











2021 Donor Impact Report



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Dear Friends,

Three themes emerge when we reflect on our work together to advance research for Friedreich's ataxia throughout 2021: the persistence of the FA community, the power of our collective voice, and the progress that results from such action.

The FA community's persistence was evident in your ongoing commitment to engagement, education, fundraising, and clinical research. Over the past year, individuals offered their time to enroll in clinical research like the TRACK-FA neuroimaging study, volunteers brought back in-person fundraising events, and community members engaged in important education about gene therapy.

At the outset of the year, FARA issued a call to action to the FA Community to submit testimony, photos, and signatures for an FA Community Petition to the Food and Drug Administration and Reata Pharmaceuticals to allow individuals with Friedreich's Ataxia access to Omaveloxolone, and you responded 74,000 signatures strong! The community's submissions were assembled to create a compelling document that brought the patient voice to the drug development process. Following the petition, Reata Pharmaceuticals submitted a New Drug Application to the Food and Drug Administration, where it is now being reviewed.

As you will see in the pages that follow, FARA has deployed the resources you've entrusted to us across a growing number of research initiatives. FARA's research strategy now includes a competitive peer-reviewed grant

program, institutional research funding, and FARA-directed research projects. The aim of this strategy is to harness the intellectual resources of the research community, proactively pursue scientific priorities, and leverage new technologies, insights and resources to expedite the discovery and development of treatments and cures for FA.

In this Donor Impact Report, we hope to convey the many ways your resources have strengthened FARA's work. Some of those key milestones are listed on the opposite page, including a diverse treatment pipeline with > 18 candidates across six treatment approaches in development. These potential opportunities to treat FA exist because of your support. On behalf of the entire FA community, thank you!

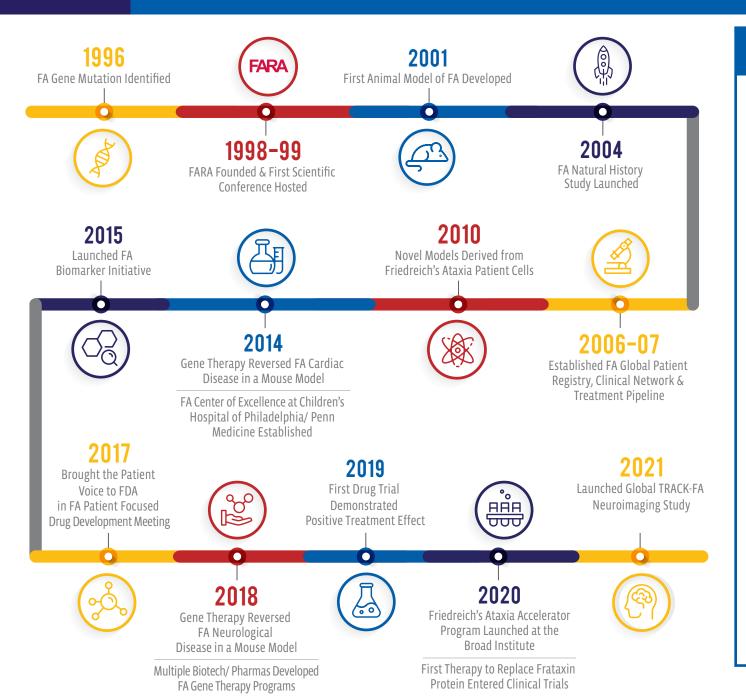
With our gratitude,

Jennifer Farmer, Chief Executive Officer

Ron Bartek, President



IMPACT & MILESTONES



2021 MILESTONES



FUNDED > 7M IN RESEARCH

to fuel drug discovery and research tools to accelerate therapeutic development

FACILITATED THE FA TREATMENT

PIPELINE with >18 candidates across 6 treatment approaches in development or clinical trials



GREW THE COLLABORATIVE

Clinical Research Network (CCRN) by two sites

EXPANDED GLOBAL RESEARCH ENGAGEMENT



SUSTAINED RESEARCH & BUILT

insights at the Center of Excellence and the FA Accelerator Program









LAUNCHED TRACK-FA NEUROIMAGING STUDY

RESEARCH GRANT PROGRAM

The FARA Grant Program funds research to further the understanding of FA and to promote therapeutic discovery and development. This investigator-initiated, peer-reviewed mechanism was designed to provide support to established and new investigators in the FA field, both in academic and industry settings, and to facilitate collaborations among scientists.

