

WINTER 2013-2014

the Advocate

Your connection to the Friedreich's Ataxia Research Alliance



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FARA

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You Are The Key To Our Success!

By Ron Bartek

Dear friends,

This letter is entirely for you — the FA patient and family members. I know you will agree that this issue of The Advocate is full of really good, really exciting news. The evidence on these pages is clear and mounting. With every additional scientific discovery, every additional pharmaceutical partner (and they are getting larger in number and size) that gets involved with us, every additional supportive NIH, FDA or congressional action, every additional advocacy organization that agrees to co-fund a grant with us, and with every additional clinical trial that gets under way, we know with more and more certainty that, together, we will cure FA. What I want to say to you, here, is simple and true — NONE of that would be happening without you.

My wife and FARA co-founder, Raychel, said in the beginning, “If FA research is a wheel, the patients are every spoke — without them, the whole wheel collapses.” That was true then and is even more so now. We knew from the beginning that to cure FA we would all have to pull together to build and nurture effective public-private partnerships — with scientists, government, pharmaceutical companies, and other advocacy organizations. First, we had to get the attention of those four potential partners. This is especially true because FA is a rare disorder; we could not get their attention with a single voice. It was only when you all came together in support of the whole FA family that FARA could speak effectively with your full voice. What we found is that, collectively, your voice is not rare — it’s a roar! All four partners have heard it loud and clear!

And, yours is not an empty roar. You always back it up with solid actions that have made you the essential spokes of all four of our partners’ wheels. For FA scientists around the world, you are inspiration and important support. Many of them who have met you tell us that you have changed their lives. Our government partners at the NIH and FDA know that FARA speaks with your

collective voice and that your voice has been raised in their behalf. Because they have listened to your collective voice, they also know FA far better, now, and they want to help. Congress, too, has heard your voice along with millions of others with rare disorders and continues to pass legislation that facilitates therapy development for rare conditions such as FA. Our growing number of pharmaceutical partners are drawn to FA largely because they see you continue to enroll in the world’s largest FA patient registry, and visit FARA’s clinical centers where your data builds the natural history data they are mining to design their clinical trials. They see that you are eager to participate in clinical research — their trials will not fail due to insufficient participation. FARA’s co-funding partners in other advocacy organizations hear your collective voice, too, and know that we are all in this together.

I guess I like to think of FARA in the role of bringing these four wheels together and providing the connective frame for the vehicle needed to drive the fruit of these essential partnerships — treatments and a cure — across the finish line. Of course, no such vehicle can move at all without fuel. And, there you are again! You can see from the amazing number of FARA events you and your families are holding throughout the year how wonderfully you are fueling our cure-development vehicle. I hope you feel excited as you read in this issue about how much momentum and acceleration our vehicle is gaining. I hope you feel proud, too, because NONE of this would be happening without you. With you, we will treat and cure FA. That’s how we roll!

Warm regards,

Ron



Progress Continues in Treatment Pipeline

By Jennifer Farmer

Preparing this article and updating the research pipeline is one of my best activities. It engages a reflective and analytical review of where have we come during the past year and where are we going. Compared to this time last year we can see real progress in advancing treatments.

• **Five new clinical trials have been initiated.**

- Safety and Efficacy of EPI-743 in Patients with FA – Phase 2
- EPI-743 in Friedreich's Ataxia Point Mutations
- Safety and Pharmacology Study of VP20629/OX1 in Adults with FA – Phase 1
- Interferon Gamma-1b in children with FA – Open label, proof of concept
- Effect of Nicotinamide (B3) in FA

• **18 new biopharmaceutical, development and venture capital companies have contacted FARA with interest in learning more about FA, the pipeline, and our Clinical Research Infrastructure**

(Patient Registry, Natural History study and Collaborative Clinical Research Network). We hear that the interest in FA is due to the scientific progress in FA to understand the mechanism of the disease, multiple ways to approach treatment at genetic, protein and biochemical levels, the slowly progressive nature of the disease (window of treatment opportunity), the high unmet medical need, and a patient community that is engaged in research. Few rare diseases have >1400 individuals participating in natural history and clinical outcome studies (600 US, 100 Australia, and 700 Europe).

• **Three new lead candidates added to our treatment pipeline.**

The treatment pipeline has been updated to show advancement of some key programs and further clarification of mechanism of action. A new category along the horizontal access has been added – Modulation of Frataxin Deficient Pathways. These are approaches that target effects of frataxin deficiency in the cell that might have a direct effect on improving function, correcting dys-

function, or breaking a vicious cycle.

Below are summaries of three new lead candidates.

Dietary/Nutritional Approaches – Dr. Rob Wilson at the University of Pennsylvania has identified certain nutritional compounds that can activate PGC1 α , which is decreased in frataxin deficient cells. Normally, when there is mitochondrial dysfunction in a cell, PGC1 α is recruited to try to correct the damage. PGC1 α is a special type of protein that recruits and controls expression of other genes involved in energy metabolism. Dr. Wilson at the CHOP symposium in Oct 2013 talked about trying to break a vicious cycle as a therapeutic approach that includes trying to increase PGC1 α through other mechanisms, such as with nutritional compounds. Of note, individuals with FA recently completed a trial in France of Pioglitazone, a drug used in treating diabetes that increases PGC1 α . We anxiously await those results; however, it is unlikely that Pioglitazone will be able to go forward as a treatment for FA because it has significant cardiac side effects.

Nrf2 Activators – Dr. Gino Cortopassi and other groups have observed that Nrf2 (Nuclear factor (erythroid-derived 2)-like 2, a protein that is critical in a pathway to protecting the cell from oxidative stress), is paradoxically decreased. Specifically, Dr. Cortopassi's group has shown that Nrf2 protein is decreased in frataxin deficient cells and FA mouse models. Through a drug discovery program that screened a library of clinically-approved drugs the group has identified several compounds that act as Nrf2 activators and rescue biochemical and cellular deficits related to frataxin deficiency. Dr. Cortopassi is collaborating with Dr. Susan Perlman at UCLA to provide further validation of these therapeutic targets. Ixchel Pharma LLC has options on this intellectual property. In September 2013, Dr. Cortopassi received Orphan Drug designation of dimethyl fumarate for the treatment of Friedreich ataxia. Dimethyl fumarate is a drug that is approved for multiple sclerosis; however trials in Friedreich ataxia have not been done

