FARA Friedreich's Ataxia Research Alliance

2020
Donor Impact Report

BOARD OF DIRECTORS

Dear Friends,

We hope this note and report find you and your families well. While many would characterize 2020 as a year of unexpected challenges, our Friedreich's ataxia community has long been a remarkable model for adaptability, resilience, and collaborative action. As we sought new ways to connect, educate, raise funds, and advance research, we repeatedly consulted the community's playbook.

As depicted in the Strategy House on the next page, our work and growth in 2020 continued to establish and hone the building blocks, or "focus areas," within our four pillars:

- Attracting and Facilitating Collaboration
- Sharing Knowledge and Know-How
- Deploying Financial Resources
- Creating Domain Resources

FARA continued, for example, to fund a robust research grant program of peer-reviewed science by leading researchers, the Collaborative Clinical Research Network in FA, and the FA Center of Excellence at Children's Hospital of Philadelphia/ University of Pennsylvania in partnership with the CureFA Foundation.

FARA received significant restricted grant support which allowed us to expand our research staff, make new institutional investments, and take on more FARA-directed research initiatives. In support of this strategic research growth, FARA expanded the research team to include Dr. Barbara Tate as FARA's Chief Scientific Officer. Barbara brings experience in neuroscience, drug development, venture funding, and company creation to FARA which she applies in leading research programs and setting priorities.

FARA helped create the FA Accelerator Program at the Broad Institute at MIT and Harvard to apply the team's field-leading genetics expertise to study novel therapeutic approaches for FA. FARA also proactively tackled pivotal research questions raised by the scientific field through directed research initiatives led by staff and Scientific Advisory Board members.

As you turn the pages of this 2020 Donor Impact Report, we hope you not only learn about new FA research milestones and FARA programs but also see yourself in this progress. Regardless of whether you directly touched a specific program, your support with funds, time, an advocacy voice, expertise, and research participation, vibrates throughout the FA research continuum and fuels everything FARA is able to accomplish. This progress belongs to you. The next breakthrough will be because of you. Thank you for being a part of this movement at such a critical inflection point of the FA research and development timeline.

With our gratitude,

Ron Bartek, *President*

Jennifer Farmer, *Chief Executive Officer*

FARA STRATEGY HOUSE

Treat and cure FA by marshaling and focusing global resources and relationships

MISSION

Marshal: Bring together people and funds
Focus: Direct and deliberate action, in line with our strategy, creating a deep and diverse pipeline of treatments

STRATEGIC PILLARS

ATTRACTING & FACILITATING COLLABORATION	SHARING KNOWLEDGE & KNOW-HOW	DEPLOYING FINANCIAL RESOURCES	CREATING DOMAIN RESOURCES
Recruit and retain all the relevant stakeholders, specifically individuals and organizations with knowledge, resources, technology, talent, and connections. Develop opportunities for partnership.	Share knowledge and know-how to inform and advance research. Strive to be the credible resource of up-to-date FA information for all statekholders.	Focus on advancing research and the discovery and development of treatments through a competitive grant-making program, requests for proposals, and directed sponsorsed research.	Develop research tools to accelerate progress. Shared/ open source resources reduce timelines and eliminate redundancy.

FOCUS AREAS

Regulatory Agencies – FDA and EMA	FA Treatment Pipeline	Investigator-Initiated Research / FARA Grant Program	Collaborative Clinical Research Network and Natural History Study
Optimize Industry and Academia Engagement	Clinical Management Guidelines	FARA Directed Research Projects	Research Tools- Cell Lines, Animal Models, Assays, ETC.
FA Community - Initiating, Enrolling, and Completing Trials	Clinical Trial Readiness / Education – Gene Therapies	Institutional Programs	FA Global Patient Registry

FACILITATORS

Operations | Fundraising | Leadership | Communications

FOUNDATION

URGENCY | WISDOM | CARING | QUALITY | SPIRIT | INTEGRITY

FARA GUIDING PRINCIPLES

RESEARCH GRANT PROGRAM

2020 Grant Program by the Numbers

34 ACTIVE GRANTS

18 NEW GRANTS AWARDED

13 NEW INVESTIGATORS

3 JUNIOR INVESTIGATORS

10 COUNTRIES

FARA believes in supporting basic, translational, and clinical research, all equally important to developing treatments. Through the grant program, investigators propose ideas to meet research challenges in FA. These proposals are reviewed by other scientists who generously volunteer their time to make sure the projects funded by FARA adhere to the most rigorous scientific standards.