This program aims to reduce barriers for new investigators and increase the number of quality applications received, especially in key and high priority research areas like cardiac research and biomarker discovery. FARA believes that attracting new investigators will bring new technologies and insights to FA research, build interdisciplinary expertise, and challenge our assumptions. FARA also believes that maintaining a strong relationship with established FA investigators is essential for advancements towards an effective treatment.



Featured New FA Investigator: Muscle weakness is associated with FA, but little is known about the molecular mechanisms underlying this symptom. **Dr. Chen Liang** at the University of Rochester received a grant to investigate how altered skeletal muscle function contributes to the development and progression of FA. Dr. Liang will generate new mouse models that will enable detailed analyses of the role of frataxin in muscle development and function, and testing of new therapeutic interventions.



Featured General Research Grant: Modeling the human heart in a dish is crucial to understand the cardiac dysfunction in FA. **Dr. Paola Costantini** from the University of Padova, Italy will use an innovative tool, cardiac microtissue or "mini-heart", obtained from patient stem cells to investigate why the shape of mitochondria, which is crucial for their function, is altered in FA heart cells. Dr Costantini will investigate if remodeling of the mitochondrial shape can correct cardiac dysfunction in the FA "mini-heart".

GRANT PROGRAM
BY THE NUMBERS

3 7 Active Grants

New Investigators

New Grants Awarded

Countries Receiving Funding



Research Funding Awarded

Drug Discovery
Mechanism or Pathway of Disease
Cell & Animal Models
Gene & Stem Cell Therapy
Lead Candidates
Natural History & Biorepository
Outcome Measures & Biomarkers
Cardiac Research
Improving Clinical Outcomes

RESEARCH GRANT PROGRAM

The successful "Award for Innovative Mindset" (AIM) program, established in 2020, increased the number of grant submissions to FARA and brought new investigators into the FA field.



Award for Innovative Mindset: Dr. Gilles Naeije from the Université libre de Bruxelles, Belgium will investigate a non-invasive technique based on applying a weak electrical current to the scalp, called "Cerebellar transcranial direct current stimulation", to see if this intervention can alleviate FA symptoms. This technique will also help Dr. Naeije understand how important connections between the cerebellum and the brain cortex are disrupted in FA. *Co-funder: fara Australia*

FARA provides ongoing support for the Collaborative Clinical Research Network (CCRN) in FA, an international network of 15 clinical research centers that work together to understand the natural history of FA, conduct clinical research and trials, and provide care for individuals with FA.

Summaries of all research grants awarded by FARA, as well as grant application guidelines are available at curefa.org/grant and publications on FA, many of which report results of research funded by FARA, can be found at curefa.org/scientific-news.







All India Institute of Medical Sciences New Dehi, India

St. Jude Children's Research Hospital Memphis, TN



Clinical Trials in 2021



FRIEDREICH'S ATAXIA CENTER OF EXCELLENCE

at Children's Hospital of Philadelphia (CHOP) and Penn Medicine

FARA funds research at institutions where there are multiple investigators with an expertise and commitment to FA research. Currently, FARA provides institutional-based research support for the FA Center of Excellence at Penn Medicine/ Children's Hospital of Philadelphia and the FA Accelerator program at the Broad Institute of MIT and Harvard.

Institutional programs can seamlessly promote collaboration and synergy across basic, translational, and clinical research within one institutional community, with the goal to speed insights from foundational basic science into potential therapies. Institutional programs also provide a longer-term commitment for research, attract new investigators, and leverage the institutions' resources and engagement.