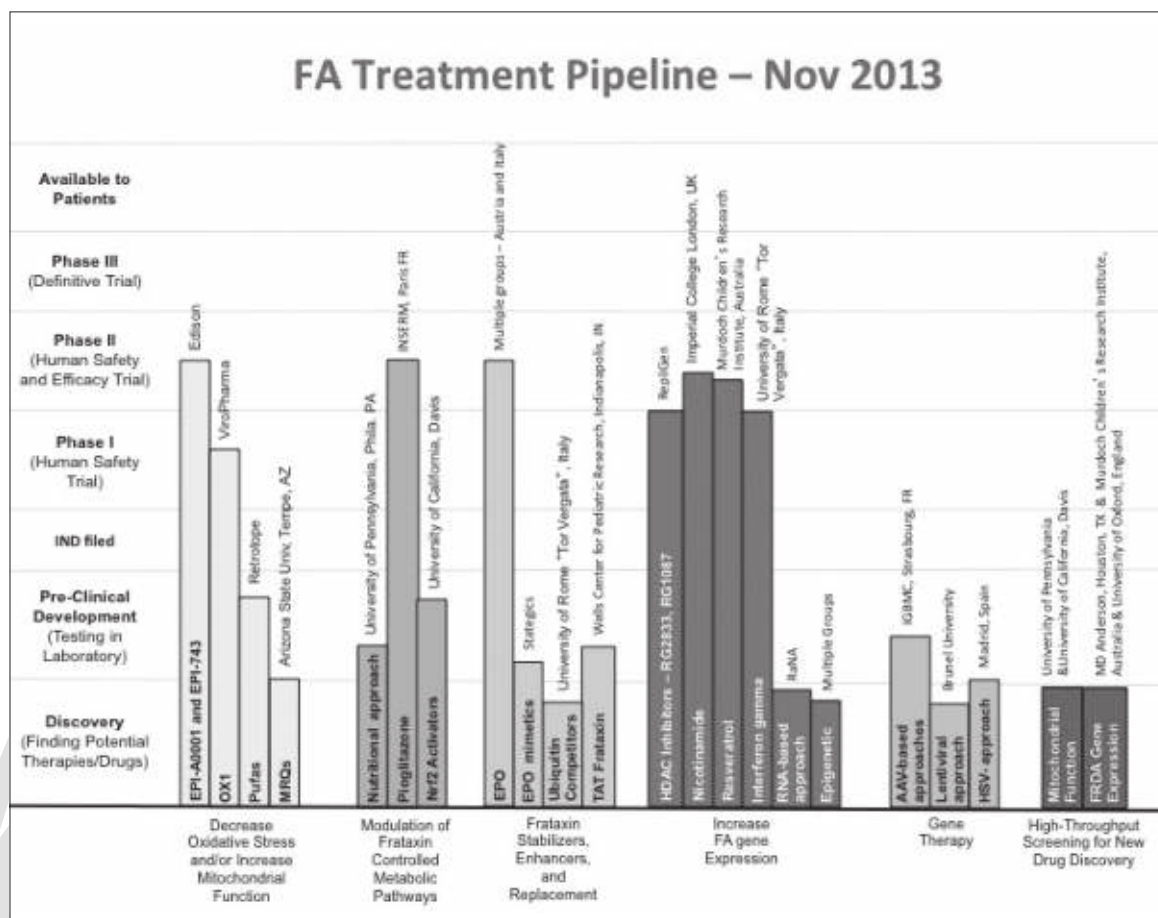
so we don't yet know if there is benefit in treating FA.

RaNA – RaNA is focused on increasing frataxin through increasing expression of the gene with a novel approach that we are excited to add to the pipeline. In FA we know that the gene is silenced and therefore individuals don't make enough frataxin. Many FA scientists and pharmaceutical partners are working to understand why the gene is silenced and how to un-silence it. RaNA's approach employs scrutinizing the epigenetics (other inherited factors, such as RNA targets) that influence expression of the FXN gene. Their strategy has identified novel non-coding RNA (ncRNA) potentially responsible for directing the localized epigenetic silencing of the FXN gene. "Degrading this ncRNA led to at least partial heterochromatin reversal and FXN mRNA and protein level upregulation to therapeutically significant levels." These results were recently presented at the American Society for Human Genetics meeting in Boston, MA, October 2013. *See F. Ozsolak, www.ashg.org/2013meeting/pdf/46025_Poster_book-mark%20for%20Web%20final%20from%20AGS.pdf*

In the year ahead we look forward to results from the trials initiated this year and to several others that are just finishing such as pioglitazone (France), nicotinamide (United Kingdom) and EPO (Italy).

Our treatment pipeline continues to remain diverse and robust, essential factors to treating and curing FA. We can't be naïve — we know that some of our best attempts at new therapies will fail (if doing this were easy we would be done!). However, many of our lead candidates have passed significant hurdles and have made it to Phase 2 trials which is incredibly encouraging and reason for us all to remain steadfast in our efforts. Also, as Ron always says, we will need a cocktail of treatments and together we will Cure FA.

Please visit the FARA website, pipeline page for a complete summary of all lead candidates and approaches: curefa.org/pipeline.html.



Awards, Deadlines and Research Updates

By Bronya Keats, PhD

Researchers in Belgium, Australia and the United States received funds from FARA recently through the 2013 Phillip Bennett & Kyle Bryant Translational Research Award and the Bronya J. Keats International Research Collaboration Award. As described below, these two research projects have the potential to establish incretin analogs as effective therapeutics for FRDA and to develop new cardiac biomarkers that measure change in FRDA cardiomyopathy and are critical for clinical trials.

During 2013, FARA received 39 Letters of Intent (LOIs) for our named and general research awards, and reviewed 26 new grant applications of which nine were funded; we anticipate that at least four more will be approved for funding before the end of the year. As well as the nine new grants, continuation funds were provided for 15 projects; so far FARA has provided a total amount of approximately \$3 million in research funding during 2013. Additionally, FARA recently announced a joint Request for Proposals with Ataxia UK and GoFAR (Italy) to attract research projects that investigate the molecular and pathological features of affected neurons directly in FRDA patients using minimally invasive approaches. Following careful review of the 18 LOIs received, FARA invited 6 researchers to submit applications by the January 15, 2014 deadline.

All ongoing FARA-funded research projects directly target FARA's research priorities. They include major initiatives such as:

- 1. Dr. Hélène Puccio's FRDA cardiac and neuronal gene therapy work**
- 2. Dr. Alice Pébay's optimization of FRDA cardiac cell models derived from induced pluripotent stem cells (iPSCs) and success with cardiac tissue engineering (see Recent Publications below)**
- 3. Dr. Jordi Magrané's mitochondrial morphology, distribution and dynamics (axonal transport, fusion, fission) studies both in vitro in specific neuronal types from FRDA mice and in vivo using a cross between FRDA and mitoDendra transgenic mice, which have fluorescently-labeled mitochondria in both the pe-**

ripheral and central nervous systems, to advance understanding of disease pathophysiology.

Recently Awarded Grants

• **Phillip Bennett & Kyle Bryant Translational Research Award: Incretin analogs as new therapeutics for Friedreich's ataxia**

Principal Investigator: Dr. Miriam Cnop, Université Libre de Bruxelles, Belgium

Co-Investigators: Drs. Mariana Igoillo-Esteve and Massimo Pandolfo
Initial research by Dr. Cnop focused on the cause(s) of diabetes in FRDA and demonstrated that diabetes develops due to dysfunction and death of pancreatic insulin-producing β -cells. This preliminary work also showed that incretin analogs are protective for frataxin-deficient β -cells. Incretins are gut hormones that control blood sugar levels and stable hormone analogs have been developed in recent years to treat diabetes. Unexpectedly, Dr. Cnop observed that these drugs induce frataxin expression in pancreatic β -cells. Importantly, she confirmed that incretin analogs also induce frataxin expression in neuronal cells derived from FRDA patients. The aim of this preclinical project is to evaluate the potential of incretin analogs to induce frataxin and prevent or improve neurodegeneration and diabetes. Studies of frataxin induction by incretin analogs in cultured cells will be completed, and it is likely that the findings will lead rapidly to a clinical trial of incretin analogs in FRDA patients, since drugs are commercially available for the treatment of diabetes.