The pandemic did not slow the FARA grant program. FARA strived to solicit innovation and keep researchers connected by instituting a new grant named the Award for Innovative Mindset, that is meant to reward out-of-the-box thinkers, and by launching the FARA Forum, a monthly webinar where grant awardees are encouraged to share their most recent results with FARA's Scientific Advisory Board and other grant recipients.

The FARA grant program encourages public-private partnerships and aims to bring together academic and industry researchers, with their specific knowledge of FA and drug development. In addition to funding investigator-initiated proposals, FARA tackles research areas that remain poorly explored by reaching out directly to scientists to fill key knowledge gaps and create needed resources for the whole research community.

FARA also provides ongoing support for the Collaborative Clinical Research Network (CCRN) in FA, the FA Center of Excellence at the Children's Hospital of Philadelphia, the FA Accelerator at the Broad Institute, the biomarker development consortia, and clinical research infrastructure needed to facilitate clinical trials.

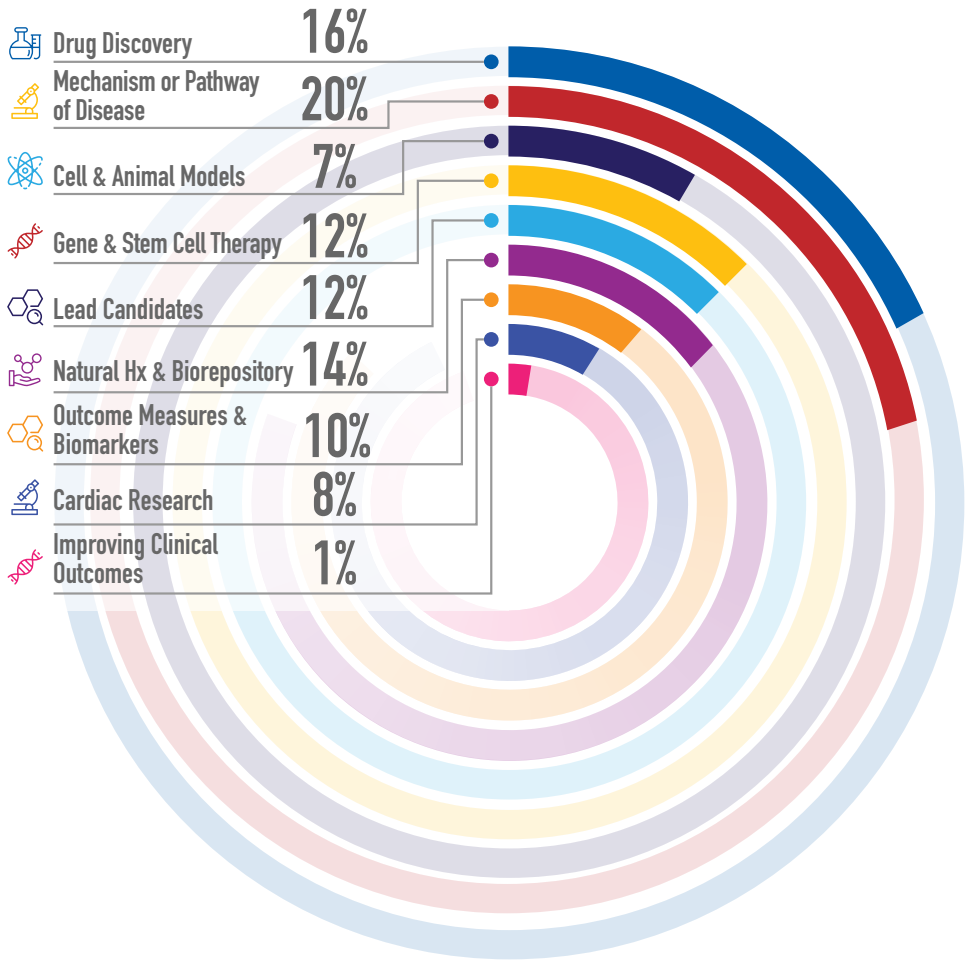
Summaries of all research grants awarded by FARA, as well as grant application guidelines, are available at curefa.org/grant and publications on FA, many of which report results of research funded by FARA, can be found at curefa.org/scientific-news.