The FA Center of Excellence at Children's Hospital of Philadelphia / Penn Medicine (COE at CHOP) was established in March 2014 to advance translational and clinical research in FA. FARA, in funding partnership with the CureFA Foundation (established by the Hamilton and Finneran families), has sustained and nurtured the COE at

CHOP. Today there are >30 dedicated clinicians, scientists, research coordinators, lab techs, post docs and graduate students involved in COE research. More than 21 medical and scientific publications have been shared with the wider community.

The impact of COE funding also includes successful grant applications to the National Institutes of Health (NIH) based on foundational research previously funded by FARA. For example, a COE investigator, Shana McCormack, MD, received a 2021 NIH grant to study potential mechanisms for improving muscle function and aerobic capacity as a means for reducing symptoms of FA.





Some of the ongoing studies include:

- ▶ Natural History of FA in Children− Dr. David Lynch
- ► Drug and drug target validation for Friedreich's ataxia Dr. Rob Wilson
- Analytical validation of frataxin and studies of lipid metabolism as biomarkers of FA – Dr. Ian Blair and Dr. Clementina Mesaros
- NAD+ precursor supplementation with exercise training to improve aerobic capacity in Friedreich's Ataxia
- Drs. Kim Lin and Shana McCormack
- Elucidating the link between genome topology and repeat instability in FA
 Dr. Jennifer Phillips-Cremins
- ► Identification and rescue of functional neuro-circuit dysfunctions underpinning FA – *Dr. Donald Joseph, New Investigator to COE*
- Nuclear frataxin and the regulation of macrophage activation – Dr. Marco Carpenter, 2021 AIM Grantee and New Investigator to COE

FRIEDREICH'S ATAXIA ACCELERATOR

at the Broad Institute of MIT and Harvard



The FA Accelerator (FAA) program at the Broad Institute of MIT and Harvard was established in August 2020 through funding from FARA, the CureFA Foundation, and EndFA. Initially, the accelerator supported the work of Vamsi Mootha, MD, Gary Ruvkun, PhD and David Liu, PhD, three world class scientists who have applied their expertise to the discovery of new approaches that could lead to treatments for FA. In 2021, the Seidman Lab joined the FAA. Co-directed by Christine E. Seidman, MD and Jonathan G. Seidman, PhD and located within the Departments of Genetics at Harvard Medical School and the Cardiovascular Division of Brigham and Women's Hospital, the lab focuses on discovery of the genetic contributions to cardiovascular disease, including dilated and hypertrophic cardiomyopathy. In 2021, with funding from the FA Accelerator program, the lab began applying their knowledge and expertise in cardiomyopathy research to FA.

FARA's support of institutions (e.g. Penn Medicine / CHOP and Broad Institute) has helped to create learning communities of investigators that span early discovery to later stage clinical efforts, providing basic understanding of FA, biomarker strategies, and potential targets of therapies, all focused on bringing forward effective treatments for FA.

FARA-directed projects are research initiatives of high priority that are not fully addressed through the grant program. FARA's goal is to be most impactful in these areas by proactively tackling these difficult questions. These projects aim to fill gaps in knowledge, create resources and research tools, and promote new drug discovery. FARA leads these efforts and partners with academic researchers and biotech companies who have the knowledge, interest, and capabilities to conduct the research.



Development and Validation of a Potency Assay for Use in Development of Gene and Protein Replacement Strategies

Potency tests are used to measure drug product purity, strength (potency), and stability. A potency assay will be required for all entities pursuing gene therapy for FA, and several gene therapy experts have advised FARA that the development and validation of such assay could avoid delays in clinical trials and approvals of new therapies. FARA has been working with academic investigators in the precompetitive space to develop a potency assay that can be used by all gene therapy stakeholders to measure whether frataxin is delivered to cells and is functional.



Update of the Clinical Management Guidelines

One of the ways that FARA works to improve treatment and medical outcomes for people living with FA is to create and provide access to educational materials for people with FA and their physicians. In 2014, >35 clinicians contributed to the first comprehensive Clinical Management Guidelines for FA. These guidelines document the diagnosis, treatment, and management of FA, and they need periodic updates as our understanding of the disease progresses. FARA facilitated the formation of a committee of clinician experts and individuals with FA to provide recommendations on updating the Clinical Management Guidelines, and these newly updated guidelines will be published in 2022.