• **Bronya J. Keats International Research Collaboration Award: Interstitial fibrosis, the renin-angiotensin-aldosterone system and biomarkers in the cardiac disease of Friedreich ataxia**

Co-Investigators: Drs. Martin Delatycki, Roger Peverill and Louise Corben (Murdoch Childrens Research Institute and Monash University, Melbourne, Australia) and Drs. David Lynch and Kimberly Lin (Children's Hospital of Philadelphia, PA)

The large gaps in knowledge regarding the nature and causes of the heart involvement in FRDA limit the ability to investigate

potential treatments. Increased thickness of the heart walls, a common feature in FRDA, is a predictor of symptomatic heart disease and premature mortality. Based on this information alone, a reduction in wall thickness has been considered a valid clinical endpoint in some clinical trials. It is suspected that the increase in wall thickness in FRDA involves both loss of heart muscle cells and an increase in scar tissue. A new cardiac magnetic resonance imaging (CMR) technique has shown promise in detecting early scarring but has not yet been studied in FRDA. In this collaborative study between the Melbourne and Philadelphia Collaborative Clinical Research Network (CCRN) sites, CMR will be performed on 105 individuals with FRDA to determine the frequency and extent of scarring in the heart muscle wall. An important component of this study is the investigation of the relationship of heart changes in FRDA with one of the body's natural hormonal systems (the renin-angiotensin-aldosterone system), which is already known to play a role in other types of heart disease. A second important component will be measuring a number of blood markers of heart function in individuals with and without FRDA, in order to understand the mechanisms that may contribute to the heart muscle changes. Some individuals with FRDA will undergo repeat CMR and blood testing at 12 months to determine changes in these biomarkers, so that their potential usefulness in future FRDA clinical trials can be assessed. The findings arising from this study will provide vital information regarding the nature of heart involvement in FRDA and help us to identify the best techniques to use when testing drugs for FRDA in the future.

Titles and summaries of most of the projects presently funded by FARA are available at:

curefa.org/RPMP/public/pggrantlist.aspx and complete listings of grants awarded by year can be accessed at: curefa.org/grants-awarded.html

Recent Publications — FARA Funded Research

In August 2013 the Journal of Neurochemistry published a special issue with the title "150 Years of Friedreich Ataxia Research." Several of the articles were based on research studies funded by FARA. Other recently published papers based on FARA-funded research include:

- An evaluation of vision in FRDA patients coordinated by Dr. David Lynch and including data from several CCRN sites. The vi-

sual system was characterized using high- and low-contrast letter acuity and optical coherence tomography (OCT) to determine retinal nerve fiber layer (RNFL) and macular thickness. Letter acuity was highly correlated with neurological outcomes. RNFL thickness values were below the 5th percentile (based on age-matched normal controls) for 58 of 110 FRDA eyes, and macular thickness values were below the 1st percentile for six of 29 FRDA eyes. These measures capture visual and neurologic function in FRDA, suggesting they are useful markers of disease progression. (Seyer L, Galetta K, Wilson J, Sakai R, Perlman S, Mathews K, Wilmot G, Gomez C, Ravina B, Zesiewicz T, Bushara K, Subramony S, Ashizawa T, Delatycki M, Brocht A, Balcer L, Lynch D. *Journal of Neurology* 260:2362-2369, published online June 2013.)

- An assessment of the therapeutic potential of deuterated polyunsaturated fatty acids (D-PUFAs) by Dr. Robert Wilson's group in collaboration with Retrotope, Inc., titled "Insights into the role of oxidative stress in the pathology of Friedreich ataxia using peroxidation resistant polyunsaturated fatty acids." This study showed that isotopically reinforced (deuterated) PUFAs rescued oxidative-stress-challenged FRDA cells, suggesting that oral delivery of D-PUFAs may be of therapeutic value for FRDA patients. (Cotticelli G, Crabbe A, Wilson R, Shchepinov M. *Redox Biology* 1:398-404, published online June 2013.)

- A study by Dr. Alice Pébay and colleagues demonstrating that human iPSC-derived cardiomyocytes can be used to engineer functional cardiac muscle tissue, which has the potential for generating cardiac grafts to replace damaged myocardium, as well as providing tissue for studying the pathophysiology of cardiac disease and for drug discovery. This research also identified a novel strategy for enhancing cardiac differentiation of FRDA human iPSCs using a histone deacetylase inhibitor, trichostatin A. (Lim S, Sivakumaran P, Crombie D, Dusting G, Pébay A, Dilley R. *Stem Cells Translational Medicine* 2:715-25, published online July 2013.)

- A report by Dr. Devin Oglesbee and colleagues of a new diagnostic method for measuring the amount of frataxin in whole blood and dried blood spots. This high-throughput immunoassay for measuring frataxin facilitates the diagnosis and therapeutic monitoring of FRDA patients. It also provides a reliable means of differentiating among patients, carriers and individuals with normal frataxin levels using a minimal amount of blood. Thus, a potential use is high-throughput population screening for FRDA.

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(Oglesbee D, Kroll C, Gakh O, Deutsch E, Lynch D, Gavrilova R, Tortorelli S, Raymond K, Gavrilov D, Rinaldo P, Matern D, Isaya G. *Clinical Chemistry* 59:1461-69, published online July 2013.)

• Research by Dr. Michele Lufino and colleagues focused on developing a GAA-expanded frataxin genomic DNA model of FRDA. This genomic reporter cell model has 310 GAA repeats and using it to screen a library of small molecules identified one that up-regulates frataxin expression in patient cells and restores normal histone acetylation around the GAA repeats, suggesting that it may be of therapeutic benefit. (Lufino M, Silva A, Németh A, Alegre-Abarrategui J, Russell A, Wade-Martins R. *Human Molecular Genetics*, published online August 2013.)

A comprehensive list of FARA-funded and other research publications on FRDA is available at: curefa.org/scientific-news.html.

Grant Application Deadlines

Grant Type	2014 LOI Deadlines	2014 Application Deadlines	Maximum Budget (in US dollars)
General Research Grant	February 1 July 15	April 1 September 15	\$150,000 per year for 1 or 2 years
Keith Michael Andrus Cardiac Research Award	January 15	March 1	\$150,000 per year for 1 or 2 years
Phillip Bennett and Kyle Bryant Translational Research Award	May 15	July 15	\$250,000 per year for 1 or 2 years
Bronya J. Keats International Research Collaboration Award	May 15	July 15	\$200,000 per year for 1 or 2 years

Exceptions to these deadlines are projects that the investigator believes may be of high priority to FARA. An LOI for such a proposal may be submitted at any time during the year. However, the justification for such special consideration must be compelling.

Grant application guidelines are available at: curefa.org/grant.html •

Clinical Studies are Critical to Research Advancement!