FARA 2020 Grants by Strategic Research Initiative

Featured New FA Investigator: Dr. Jennifer Phillips-Cremins at the University of Pennsylvania is a new investigator to FA. Dr. Phillips-Cremins and her team have discovered that nearly all genes that cause triplet repeat disorders, like FA, are folded into the same unique 3D structure and that the location of these genes within the 3D structure can explain why certain repeats, like GAA, expand. Dr. Phillips-Cremins's group proposes to create a 3D map of the genome in FA cells and compare it to unaffected cells with the long-term goal to find ways to restructure the 3D genome to reverse FXN gene silencing.

Featured General Research Grant: Dr. Natalia Gomez-Ospina at Stanford University proposes to investigate the application of blood stem cell transplantation to treat Friedreich's ataxia. Dr Gomez-Ospina will perform stem cell transplantation experiments in a mouse model of Friedreich's ataxia, use genetic engineering to investigate whether expression of the protein frataxin is required in specific blood cell types for the therapeutic benefit of stem cell transplant, and assess if mitochondria are transferred from stem cells to neighboring cells in the nervous system. These studies will provide support for further development of a blood stem cell-based therapy for FA, in which the patient's own genetically corrected stem cells can be used. *This grant is co-sponsored with FARA Ireland.*

Featured Award for Innovative Mindset: One of the recipients of the Award for Innovative Mindset is **Dr. Christina Cortez-Jugo** from the University of Melbourne, Australia. Dr. Cortez-Jugo's application proposes to use nanoparticles instead of viruses to deliver the frataxin gene in gene therapy approaches. Nanoparticles are small aggregates made of polymers, lipids, and other molecules that can deliver a specific cargo (in this case the frataxin gene) to cells. This investigator proposes to improve the delivery of the cargo to the specific cell types that are mostly affected in FA, by coating the nanoparticle surface with antibodies and ligands that will promote their binding and uptake by the target cells. *This grant is co-sponsored with the CureFA Foundation and fara Australia.*



COLLABORATIVE CLINICAL RESEARCH NETWORK (CCRN)

The Collaborative Clinical Research Network (CCRN) is an international network of 13 clinical research centers that work together to advance treatments and clinical care for individuals with Friedreich's ataxia. Having such a network means that there are trained physicians and research coordinators ready to do clinical research studies and trials. Prior to the COVID-19 pandemic, telemedicine was an emerging concept in clinical care and research; however, the height of the pandemic pushed it to the forefront. To maintain continuity of clinical care and research visits, CCRN investigators successfully conducted hundreds of telemedicine visits. While there are some aspects of a clinical and research visit that cannot be replicated through a video screen, the successful practice of telemedicine visits brought thoughtful exploration of how future research may be designed to ease some of the travel burden for participants.

Additionally, the CCRN teams meet quarterly to share research findings and insights. In 2020, a new initiative was presented by the Australian Stem Cell and Gene Therapy Consortium in Melbourne, Australia. Dr. Martin Delatycki established this consortium to determine locally what his site needed to be prepared to carry out gene therapy trials. This led to an important exchange among all CCRN investigators and FARA on projects to build gene therapy patient education, Institutional Review Board education, pharmacy facility preparations at each center, and an understanding of the regulatory differences between countries.

New ICD-10 Diagnosis Code Approved in the U.S. for Friedreich's Ataxia G11.11

Effective October 1, 2020, all people with a confirmed diagnosis of FA should have their medical records updated with the G11.11 diagnosis code. This new ICD-10 code should facilitate referrals to specialists and appropriate health insurance coverage of future FDA-approved treatments.

Spotlight Dr. Antoine Duquette – Centre hospitalier de l'Université de Montréal (CHUM)

What was your primary reason(s) for joining the CCRN?
It is extremely important, when dealing with rare diseases, to join forces with other groups to make and confirm meaningful observations. For many years, we've been working with patient advocacy groups to bring FA clinical trials to Canada and we're happy that is becoming more of a reality. I was able to bring together a group of investigators and support staff who will bring new ideas and technologies to increase our understandings of FA, work on clinical research, and provide care.

What does the CCRN offer to patients?
The prevalence of FA is slightly higher in Québec than in most other parts of the world, with research going back to the 1970s. Because of the history of the disease in the province and the amazing research that has been going on for decades, CHUM and the CCRN bring a great deal of expertise to the patients when they come and visit the site and meet the senior researchers. We are enrolling patients in the FACOMS study, drafting of new guidelines of clinical management of the disease, consulting with pharma, and bringing clinical trials to Québec; it's all exciting for patients and families that more FA research is coming back to CHUM, the CCRN, and Canada.