Development of a Friedreich Ataxia Rat Model

Lack of an appropriate animal model that possesses all or most aspects of the disease has been a major hurdle in pre-clinical studies of potential therapeutics for FA. To try to overcome this limitation, FARA is directing the development of a rat model of FA. It is FARA's hope that an FA rat model would better recapitulate more aspects of the human disease. Moreover, since rats are widely used for toxicology and pharmacology studies, FA rat models would be ideal to simultaneously evaluate safety as well as therapeutic benefits of potential drugs and perform pharmacokinetics and pharmacodynamics studies.



TRACK-FA: International Neuroimaging Biomarker Study

TRACK-FA, a global neuroimaging consortium, is a natural history study to TRACK the changes in the brain and the spinal cord in FA. Sponsored by FARA, there are six clinical sites participating in this MRI protocol located in the United States, Australia, Brazil, and Germany. The study continued ongoing enrollment of individuals with FA in 2021. The study is a world-first intensive collaborative effort among academic and industry researchers to track disease progression and address the urgent need for clinical trialready biomarkers.

GLOBAL PARTNERSHIPS

Many global advocacy organizations work to support the FA community and advance FA research. FARA collaborates with several of these organizations to engage the FA community in education, research, advocacy, and the patient registry as well as to fund research. FARA's foundational pillars include collaboration and sharing knowledge – a united and informed community is a stronger one.

Some of the past year's collaborative global initiatives included:



FARA has helped local organizers launch a patient advocacy group in the Czech Republic: FRIEDA, and worked with neurologists to establish a clinical research network site affiliated with the European consortium, EFACTS.



FARA and colleagues at Hellenic Friedreich's Ataxia Association (HEFAA) in Greece collaborated to introduce a letter of intent to a philanthropy to support FA cardiac research in Europe and USA.



The leadership at the Brazilian Association of Hereditary Ataxias (ABAHE) has been instrumental in continuing to help people living with FA get registered in the FA Global Patient Registry.





The 2021 edition of rideATAXIA Europe was hosted in The Netherlands by the Dutch association Stichting-Friedreich Ataxie Nederland (FAN) in collaboration with the German association Friedreich Ataxie Förderverein e.V. (FAFVeV) and FARA. After a year in the virtual world, the community enjoyed coming together in-person to ride and support one another.







From France, Australia and Ireland, the organizations L'Association Française de l'Ataxie de Friedreich (AFAF), fara Australia, and FARA Ireland have continued to co-fund many research grants with FARA.

2021 had some amazing advocacy accomplishments thanks to an incredibly engaged FA community!

To keep FARA advocates well informed of all initiatives, FARA launched a new website (curefa.org/advocacy) and created an advocacy newsletter.



In January, 74,000 people signed a petition asking the Food and Drug Administration (FDA) and Reata Pharmaceuticals to move forward on a New Drug Application (NDA) for Omaveloxolone. Subsequently, Reata Pharmaceuticals filed an NDA in the first quarter of 2022.





In February, FARA joined 670 advocates in 373 Rare Across America legislative meetings for Rare Disease Day. FARA also participated in Rare Disease Week on Capitol Hill in July. Some of the highlights from the week included FARA Ambassador, Shandra Trantham's graduation from the YARR Leadership Academy and the Rare Artist Award exhibit which featured Sophia Sieber-Davis's artwork.



For the second year, the Senate passed a resolution recognizing September 25 as National Ataxia Awareness Day. Days later, 250 advocates from 44 states engaged in 100 Congressional meetings for the third United Against Ataxia Hill Day. The day culminated in a virtual celebration honoring Senators Cindy Hyde-Smith (KY) and Chris Murphy (CT) with the first Ataxia Research Champion (ARC) award.

In meetings throughout the year, FARA advocated for the Accelerating Access to Critical Therapies Act (ACT for ALS) (H.R. 3537/S. 1813) which has several provisions that will help expedite ataxia research. The ACT for ALS became law on December 23, 2021.