For more information on the latest clinical research and to learn how you can participate, please visit:

Patient Registry

curefa.org/registry

Collaborative Clinical Research Network

curefa.org/network.html

Autopsy Program

curefa.org/trial.html

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Dr. Sanjay Bidichandani

By Marilyn Downing

Sanjay Bidichandani is our featured scientist and we are proud to announce that he is the newest member of our FARA Board of Directors. Dr. Bidichandani earned his MBBS from the University of Pune, India and his PhD from the University of Glasgow, Scotland, UK. He completed his post-doc and assistant professorship in Neurology at Baylor College before becoming Professor of Biochemistry, Molecular Biology and Pediatrics at the University of Oklahoma Health Sciences Center, and served as Vice-President for Research at the Muscular Dystrophy Association. He returned recently to the University of Oklahoma to become head of the Section of Genetics, Department of Pediatrics.

Dr. Bidichandani's father taught him that while it's important to be clever, it is even more important to work hard and surround oneself with like-minded dedicated people. His father explained that your best chance to encounter "luck" is through a focused and collaborative effort.

Dr. Bidichandani has worked diligently in an effort to find a cure for Friedreich's ataxia, and he also had some luck early in his career — to be a part of the research group that found the FA gene in late 1995. Dr. Bidichandani excitedly recounts the story of when his research team at Baylor College in Houston, led by Massimo Pandolfo, discovered the triplet repeat expansion on what is now known as the FXN gene, on chromosome 9.

Today, with the genome mapped, this is a much simpler process, but in 1995 the group had to spend a tremendous amount of time manually screening the coding portions of the gene. They were even beginning to question if they were looking at the correct gene. Then, with a hard-to-read southern blot test and Dr. Pandolfo's persistence, the needle in the haystack was found in the non-coding region of the gene. The problem was a triplet repeat expansion. The protein affected was named frataxin. History was made and Sanjay had been a part of it. Luck? Intelligence? Determined hard work? Dr. Bidichandani would say it was all three.

What does this triplet repeat expansion do and why does it translate to less frataxin? Researchers have found the expansion causes the gene to fold/close up so that it cannot be accessed and the "recipe" for frataxin is not read properly. Put simply, this lack of the frataxin protein causes the disease progression in Friedreich's ataxia.

Dr. Bidichandani continues his FA research in the field of epigenetics, a quickly growing and fast moving field. Epigenetics is the study of heritable traits that are not in the DNA/gene of interest, in this case the FXN gene, but in traits that surround it or control the expression of the gene. He says FA researchers are "surfing the epigenetic wave" and applying what's being learned to FA research. Dr. Bidichandani finds there are continued challenges as they discover that the epigenetic defect in FA can actually turn off/silence expression of the gene. Also, mouse models show that the genetic defect is not static but expands in the dorsal root ganglia and the cerebellum. However, Dr. Bidichandani states, bringing patient frataxin levels to half the normal level — even a quarter of the normal level — will make a huge difference in their lives.

Notably, while at Baylor, Dr. Bidichandani was involved with the discovery of the G130V mutation in Friedreich's ataxia, after studying the Ramsey family, which presented with a milder form of FA. He finds it remarkable that he now is sitting on the FARA board with Ed Ramsey as chairman.

Dr. Bidichandani attributes much of the growth in FA research to FARA, due to the efforts to collaborate with/between scientists, develop relationships with the pharmaceutical industry, the FA rating scales, the patient registry, and the drive to move projects along. He feels FARA has made those with FA feel a true community. He senses this major partnership between scientists and this FA community motivates the scientists to do their best.

What does Dr. Bidichandani think are the two most exciting advances in FA research in 2013? He says without hesitation the completion of the first phase of the HDAC inhibitor trial in Italy. This trial showed a signal that frataxin could be raised in people through this approach — a significant milestone since the founding of the gene 18 years ago. Going forward we can hope for a

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Young Family's Involvement Is A Team Effort

By Kyle Bryant

At Ride Ataxia Chicago this year, the Young family recruited the largest team in Ride Ataxia history. Team Emily consisted of 76 riders from their central Illinois hometown of Gibson City, which has a population of about 3,400. "We have been here our whole lives and have made some amazing friends so we are able to bring together a lot of people for the ride," says Emily's mom, Becky Young.

The strong community support goes beyond the impressive team numbers. "It is important for Emily to know that she has support. We have not been going through this on our own.

When you are first diagnosed you go through that period of shock and disbelief. Then it has time to absorb and it just makes you realize how important today is — we try to live for today. After we let it sink in we decided we want to be proactive and that's what led us to FARA."

The Young family has been involved in a huge way. They have had two "Barnraisers" (a fundraiser party in their barn), a Team FARA for the Philadelphia Half Marathon and the Chicago Half Marathon, and the largest team in Ride Ataxia Chicago for the past two years.

"Since we have become involved we discovered a great community of doctors and scientists who care about a treatment just as much as we do," Becky adds. "They are in this with us and that goes a long way when you're sitting up late at night thinking."

Along with participation and fundraising, the Young family takes a huge role in planning and execution of the ride: scouting the route, communicating with the venue and police support, passing out flyers, handling web posting, and outreach to local media.

Being involved in the ride is great for the Young family, says Becky. "It's a good opportunity for Emily to set and achieve goals," she says. Emily rode her furthest to date with a 12-mile ride on her new Catbike. Fundraising also helps the Youngs know that



Team Emily gets ready to ride at Ride Ataxia Chicago.

they are part of the solution — they are pushing the treatment and cure closer and closer to the finish line. The Youngs' community is a huge part of that solution. "We have had so many friends get involved and touched by the spirit of FARA," says Becky.

Families like the Youngs have assembled in six Ride Ataxia locations across the country to ride and raise awareness and funds for FA research. And in 2013 they reached some new milestones:

- **More people with ataxia cycled on adaptive equipment than ever before in the ride program**
- **We reached a new fundraising record of more than \$220,000 for a single ride in Philadelphia**
- **In 2013, the Ride Program raised over \$660,000 (gross)!**

None of this would be possible without the tireless efforts of our FA families, presenting sponsor Outback Steakhouse, and the hundreds of volunteers. We hope you can join us for a Ride Ataxia event near you in 2014 — Ride to Cure FA! ●

Ride Ataxia 2014 Schedule

RA Dallas (Denton, TX)	March 29
RA NorCal (Davis, CA)	May 31
RA Chicago (Channahon, IL)	July 20
RA Seattle	August TBD
RA Philly (Blue Bell, PA)	October 12
RA Orlando (Clermont, FL)	November 2

For more information, visit rideataxia.org

Ataxian Athlete Initiative

By Kyle Bryant

FARA's Ataxian Athlete Initiative (AAI) provides adaptive cycling equipment to people with Ataxia who have demonstrated the desire to stay active and healthy despite their disabilities.

AAI grants are administered through a competitive application process. Applicants are invited to submit an essay summarizing their experience with Ataxia and their efforts to stay active. Individuals then select the most appropriate adaptive cycling equipment to suit their abilities and describe how such equipment would help them to reach their fitness goals. AAI grants are awarded based on the merit of the applications, equipment requested, and resources available in terms of funding.

The 2013 AAI was funded by The FA Project, Catrike, UVA Sun Systems, The Texas Irish Foundation, and a donation in memory of Gladys Lacativo.