Can you share some thoughts about the significance of the natural history study through the CCRN?
Natural history studies such as FACOMS are extremely important to understand how a disease evolves over time. We often talk about its importance in designing better clinical trials but the information collected also allows clinicians to improve patient care. For FA and other rare diseases, bringing together a large number of patients often shines a light on disease features that would not be obvious otherwise. The FA community is actively engaged in research and is very well organized. This clearly stimulates interest from pharmaceutical companies to develop new therapies and, at a local level, helps centers attract more studies.

FRIEDREICH'S ATAXIA CENTER OF EXCELLENCE

at the The Children's Hospital of Philadelphia/ University of Pennsylvania

The Friedreich's Ataxia Center of Excellence (COE) is a translational research and clinical care center devoted to Friedreich's Ataxia: expediting basic science and drug discovery findings to new treatments and dedicating resources to clinical research and care to further understand the disease, inform drug development, and improve outcomes for individuals living with FA. The Center was established in March 2014, with a commitment to Children's Hospital of Philadelphia/ University of Pennsylvania, presented by FARA in partnership with the Hamilton and Finneran families. FARA has maintained this funding partnership with the CureFA Foundation (established by the Hamilton and Finneran families) to advance research through the COE. **Investment in the COE has demonstrated sustainability and growth through new funding from the National Institutes of Health (NIH) with 5 research grants providing >$2.5M to COE projects.**

Projects and investigators with continued funding included Dr. Rob Wilson- Drug Discovery, Dr. David Lynch- Translational and Clinical Neuroscience Research, Drs. Ian Blair & Clementina Mesaros- Biomarker Discovery, Dr. Kim Lin- Cardiac Research and Dr. Shana McCormack- Metabolism and Endocrinology as well as the addition of Dr. Jennifer Phillips-Cremins- Genetic Modeling in 2020.

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 proteoforms in blood as biomarkers of FA- *Dr. Ian Blair*
- Lipid metabolism disruption as a consequence of mitochondrial dysfunction in FA – *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*

Meet Dr. Jaclyn Tamaroff

FARA has prioritized the development of young clinician scientists in growing the Friedreich's ataxia research field. As part of Dr. Jaclyn Tamaroff's fellowship with the Division of Endocrinology and Diabetes at the Children's Hospital of Philadelphia, she engaged in research through the COE. Dr. Tamaroff received a postdoctoral fellowship award from FARA in 2020 to study glucose excursion in youth with FA without known diabetes. She was able to use the data from this study to apply for and earn multi-year funding from the NIH to continue and expand her work beginning mid-2021.

FRIEDREICH'S ATAXIA ACCELERATOR

at the Broad Institute of MIT and Harvard

BROAD INSTITUTE

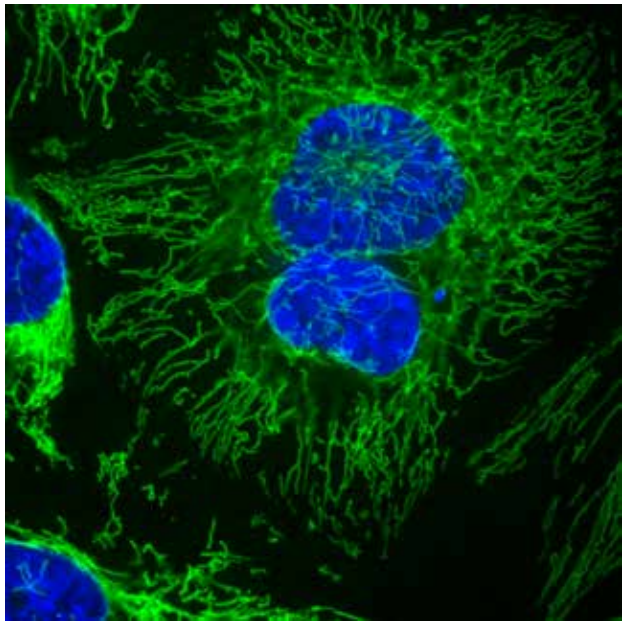
The Friedreich's Ataxia Accelerator at the Broad Institute of MIT and Harvard was established in August 2020. Funded by FARA, in collaboration with the CureFA Foundation and EndFA, the accelerator is currently supporting the work of three world class scientists as they apply their expertise to the discovery of new approaches that could lead to treatments for FA.

