Omaveloxolone in FA based on the existing evidence from clinical trials.
While we always respect the FDA’s processes in approving drugs and biologics, it is important for the FDA to appreciate that time is imperative in their evaluations of data for rare diseases. Each day that passes for these patients is a day for additional functional losses to occur. For all diseases, and for rare diseases in particular, law and regulation allow for a collaborative process for review where patients and caregivers have an equal seat at the table to describe their lived experiences with their disease and with taking the drug or biologic under review.

We believe that we are at an important inflection point in FA drug development with positive clinical results and believe that we need to achieve clarity on guidance regarding what level of evidence is necessary for approving new drugs for FA. This guidance could help inform similar decisions for related rare diseases, especially other inherited Ataxias, and/or could influence similar decisions by other regulatory bodies, ex-US, where individuals with Ataxia are living.

We thank Reata and the FDA for your urgent review of the attached letter, especially the patient testimonies, and request that you work together to provide access to Omaveloxolone for people with FA as soon as possible.

Sincerely,

Andrew Rosen
Executive Director

Samuel Kirton
President, Board of Directors

Vikram Shakkotai, MD, PhD
Chair, Medical and Research Advisory Board