COMMUNITY ENGAGEMENT & EDUCATION

This past year, the FA community promoted awareness by connecting with industry partners and genetic counseling students at 15 events. These events included screenings of "The Ataxian" as well as individuals sharing their lived experiences with FA. The community also provided constructive and thoughtful feedback on study protocol designs and on medication packaging preferences.

The FARA Ambassador Program continued to grow and evolve, engaging adult members of the community who are motivated to be knowledgeable on the treatment pipeline. This group of 80 members shared their support for FARA's work and the larger FA community by creating social media content, sending appreciative notes to donors, practicing public speaking, and hosting virtual hangouts for adults with FA and teens with ataxia.

FARA also released several engagement and education initiatives in 2021.



The FA App went live in April, and FARA was proud to be a launch partner. The aims of the App included connecting and empowering the global FA community, and some of its features include the latest research news as well as the ability to connect with others in the FA community. (Search "The FA App" in your Apple or iOS App store.)



The Flash Talks series in May included weekly virtual sessions where young investigators explained their FARA-funded research in short presentations accompanied by one slide for the community. Each session was expertly moderated by someone living with FA or a caregiver.



In September, FARA released new education for gene therapy. Background concepts, informed consent, and facilitated decision-making were covered in a whiteboard video and in online modules for self-directed learning. The modules are available at: curefa.org/trial



The FA Symposium, for people living with FA and caregivers, was held in King of Prussia, PA and also live-streamed. The October event featured several panel discussions from representatives of pharmaceutical companies with therapeutic development programs in FA.

THE FARA ENERGY BALL: PEACE, LOVE & THE CURE



The 2021 FARA Energy Ball raised \$1.7 million! Thank you to the event founders-The Avery Family, the hardworking planning committee, generous sponsors, giving auction donors, and all who attended.

In September, the Tampa, Florida community held the 13th FARA Energy Ball as a hybrid event with 450 guests in the

Grand Ballroom at the Tampa Marriott Waterside and many households streaming live online. The theme for the night was "Peace, Love, and the Cure", and the room was awash in vibrant tie-dye and the tables adorned with wildflowers. The centerpieces were equipped with all of the key accessories to get guests in a groovy spirit such as sunglasses, flower crowns, and peace symbols.

The evening, expertly emceed by ABC News Anchor, Wendy Ryan, included both signature and surprise elements. The live and silent auctions featured exclusive getaways and experiences and the Fund-a-Cure generated some friendly competition, as guests vied to be one of the top six giving tables. Attendees also had the rare opportunity to take a photo with BOTH the Lombardi Trophy and the Stanley Cup. Go Champa Bay!











\$10M in fundraising since 2007

Whether riding in their own neighborhoods or together at an event, all of the rideATAXIA teams helped the program reach an incredible milestone of over \$10M raised since it was founded in 2007!

rideATAXIA is a nationwide cycling program that welcomes people of all abilities to ride and raise funds for Friedreich's ataxia (FA) research. In 2021, 1,500 teammates gathered virtually and in-person across five different events to raise over \$1.3 Million.



rideATAXIA Coastal Challenge

Early in the year, the rideATAXIA Gainesville and SoCal teams joined in some friendly virtual competition for the rideATAXIA Coastal Challenge. Teams competed in a scored contest based on physical activity, fundraising, and social media challenges.



rideATAXIA NorCal

Next, rideATAXIA NorCal was held as a weeklong series of local rides as rideATAXIA Director, Kyle Bryant joined teams to ride in each of their neighborhoods throughout the Bay area.



rideATAXIA Chicago

The program then returned to in-person events with rideATAXIA Chicago. Teams rode on a trail along the beautiful I & M Canal in Channahon, IL and decorated their event tents with spirit chains- each link representing one of their donors.



rideATAXIA Philly

Then, in the Fall, teams throughout the northeast and beyond gathered at a new event location in Harleysville, PA for rideATAXIA Philly. There, participants enjoyed scenic route offerings of 3, 6, 21, and 48 miles and lunch catered by Outback Steakhouse.



rideATAXIA Dallas

Finally, the program capped off an incredible year at rideATAXIA Dallas with a day of camaraderie and cycling through Denton, TX where a record number of FA families joined from throughout Texas, Oklahoma, and Louisiana.