The leader of the accelerator, Dr. Vamsi Mootha, a Howard Hughes Medical Institute investigator, and his collaborators previously discovered that limited oxygen in cells, or hypoxia, rejuvenates cells that lack frataxin. They are now working to discover why low oxygen allows cells to bypass the need for frataxin and whether a therapy can be developed that mimics the effects of low oxygen.

One of the two other founding investigators, Dr. Gary Ruvkun, a professor of genetics at Harvard Medical School and Massachusetts General Hospital, is using simple model systems to test different molecules for their ability to rescue frataxin-deficient cells.

Dr. David Liu, who is also a Howard Hughes Medical Institute investigator, is applying new gene editing technologies to directly correct the genetic causes of Friedreich's ataxia.

Finally, an important element of the Friedreich's Ataxia Accelerator is additional research support via "catalyst" projects that will bring in other researchers at the Broad Institute to explore FA. Broad Institute investigators focus on using genetic tools to understand human disease and to help lay the groundwork for new therapeutic approaches, which aligns well with the effort to find a treatment for FA.



HeLa cells stained for frataxin (green) and nucleus (blue)

FARA DIRECTED RESEARCH PROJECTS

FARA directed projects are research initiatives identified and led by FARA's Scientific Advisory Board and staff. All of these research projects are high priority as they aim to provide research resources, address specific gaps in knowledge or deepen our understanding of disease mechanism, pathology, and progression as well as discover innovative approaches to therapy.

Key 2020 initiatives included:

Establishing a Friedreich's Ataxia Cell Line Repository

With support of The Crisp Family Fund, FARA helped facilitate the creation of a repository of Friedreich's Ataxia cell lines at the University of Alabama. The repository currently includes more than eighty FRDA and control fibroblast lines and twenty FRDA and control iPSC lines. In 2020, more than twenty worldwide researchers utilized these cell lines in their FA research projects. Additional information can be found at: **https://sites.uab.edu/thenapieralalab/frda-cell-line-repository/**

Studying the Mechanisms of Frataxin Gene Silencing

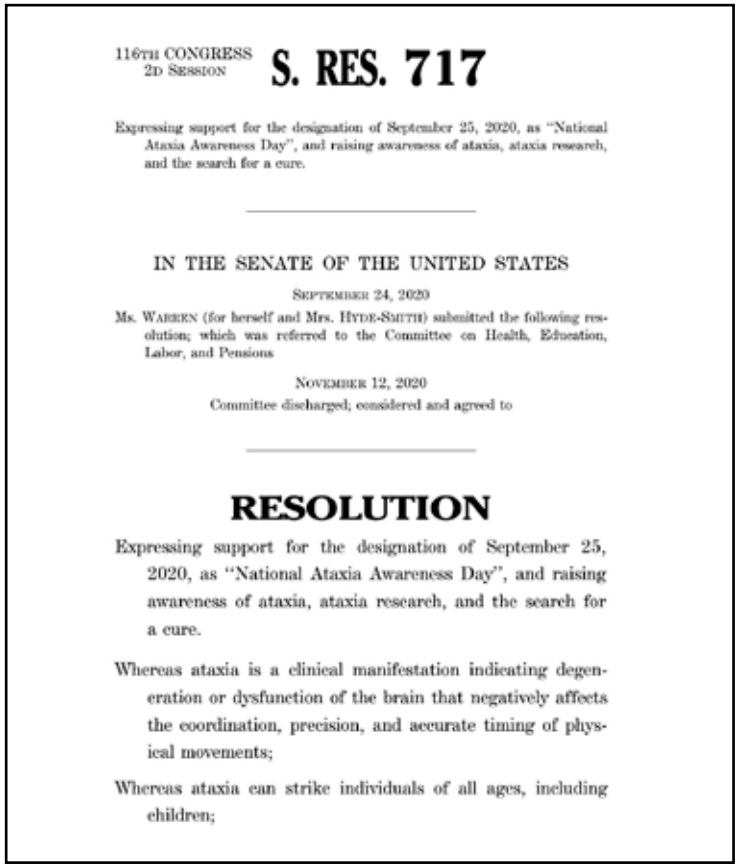
In 2020, the laboratories of Dr. Sanjay Bidichandani (University of Oklahoma), Dr. Marek Napierala (University of Alabama) and Dr. Jennifer Phillips-Cremins (University of Pennsylvania) launched a collaborative effort to study the mechanisms of frataxin gene silencing in FA patient cell lines and FA mouse models over time. If we understand how the frataxin gene is silenced, this could lead to new therapeutics that unblock expression and restore frataxin levels.