With the 2013 grant awards, the AAI has provided equipment for 21 individuals since its 2009 inception. In 2013, the AAI sent equipment overseas for the first time to Ireland and Australia. Additionally Ride Ataxia teamed up with the Texas Irish Foundation for the first time specifically to provide equipment in the North Texas area.

The 2013 AAI recipients are Lealan LaRoche of Atlanta, GA, Regina Russo of St. Petersburg, FL, Eric Pogulis of Elk River, MN, Liberty Griggs of Anchorage, AK, Alex Dagley of Frisco, TX, Barry Rice of Dublin, Ireland, and Terrence O'Hanlon of Cleveland, Australia.

Applications will be available February 1 for the 2014 AAI. View more info and sign up to receive email alerts at rideataxia.org/aai. ●



Lauren Williams is a 2012 recipient of a Top End Excellerator XLT

Featured Scientist, Continued from page 7

U.S. trial of perhaps an even better HDAC molecule. Secondly, he notes the involvement of larger pharmaceutical companies, which is new within rare diseases. One very encouraging example is a recent meeting with Pfizer in which experts attended from different disciplines within the company that were well versed in FA— a truly collaborative exchange and a strong interest in the FA program. Having corporations such as this come to the table offers additional resources for FA research.

This writer would like to say that Dr. Bidichandani is not only a brilliant scientist, but a kind and gentle man. There is no question that the FA community was lucky when Dr. Bidichandani chose this field of research. With such hard work, good people and perhaps a little luck, we will be brought to our next milestone of an approved treatment. ●



A Disease Unlike The Rest

*This disease is strong, stronger than the rest
I can feel it attacking so I can't rest
I need to stand next to those who win
Because if I win then I'll be the one with the biggest grin
But if I rest and take too long of a breath
Then the disease will take me over just like the rest
But if I fight back I will know that the disease
Can't take me over or at least not with ease
So I will fight back and I will be the one who is pleased
I need to gain up my strength and go full force
Because I need to be divorced
'Divorced from what?' you will probably ask
The answer is from this disease because that is my task
A task that is hard, that very few can do
But we can do it together me and you
I'm fighting FA and I'm going to win
So can you help me and my twin?
Yes, it is true this disease is affecting two
But we will fight back and win
We will be the ones to overcome this disease
We will be the ones who bring the disease to its knees
We will try our best not to rest
So our disease will know it's just a guest
We will fight this disease and let it know it can't rest
We will win and be the best of the bests
This disease is stronger than the rest
But it must know it's fighting the best of the bests
With your help we can fight the disease
FA is a degenerative disease
So it will be hard to bring it to its knees
But you hold the keys to our fate
So will you help us before it is too late?*

— Christian Maugee, age 14



Isabel and Christian Maugee

What is Friedreich's Ataxia?

Friedreich's Ataxia is a debilitating, life shortening, degenerative neuro-muscular disorder. Onset of symptoms can vary from childhood to adulthood and can include loss of coordination (ataxia) in the arms and legs; energy deprivation and muscle loss; vision impairment, hearing loss, and slurred speech; aggressive scoliosis (curvature of the spine); diabetes mellitus; and a serious heart condition. While the mental capabilities of people with FA remain completely intact, the progressive loss of coordination and muscle strength in FA leads to motor incapacitation and the full-time use of a wheelchair. There is currently no treatment or cure for FA. FARA is a 501 (c) (3) tax exempt, non-profit organization dedicated to supporting research that will improve the quality and length of life for those diagnosed with Friedreich's Ataxia and will lead to treatments that eliminate its symptoms.



(L to R): Auctioneer Scott Robertson, Energy Ball Co-Chair Suzanne Avery, Emcee Wendy Ryan and Energy Ball Co-Chair Paul Avery

Ladies and gentlemen start your engines!

FARA Energy Ball Races Towards a Cure

By Felicia DeRosa

With the ballroom adorned with racing stripes, spotlight centerpieces, a checkered flag finish line, and broadcast sights and sounds from renowned historical races, it was a race to the finish line for this year's FARA Energy Ball. The racing theme at the event in the À La Carte Event Pavilion in Tampa, FL mirrored the urgency of FARA's own race to the finish line of treatments and a cure for FA. The sold-out event's crowd of 750 guests provided the fuel to get ahead in that race. The 2013 FARA Energy Ball reached an astounding \$1.8 million (gross) in donations and in-kind gifts to benefit FARA and our partners at the University of South Florida Ataxia Research Center!

The week kicked off with an informative Scientific Symposium hosted by the USF Ataxia Research Center at the Center for Advanced Medical Learning and Simulation. The symposium featured talks by Dr. Guy Miller of Edison Pharmaceuticals, Dr. Mirella Dottori of the University of Melbourne and Dr. Hélène Puccio of INSERM, as well as USF Health researchers, FARA staff and an FA patient panel. The researchers offered updates on projects such as mitochondrial agents, induced pluripotent stem cells, and gene therapy, while the patient panel added a unique

perspective on the challenges of living with FA and their own personal achievements. Two hundred supporters attended the symposium and hundreds of others viewed online as it was live-streamed. To view the video playback of the symposium, visit: www.facebook.com/CureFA/app_196506863720166

The Energy Experience went tropical for a Hawaiian Luau-themed Patron Party generously hosted by three-time Energy Ball Honorary Chair and CEO of the Tampa Bay Lightning and the Tampa Bay Times Forum, Tod Leiweke. Top level sponsors dined on seafood fare provided by Roy's Hawaiian Fusion and Bonefish Grill in a private party at the Forum lit with the FARA logo and curefa.org on the big screen.

The week culminated in a high octane Energy Ball that was meticulously orchestrated and creatively executed by a dynamic and talented planning committee. The evening, hosted by Emcee Wendy Ryan of ABC Action News, included hundreds of silent auction items spanning the spectrum of signed memorabilia, art, unique excursions, and certificates to Tampa's local spas and eateries. It also included a rousing live auction with exclusive get-aways to Napa Vineyards, Nantucket, Jimmy Buffet's former home in Key West, Pebble Beach, a Montana Ranch, and even a new Volkswagen Beetle! Thanks to the generosity of all in attendance, the Fund-a-Cure donation live pledge raised a record smashing \$260,000 for FA research in a matter of minutes. Highlights included many individuals digging deep to contribute to research and gain access to two admissions in the Party Suite at the Eagles concert and a chance to meet the band, generously donated by the Lightning Foundation. It also included tables pooling



FARA Board Chair Ed Ramsey and his wife Lisa

Energy Ball

their resources to compete against one another and earn the top contributing table spot. The night finished at an all-time Energy high with a live electric performance by The Black Honkeys (aka The Soul Power Review).

Thank you to an amazingly dedicated planning committee, our tireless volunteers, and our generous in-kind and financial donors. You are an invaluable "pit crew" that keeps this research vehicle on the track and racing towards the finish line. ●

SAVE THE DATE!
FARA Energy Ball
September 4-6, 2014



FARA Spokesperson and Ride Ataxia Director Kyle Bryant with the USF Cheerleaders

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Partners, Friends And Ally Awards

By Felicia DeRosa

A Jack Johnson and Ben Harper song came out a few years ago that celebrated the ability within each of us to make a difference for the better: "With My Own Two Hands." It opens:

*I can change the world
With my own two hands
Make it a better place
With my own two hands
Make it a kinder place
With my own two hands*

FARA's story is a story of what a cohesive team can do when the members move their "hands" and their hearts towards a common goal. With this year's Partner of the Year Award, Friend and Ally Awards and Media Partner Award, we honor the partners, friends and allies among us who have changed our world with their own hands.