GRASSROOTS > \$1M RAISED

When FARA was founded in 1998, FAmily-led fundraising events were the primary means of funding FARA's research grants. Grassroots campaigns continued to be integral to moving FA research forward in 2021, raising over \$1 million. Over the past year, many fundraising groups and families that make up the grassroots program reached impressive milestones. The family of Caroline Smith in Alabama celebrated her milestone sweet sixteen with a big concert that raised funds for FARA. The Race for Matt & Grace also celebrated some milestones of their own: they surpassed their annual fundraising record, and they hosted their first research blood draw at the event. Thank you to all of FARA's hardworking grassroots fundraisers.



2021 Grassroots Campaigns (>\$5,000)

>\$100,000

Caroline's Sweet Sixteen – A Soirée for FA *Tuskegee, AL*

Cure FA Soirée Edmond, OK

Pull for a Cure Tampa, FL

Race for Matt & Grace Providence, RI

\$60,000-\$99,999

The Burrows Hill Foundation Annapolis, MD

Juip Family's Movie Fundraiser for FARA Sterling Heights, MI

Team FARA: TCS New York City Marathon New York, NY

\$20,000-\$59,999

Fuzzy Buzzy Golf Tournament Windham, NH

Gasparilla Concours d'Elegance *Tampa, FL*

Lend Us Some Muscle Virtual

North Street Fair to Cure Friedreich's Ataxia North Branford, CT

\$10,000-\$19,999

Fine Arts for Friedreich's Ataxia Sioux Falls, SD

Frank Durkee's Birthday Virtual

The Lamascus Family Rancho Cucamonga, CA

Stoneham Open Golf Tournament Portsmouth, NH

\$5,000-\$9,999

Bennett Pack Horseshoe Tournament Salinas, CA

Claxton Classic Golf Tournament Crownsville, MD

Dog Run for FARA Gates, NC

F&B Run Club's #RunToTheMoon Hong Kong

Florida's Gulf Coast EggFest Tampa, FL

New Jersey FA Families

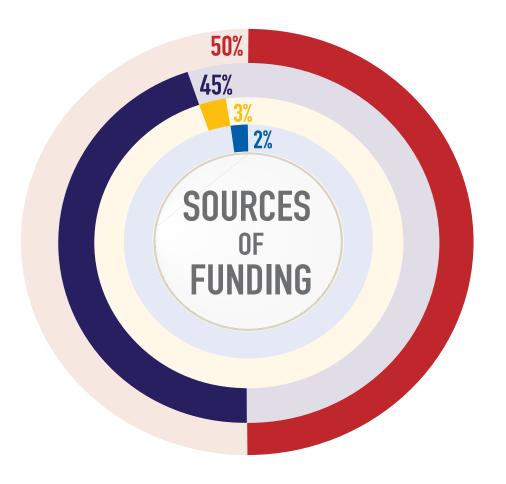
The Stacks Family Cumming, GA

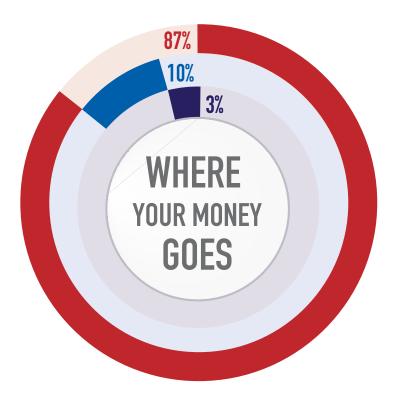
Team FARA: Team Alison Price Wake Forest, NC

Team FARA: 100 Miles for Caroline Auburn, AL

Listed as fundraising gross

FINANCIALS





- Special Events (Energy Ball, rideATAXIA, & Grassroots)
- Contributions & Conferences
- Grants
- Investment