Publishing a Central Nervous System Whitepaper on FA

FARA assembled a group of FA researchers, Dr. Ian Harding, Dr. David R Lynch, Dr. Arnulf H Koeppen and Dr. Massimo Pandolfo, to collect and analyze all the available data on what is known about how FA affects the spinal cord and brain. The team wrote a comprehensive summary of all these findings, which is now published in the scientific journal *Human Gene Therapy*. The paper is open access at: **https://doi.org/10.1089/hum.2020.264** so that other FA researchers and companies developing treatments for FA can use the comprehensive summary to plan their experiments and clinical trials.

Launching the TRACK-FA 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. The clinical sites participating in this MRI protocol are located in the United States, Australia, Brazil, and Germany. The study was successfully launched at the end of 2020 with plans to enroll a total of 300 individuals to establish an FA neuroimaging dataset to facilitate biomarker development.



116TH CONGRESS
2D SESSION

S. RES. 717

Expressing support for the designation of September 25, 2020, as "National Ataxia Awareness Day", and raising awareness of ataxia, ataxia research, and the search for a cure.

IN THE SENATE OF THE UNITED STATES

SEPTEMBER 24, 2020

Ms. WARREN (for herself and Mrs. HYDE-SMITH) submitted the following resolution; which was referred to the Committee on Health, Education, Labor, and Pensions

NOVEMBER 12, 2020

Committee discharged; considered and agreed to

RESOLUTION

Expressing support for the designation of September 25, 2020, as "National Ataxia Awareness Day", and raising awareness of ataxia, ataxia research, and the search for a cure.

Whereas ataxia is a clinical manifestation indicating degeneration or dysfunction of the brain that negatively affects the coordination, precision, and accurate timing of physical movements;

Whereas ataxia can strike individuals of all ages, including children;

2020 advocacy started strong in February with FARA joining over 900 advocates for 393 Congressional meetings during Rare Disease Week in Washington, DC. Although the pandemic stopped in-person meetings, FARA continued to be a voice for the FA community through virtual Hill days hosted by advocacy partners like the Alliance for Regenerative Medicine (ARM), Alliance for a Stronger FDA, and the Everylife Foundation Rare Across America. FARA also joined eleven coalition letters during the year, many addressing issues around the pandemic, and developed an important advocacy tool, the FA fact sheet, with Research!America. In September, FARA and NAF had over 300 people sign up for advocacy training prior to the second United Against Ataxia Hill Day. The result - the first National Ataxia Awareness Day Resolution, co-sponsored by Senators Warren (MA) and Hyde-Smith (LA), was passed because of our passionate advocates!

The FA fact sheet can be accessed here: researchamerica.org/friedreichs-ataxia

FA COMMUNITY OUTREACH

with Grassroots Fundraising & the FARA Ambassador Programs

The FA community's outreach was a powerful force in maintaining our connections with donors, academia, and industry, as well as helping to grow public awareness for FA in 2020.

In the grassroots fundraising program, which features campaigns run primarily by FA families, the year started out strong with several events held prior to mid-March. After the pandemic hit the United States, some grassroots fundraisers continued their efforts in virtual or outdoor, socially distanced formats, keeping their communities engaged, and helping FARA to honor our grant commitments.

The FA patient community also connected with many of FARA's academic and industry partners by serving on patient panels at Exicure, University of Pittsburgh Genetic Counseling Program, Voyager Therapeutics, Reata Pharmaceuticals, University of Pennsylvania Genetic Counseling Program, Larimar Therapeutics, and Takeda.

FARA and Reata Pharmaceuticals also collaborated on filming a segment for the *Behind the Mystery* series on Lifetime television, raising public awareness of FA. This segment featured Dr. Susan Perlman and FA Ambassador Frankie Perazzola explaining the FA journey and clinical symptoms leading to a diagnosis of FA.

To foster continued education and engagement, FARA also helped train community members for future opportunities by providing a virtual training program entitled *Engaging Patients in Clinical Trial Design* and by growing the FARA Ambassador Program to 87 members.

FARA Ambassador Program Now

87

MEMBERS

FA COMMUNITY EDUCATION & CONFERENCES

This year, FARA hosted a Biomarker and Clinical Endpoint meeting for FA researchers as well as three educational symposia for the FA community.