Partner of the Year — Tod Leiweke & The Tampa Bay Lightning

FARA is honored to present the 2013 Partner of the Year Award to Tod Leiweke and The Tampa Bay Lightning. We had the good fortune to meet Tod, CEO of the Tampa Bay Lightning and the Tampa Bay Times Forum, in 2011. From the start he took on the Lightning motto and was "All in" for FARA. Tod and the Lightning organization's contributions to FARA have extended farther and deeper than his three-year service as the Honorary Chair of the Energy Ball in Tampa. Earlier this year, the Lightning hosted a FARA night at one of their games: the forum was lit with cureFA.org around the rink and the FARA logo on the scoreboard! They even made a special presentation to FARA spokesperson Kyle Bryant and drew further attention to the cause in an arena full of hockey fans. The organization has also contributed numerous exclusive auction items to the Energy Ball Silent and Live auctions such as *Travel with the Team to an Away Game*, raising critical dollars for research. To further our awareness efforts, leading league scorer Steve Stamkos also taped a promotional video for FARA and the Energy Ball. The Lightning Foundation and Light-



Laura Beth Jacquin and Tod Leiweke

ning Team Owner Jeff Vinik have also been incredibly generous Energy Ball sponsors. This year, the Lightning donated their suite for the Eagles Concert to help raise the Energy Ball Fund-a-Cure pledge to an all time high of \$260,000!

Through all of these activities and many more, Tod and the Lightning have made a tremendous positive impact on FARA's ability to advance research. Furthermore, Tod has invested himself personally in the cause by participating in Team FARA events to push research forward with his personal effort. A most sincere and heartfelt thank you to Tod and the entire Lightning organization for putting their hands "All in" for FARA. They have made the FA world a better place and we are proud to call them our Partners of the Year.

Friend & Ally — Herman & Tanya Fernandez

If you've attended the FARA Energy Ball and experienced the magic of the event or felt the awe for the funds raised for research, then you've met indirectly our Friend & Ally recipients, Herman and Tanya Fernandez. In addition to building a large circle of support for FARA among their friends and providing an unparalleled in-kind wine and spirits donation through Southern Wine and Spirits of America, Herman and Tanya are key members of the Energy Ball planning committee. Two years ago, due to Herman and Tanya's creative brain storming, the Fund-a-Cure live donation pledge received an infusion of energy. They suggested live tallying and displaying the pledges from each table to cre-

Partners, Friends And Allies Of The Year



Herman and Tanya Fernandez

ate some friendly competition in the ballroom as guests pledged funds to support clinical research. This concept harnessed a unique energy that has helped triple the dollars raised in pledges and allowed FARA to advance that much more research. We owe gratitude to Herman and Tanya not only for directing their fundraising acumen to the cause but also for being the kind of friends who show up to support FARA's efforts repeatedly throughout the year. They travel to and ride in Ride Ataxia Dallas and Orlando; they host a wine tasting at the Pull for a Cure Clay Shoot Tournament; and they sponsor the Ace for a Cure Tennis Tournament. They always come with a warm smile, a sincere embrace and kind words that let you know that there is no other cause they'd rather be using their own two hands to help.

Friend & Ally — Lawrence “Superlario” Phillips

When the FARA team first started working with Larry at the end of 2009, he was known as “the jersey guy.” He designed all of the Ride Ataxia cycling jerseys and worked with the first-rate team at AK Apparel to produce them. Over time, Larry became more than just the “jersey guy.” Due to his graphic design talent and generosity with his time, Larry became the Ride Ataxia “design guy.” In addition to the jerseys, Larry has designed the new Ride Ataxia logo as well as all of the Ride electronic and printed communications. Larry always quickly turns around clean, quality designs and has introduced FARA to local printers to supply event t-shirts and brochures at competitive rates. Larry has been incredibly thoughtful about how best to communicate Ride Ataxia's message in graphics and text so as to optimize awareness garnered through these materials. Larry even volunteers to assist with smaller everyday projects, so he is not only a key contributor



Lawrence “Superlario” Phillips

to Ride Ataxia branding, but an extension of the FARA team. We are grateful that Larry has used his hands to create art for a cure.

Media Partner of the Year — Mike Barbaro & Clear Channel Outdoor

FARA hit the outdoor big screen to promote all Ride Ataxia city locations as well as the Energy Ball this year. Thanks to Media Partner of the Year, Mike Barbaro and Clear Channel Outdoor, FARA had multiple electronic billboards in seven key cities including Tampa, Orlando, Philadelphia, Chicago, Dallas, Portland and Sacramento. This was a unique opportunity to raise awareness of FA and promote participation in fundraising events in a way that complemented print and TV media in those areas. Everyone who reported seeing the billboards conveyed a sense of wonder and gratitude. Mike and Clear Channel Outdoor have used their hands/ resources to provide FARA with a dynamic platform to raise the profile of Friedreich's ataxia and encourage involvement. ●



Horses Go Wild For Fundraising!

By Jamie Young



Team Mustangs for Alison celebrate at the finish line!

Team Mustangs for Alison competed in the Savannah Rock 'n' Roll Full and Half Marathon Series on November 9. Thirty-five runners came from five different states in an effort that raised over \$50,000 for FA research!

What eventually grew to a total of 44 team participants and a combination of runners and virtual fundraisers, started with a single inspiration: Alison Price from North Carolina, who was diagnosed with FA in the summer of 2012. After her diagnosis, Alison's parents Wendi and Matt found comfort in the support of the FA community through meeting families on FAPG and at the CHOP Symposium. They quickly became interested in supporting the FA research effort.

"It's all about the Plan B of life," says Wendi. "There are so many things that we cannot control, but that doesn't mean we are going to just sit around. Reaching out to our community and raising funds for research is something we can control and help the research community help our daughter."

Several miles away in Florida, Alison's aunt, Jill Gould, wanted to connect their family and communities together to help this effort. Jill had participated in Team in Training in the past and selected

Team FARA as a way to establish an open fundraising platform to get as many participants as possible without the geographic constraints. They selected a nearby event to compete in and also gave people the option to join the Team virtually and fundraise from any location.

Team Mustangs for Alison had success with fundraising by reaching out to their community using letters, e-mails, Facebook and small fundraising events. For example, Jill held small garage sales with items people donated in her community and give-back nights at a local restaurant. They also created awareness through creating team t-shirts, bracelets and coin purses.

"The important thing our family learned while doing this is that people want to help," Jill says. "It's just a matter of asking. Team FARA created a way for them to help give back to something that was going to directly help our family and others living with FA."