- Research & Programs
- Fundraising
- **■** General & Administrative

FINANCIALS

STATEMENTS OF FINANCIAL POSITION

December 31, 2021 and 2020

ASSETS	2021	2020
CURRENT ASSETS		
Cash & Cash Equivalents	\$2,555,336	\$2,463,348
Restricted Cash	2,587,263	4,580,469
Contributions Receivable	259,819	277,880
Prepaid Expenses	94,042	42,086
Investments	1,976,866	1,944,826
TOTAL CURRENT ASSETS	7,473,326	9,308,609
OTHER ASSETS	5,458	5,458
TOTAL ASSETS	\$7,478,784	\$9,314,067

LIABILITIES & NET ASSETS

CURRENT LIABILITIES		
Accounts Payable	\$261,148	\$508,696
Deferred Revenues	22,360	100,000
TOTAL CURRENT LIABILITIES	283,508	608,696
NET ASSETS		
Without Donor Restrictions	4,608,013	4,124,902
With Donor Restrictions	2,587,263	4,580,469
TOTAL NET ASSETS	7,195,276	8,705,371
TOTAL LIABILITIES & NET ASSETS	\$7,478,784	\$9,314,067

STATEMENTS OF ACTIVITIES

Years Ended December 31, 2021 and 2020

NET ASSETS WITHOUT		
DONOR RESTRICTIONS	2021	2020
REVENUE & SUPPORT		
Contributions & Conferences	\$1,715,245	\$1,091,319
Grants	-	459,000
Special Events	4,304,328	3,192,804
Investment Return	189,134	205,273
Net Assets Released from Restrictions	4,270,568	3,874,860
TOTAL REVENUE & SUPPORT	10,479,275	8,823,256
EXPENSES		
Program Services	8,737,439	7,446,727
Fundraising	1,003,204	716,126
General & Administrative	255,521	198,984
TOTAL EXPENSES	9,996,164	8,361,837
IMPAIRMENT ON INVESTMENT IN COMMON STOCK	-	(5,458)
CHANGE IN NET ASSETS WITHOUT DONOR RESTRICTIONS	483,111	455,961
		733,301
NET ASSETS WITH DONOR RESTR	•	433,301
NET ASSETS WITH DONOR RESTR	•	8,331,353
	ICTIONS	
Contributions & Grants	ICTIONS 2,277,362	8,331,353
Contributions & Grants Net Assets Released from Restrictions CHANGE IN NET ASSETS WITH	ICTIONS 2,277,362 (4,270,568)	8,331,353 (3,874,860)
Contributions & Grants Net Assets Released from Restrictions CHANGE IN NET ASSETS WITH DONOR RESTRICTIONS	2,277,362 (4,270,568) (1,993,206)	8,331,353 (3,874,860) 4,456,493

>\$1 Million

CureFA Foundation *+

\$90,000-\$250,000

Anonymous

The Avery Family Foundation

The Crisp Family Fund +

fara Australia (Friedreich Ataxia Research

Association) +

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\$45,000-\$89,999

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\$25,000-\$44,999

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Shon and Sharon Craig Mel and Laura Klinghoffer Roberta Lindsay Meridian Retail Group Race for Matt and Grace **USF Health** Vanquard Protex Global Jason and Nancy Wilson William and Heidi Wright

\$10,000-\$14,999

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The Pathway donors help fund research progress through a monthly gift to FARA.

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In the spirit of FARA's core value- collaboration, we recognize the role of biotechnology and pharmaceutical companies in FARA's mission to treat and cure FA. Collectively, these partners contributed more than \$1,000,000 to FARA programs in 2021. Many contributions were made in the form of sponsorship for FARA events (grassroots, rideATAXIA, and the FARA Energy Ball), education initiatives (symposia and gene therapy education) as well as the Industry Advisory Summit (IAS). The IAS is a new forum that allows industry partners to directly engage with FARA Scientific Leadership along with thought leaders on precompetitive initiatives and research being supported and led by FARA. Nearly half of these funds were comprised of contributions to FARA's Core Programs and Services such as the FA Global Patient Registry, Collaborative Clinical Research Network (CCRN), and Clinical Management Guidelines as well as the TRACK-FA neuroimaging consortium and study.

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