In February, FARA hosted over 165 attendees for a one-day symposium in Irvine, CA. One of the highlight sessions was a panel consisting of three pharmaceutical companies with ongoing clinical trials in FA.

In May, FARA launched a new online series called FA Research Flash Talks. This five-part webinar series included young investigators from FARA funded labs around the world who presented on key aspects of research from gene and protein function to clinical outcomes and insights. Each flash talk was limited to five minutes and one power point slide followed by Q&A, providing an efficient and engaging way to learn about the spectrum of ongoing research funded by FARA.

The FARA Biomarker and Clinical Endpoint Meeting was held virtually on September 24th and 25th. The meeting focused on pharmacodynamic and monitoring biomarkers in FA, both for translational and clinical applications, as well as clinical outcome assessments. The four sessions covered the development of digital technologies, the status of biomarker development to detect disease progression, and updates on clinical trials in FA. The meeting was attended by over 285 academic and industry investigators.

In partnership with the Friedreich's Ataxia Center of Excellence at Children's Hospital of Philadelphia (CHOP), FARA transitioned the annual one-day patient symposium in the Philadelphia area to a virtual symposium series throughout the month of October. This eight-part series was provided via webinar through a conference app that included additional resources and engagement opportunities for the community. Four hundred attendees from over twenty countries engaged with the live presentations and each other throughout the series.

2020 was a year of unexpected opportunity for the rideATAXIA program. Together, we raised over $1M, traveled 96,875 miles as a community, and welcomed 1,385 participants from 21 different countries! The first event of the year, rideATAXIA SoCal, was held in person in February. However, as it became clear that in-person rides could not continue, the ride team reflected on the FA community's awesome model of adaptability and resilience. With lots of help and inspiration from our friends, families, researchers, and teams, rideATAXIA went virtual!

Each event was converted into a month-long virtual campaign specific to the location. Collectively, we set goals, tracked our activity mileage as a community, participated in challenges, and raised an incredible amount of money for FA research. One of the highlights for the ride program was taking the Philly ride from our backyard to all of yours with the inaugural rideATAXIA Global Challenge.

Together, we visited researchers, advocacy partners, and community members all around the world to put faces to the names of the countless people dedicating their lives towards finding treatments and a cure. Visit the official rideATAXIA Global Challenge Google Earth Map at: https://rideataxia.org/global/map/

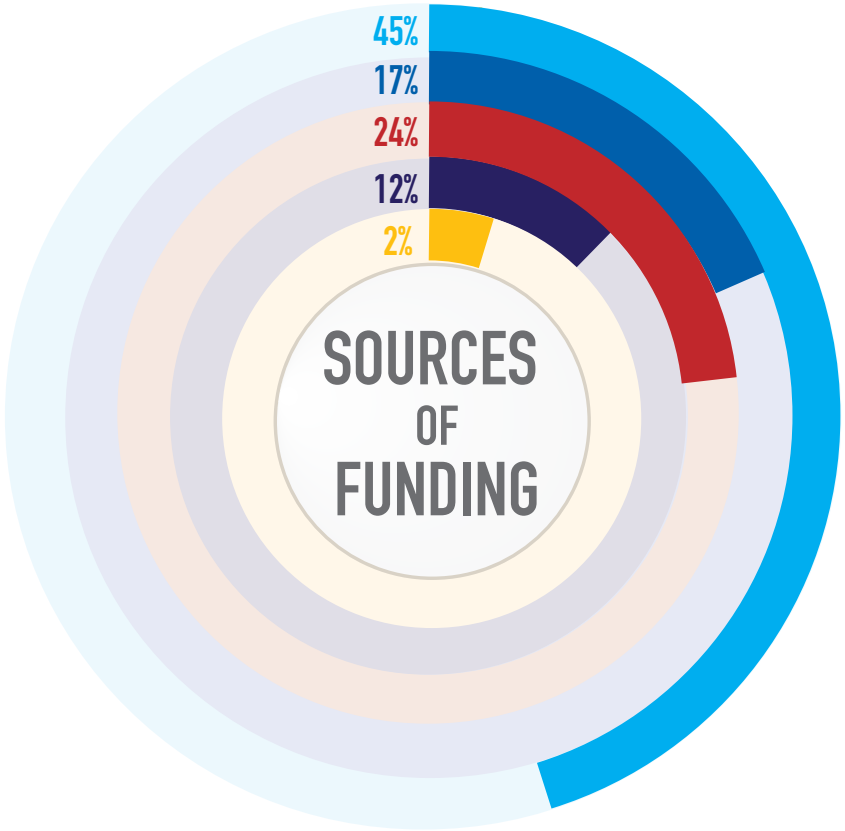
THE FARA ENERGY BALL

On November 7, the 12th FARA Energy Ball was streamed live from Tampa, Florida, transforming the typically in-person event into a virtual "party at your house." An estimated 600 people enjoyed the evening – some tuning in from their homes and others taking part in small watch parties held throughout the country.