About Team FARA

Team FARA is made up of people around the globe who participate in endurance events on behalf of the Friedrich's Ataxia Research Alliance (FARA) with the goal of raising awareness and funds for FA research. Past Team FARA members have registered as individuals and groups in local marathons, ½ marathons, triathlons, ironman competitions, bike tours and 5K runs. You can join Team FARA simply by registering in a local athletic event of your choice and deciding to do so in FARA's name. FARA will provide a fundraising webpage for you to customize with a photo and information about your event participation. For more information please contact info@curefa.org.

FARA Store

For yourself, your family and friends, or to have customized FARA items at fundraising events, visit the FARA store!

www.cureFAstore.com.

FARA caps, polo and t-shirts, wristbands, etc.



Grassroots Grid

2013 Events	Event Organizer	Location	In Honor of
Northeast			
Yellowjackets Spring Show for FARA	Galen Dole and Sarah Gelbard	Rochester, NY	The Ferrarone Family and Marlise Dole
Team FARA Flower City Half Marathon - Elizabeth Way	Elizabeth Way	Rochester, NY	The Ferrarone Family
Louise Aubrie CD Release Show	Louise Aubrie and John Sweeny	New York, NY	Connor Sweeny
Spark Hope Cocktail Party	Jean Walsh	Beverly, MA	Walsh Family
Putnam Valley Bible Club Pizza Sale	Carissa Burgard	Putnam Valley, NY	FARA and All FA Families
Race for Christina 5K	Catherine Logan	Newtown, PA	Christina Logan
The FA Project Striking Courage Bowlathon	FA Project	Wakefield, MA	FARA & FA Project
Team FARA Tri-Rock Triathlon - Evelyn Wu	Evelyn Wu	Philadelphia, PA	Matt Dilorio & Grace Hopkins
Chase-Perry Yard Sale	Becky Chase	Fairhaven, MA	Jade Perry
Flatbread and Fisherman's Fundraiser for FARA	Erin O'Neil	Bedford, MA	Erin O'Neil
Team FARA Mighty Moss Half Marathon - Jennifer Sinnott	Jennifer Sinnott	Norwalk, CT	Donovan Simpson
Welsh Bash in the Backyard	Francine Welsh	Harrisburg, PA	Brendan Welsh
Purple Summer: A Benefit Concert for Christina	Catherine Logan	Philadelphia, PA	Christina Logan
Team FARA Blackburn Challenge - Tim Gleason and Jean Walsh	Tim Gleason and Jean Walsh	Cape Ann, MA	Jean Walsh
Fuzzy Buzzy Golf Tournament	Paul Stanieich	Windham, NH	Erin O'Neil
McDonnell Music Festival	David McDonnell	Queensbury, NY	Dylan McDonnell
Race for Matt and Grace	Katie Hopkins and Dilorio family	Colt State Park, RI	Matt Dilorio & Grace Hopkins
Team Adirondack - Adirondack Mountains Hike	Mike DeISignore	Adirondack State Park, NY	Dylan McDonnell
TJ Hat Tournament	Elizabeth Way	Rochester, NY	The Ferrarone Family
Team FARA West Chester Triathlon - Team Donovan	Debra Simpson and Sally Braid	Rye, NY	Donovan Simpson
Team FARA Leaf Peepers Half Marathon and 5K Run - The Best Team	Kristen Adams	Waterbury, VT	Sydney Adams
Team FARA ING New York City Marathon	FARA	New York, NY	FARA and All FA Families
Hearts of Hope Shopping Night for FARA	Mary Caruso	North Branford, CT	Sam and Alex Bode
Socialize, Shop, Support Sunday	Krissa Lazaropoulos	Medford, NJ	Leo Lazaropoulos
Southeast			
Friedreich's Ataxia BINGO	Dawn Lambert	Palm Harbor, FL	Gavin Lambert
Olde Bay Cafe Anniversary Fundraiser	Olde Bay Cafe	Dunedin, FL	FARA
Anytime Fitness Golf Scramble	Dawn Lambert	Palm Harbor, FL	Gavin Lambert
Do Good Things Sunday	Stone's Cove KitBar	Herndon, VA	FARA and All FA Families
Donkey Basketball	Natalie McGrady	Penn Laird, VA	Anna Gordon
Anna's Army Car Wash	Melissa Gordon	Parkersburg, WV	Anna Gordon
World of Beer - FARA Fundraiser	World of Beer	Arlington, VA	FARA and All FA Families
Ace for A Cure	Sandy Callaghan	Tampa, FL	FARA and All FA Families
A Night of Mystery Masquerade Ball	Melissa Gordon	Mineral Wells, WV	Anna Gordon
Swing Away at FA	Candy Stacks	Dawsonville, GA	Hannah & Austin Stacks
Chris's Fight Car & Bike Show	Amanda Laird	Cape City, KY	FARA
Pull For A Cure	Mike Mezrah	Land O Lakes, FL	FARA and FA Families
Cobb Professional Fire Fighters Golf Tournament	Cobb Professional Fire Fighters	Marietta, GA	Laura Beth Jacquin
4th Annual Young Hearts Putt Putt Golf Tournament	Rebecca Andrus	Falls Church, VA	Keith Andrus
11th Annual DC Regional Outback Steakhouse Charity Golf Classic	Outback Steakhouse	Waldorf, MD	FARA and All FA Families
FARA Fest 2013 - CureFA 5K and 1 Mile Fun Run	Tammy Leonard	Virginia Beach, VA	Luke Leonard
Team FARA Swim Around Key West - Team Ryan and Owen Jones	Kristin Jones	Key West, FL	Ryan and Owen Jones
Outback Luncheon	Outback Steakhouse	Springfield, VA	FARA and All FA Families
FARA 100 Miller Party	Kevin Bush	Charleston, SC	Bridget Downing
Team FARA Athens Half Marathon - Team Van Schoick	Katie Kilch	Athens, GA	Robbi and Becca Van Schoick
Team FARA Savannah Rock N Roll Marathon - Team Mustangs for Alison	Matt Price, Wendi Price and Jill Gould	Savannah, GA	Alison Price
West			
Race 4 Results & Rabbit Run	Carrie Laird	Bakersfield, CA	Jerod Laird
St. Catherine's Annual Jog-A-Thon	Greg Jones	Anaheim, CA	Chelsea Lane
Izzy's Angels 3 - Dance Party	Zoe Penston	Alameda, CA	Izzy and Owen Penston
Ride Ataxia MTZ Fundraiser	Angela Lacativo Greene	Martinez, CA	Kyle Bryant
Friends of Jerod Reverse Draw	Carrie Laird	Bakersfield, CA	Jerod Laird
Century 21 Golf Classic	Brian Lamascus	Rancho Cucamonga, CA	Joshua Lamascus
Stephanie's Hope Holiday Boutique	Stephanie Magness	Santa Clarita, CA	Stephanie Magness
Team FARA Tour de Palm Springs	FARA	Palm Springs, CA	FARA and All FA Families
Team FARA SamJam 2013	Sam Bridgman	Portland, OR	Sam Bridgman
Zumba Fitness Fundraiser	Ashley Day	Libby, MT	Kyle Bryant
Team FARA American River Parkway Half-Marathon - Rachel's Runners	Breanne Moen	Sacramento, CA	Rachel Gill
Team FARA Change your Latitude Swim - Team Ryan and Owen Jones	Kristin Jones	Sitka, AK	Ryan and Owen Jones
Team FARA Running With the Buffaloes 100 Mile Foot Race - Kevin Bush	Kevin Bush	West Yellowstone, MT	Bridget Downing
Horizon High School Pie Throwing Fundraiser	Maya Rodich	Scottsdale, AZ	Alena and Alisa Wolfson
Midwest			
Lone Star Benefit Bash	Performance Award Center	Flower Mound, TX	Robbi and Becca Van Schoick
FA Woodstock	Paula and Tom Hook	LaPorte, IN	Kati & Carli Hook
GCMS & D.G. Sullivan's Charity Night	GCMS	Gibson City, IL	Emily Young
Hole Out for a Cure	Rick Peters	Peoria, IL	Rick & Todd Peters
Slim's Journey	Julie Myers	Warrenton, MO	Justin Myers
Hayden's Hope Warrior Run	Sarah Despenas	Mason City, IA	Hayden Despenas
Team FARA St. Patrick's Day 4 Miller - Kelly Alfieri	Kelly Alfieri	Powell, OH	Christopher Repass
Team FARA Fit for FARA Weight Loss Challenge - Team Brittany	George and Paula Perzee	Watseka, IL	Brittany Perzee
Outback Steakhouse Tee it Up Golf Tournament	Tulsa Outback Steakhouse	Tulsa, OK	FARA and All FA Families
Attack Ataxia Charity Luncheon - Jumping for Jazz	Virgil Harris	McCordsville, IN	FARA and All FA Families
Team FARA Chicago Marathon - Doug Finck	Doug Finck	Chicago, IL	Kati & Carli Hook
CANADA			
Comedy Night for Friedreich's Ataxia	Maids of Athena	Montreal, Quebec	FARA and All FA Families
Fun for FARA	Maids of Athena	Vancouver	FARA and All FA Families
FARA Invitational Golf Classic	Bill Alefantis	Calgary, Alberta	FARA and All FA Families
Ataxia Summer Social	The Denny Family	Nova Scotia	FARA and All FA Families

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Memorials

FARA remembers the friends we have lost, and we thank all who chose to remember a loved one with a donation to FARA. In the past year, we have received over \$56,000* in memory of the following individuals:

Aaron Kittel, Alexandra Domingue, Bil Brothers, Brent Moore, Charles Luttrell, Chelsea Lane, Clint Ziegler, Dallas Gendall, Douglas Spooner, Eileen Parsons, G.D. Parrish, Garrett Timbie, George Davies, Geraldine Schreiber, Gustav Hannu, Hugh Andrus, Hugo T. Blackfelner, Jean S. Koehler, Jerry Kusa, John Andresen, John Furey, John O'Brien, Joseph Rieder, The Fortes - Joseph, John, & Michael, Joshua and Leah Chalcraft, Karye J. Willard, Kathleen Paulsen, Keith Andrus, Larry Myers, Marcia Young, Mary Norman, Mary Szweda, Mel Caruso, Michael Hahl, Michelle Walsh, Nathan Bell, Patty Ann Lovell, Paul Flippo, Paul H. Marcotte, Peter Rossi, Phil Bennett, Robert Gannon, Robert Loudermilk, Robert Trantham, Rudolf Folts, Ruth Downs, Sally Cottrell, Sara Ferrarone, Tim Witten, Vanessa Wells, Vera Loftin, William Hymes, and Yiayia Lazaropoulos.

To request envelopes to be used for memorials, please contact FARA at info@cureFA.org.

*Year to date as of November 7, 2013.

Fundraising



Kristin Jones continues to amaze on open water swims for Team FARA in honor of her brothers, Ryan & Owen (Juneau, Alaska)



FARA friends enjoy an Outback Luncheon in Springfield, VA



Erin O'Neil's Flatbread & Fisherman's Fundraiser was a success! (Bedford, MA)



The talented Cat Logan (center) sings her sister Christina's favorites at the Purple Summer benefit concert with Mazeppa Productions (Philadelphia, PA)



The World of Beer fundraiser in Arlington, VA provided good food, good beer, and good company!



Craft time at FA Woodstock, held at the Hook Family's Flying H Ranch in LaPorte, IN

Fundraising



In addition to the fun & games, there was a chance to participate in research at FA Woodstock (LaPorte, IN)



The Young Family rides to cure FA at Ride Ataxia Chicago 2013! (Channahon, IL)



Tim Gleason & Jean Walsh paddled 20 miles for Team FARA in the Blackburn Challenge! (Cape Ann, MA)



Mike DelSignore (right) captained Team Adirondack - a 45 mile hike - in honor of Dylan McDonnell (Glens Falls, NY)



The Welsh Family Bash in the Backyard was a blast! (Harrisburg, PA)



Elizabeth Way organized the TJ Hat Ultimate Frisbee Tournament in honor of Laura Ferrarone (left) and her friend TJ (Rochester, NY)

Fundraising



The Fuzzy Buzzy golf tournament in honor of Erin O'Neil reached a 10 year total of \$105,000! (Windham, NH)



Erin and her dad Bob enjoyed a great day thanks to her Uncle Paul "Buzzy" Stanieich (Windham, NH)



Kevin Bush ran an amazing 100 miles for Team FARA in honor of Bridget Downing! (Charleston, SC)



The Alefantis family's Invitational Golf Classic raised \$40k for our Collaborative Clinical Research Network site at Sick Kids Hospital in Toronto (Calgary, Alberta)



What a great day for golf at the 6th Annual Century 21 Golf Classic in honor of Josh Lamascus (Fontana, CA)



The group enjoyed a delicious Outback Steakhouse lunch following golf (Fontana, CA)

Fundraising



A record number of runners joined the Race for Matt & Grace in honor of Matt Dilorio and Grace Hopkins! (Smithfield, RI)



Good friends Matt Dilorio, Mike Crawley, and Christina Logan enjoy race day (Smithfield, RI)



Jeff, Justin "Slim", and Julie Myers organized the wonderful Slim's Journey 5K/2.5mi walk (Warrenton, MO)



Sam Bridgman and the cyclists at Ride Ataxia Portland head out on a scenic ride on Sauvie Island (OR)



The Lambert Family is Kickin FA at their Bingo tournament leading up to Team Gavin's Marathon of Hope! (Clearwater, FL)



Team Donovan celebrates at the finish line for the 9th year at the Westchester Tri! (Rye, NY)

Fundraising



Jennie Sinnott (right) supports and inspires her good friend Deb Simpson (Rye, NY)



Brian Bianchi leads the pack at Ride Ataxia Philly dedicated to Garrett Timbie (Blue Bell, PA)



Friends & family gather at Angela Lacativo Greene's annual MTZ fundraiser for Ride Ataxia (Martinez, CA)



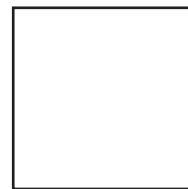
A beautiful fall day at the Stacks Family Swing Away at FA wiffleball tournament! (Dawsonville, GA)



Katie Kilch ran the AthHalf with husband Kyle and friends in honor of sisters Robbi & Becca (Athens, GA)

The FARA Advocate is brought to you by:
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WINTER 2013-2014

the Advocate

Your connection to the Friedreich's Ataxia Research Alliance



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