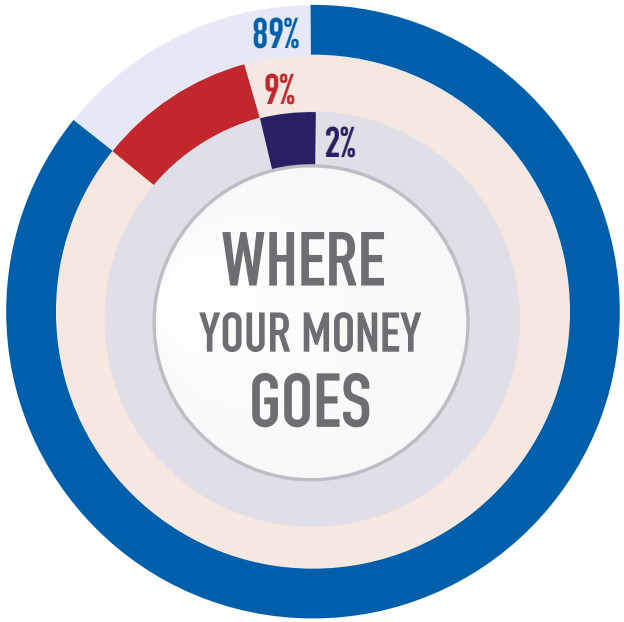
The program was hosted by Wendy Ryan, ABC Action News Anchor for WFTS Tampa Bay, and auctioneer Scott Robertson. Speakers included event founders- the Avery Family; FARA Leadership; and Janell and Steve Griggs, CEO of the Tampa Bay Lightning. The virtual program also included a moving segment from Seth and Mekayla Holm, siblings living with FA in Minnesota. The video was followed by the Fund A Cure, and a remote live auction featuring eight exclusive trip experiences. During the week leading up to the event, supporters were also able to remotely bid on over 100 curated silent auction packages, ranging from getaways, to memorabilia, to restaurant gift cards.

The event was a great success with over $1 million raised. Thank you to all of the event sponsors, the Tampa-based event committee, and the many FA community members across the country who supported this effort.

FINANCIALS



- Co-Funding of Research from Other Nonprofits
- Grant for Organizational Growth
- Special Events
- Contributions & Conferences
- Investment



- Research & Programs
- Fundraising
- General & Administrative

FINANCIALS

STATEMENTS OF FINANCIAL POSITION

December 31, 2020 and 2019

ASSETS	2020	2019
CURRENT ASSETS		
Cash & Cash Equivalents	$2,463,348	$1,697,091
Restricted Cash	4,580,469	123,976
Contributions Receivable	277,880	191,637
Prepaid Expenses	42,086	35,477
Investment in Securities	1,944,826	2,128,027
TOTAL CURRENT ASSETS	**9,308,609**	**4,176,208**
OTHER ASSETS	5,458	11,035
TOTAL ASSETS	**$9,314,067**	**$4,187,243**

LIABILITIES & NET ASSETS

CURRENT LIABILITIES		
Accounts Payable	$508,696	$385,252
Deferred Revenue	100,000	9,074
TOTAL CURRENT LIABILITIES	**608,696**	**394,326**
NET ASSETS		
Without Donor Restrictions	4,124,902	3,668,941
With Donor Restrictions	4,580,469	123,976
TOTAL NET ASSETS	**8,705,371**	**3,792,917**
TOTAL LIABILITIES & NET ASSETS	**$9,314,067**	**$4,187,243**

STATEMENTS OF ACTIVITIES

Years Ended December 31, 2020 and 2019

NET ASSETS WITHOUT DONOR RESTRICTIONS	2020	2019
REVENUE & SUPPORT		
Contributions & Conferences	$1,091,319	$1,575,358
Grants	459,000	116,500
Special Events	3,192,804	4,556,102
Investment Return	205,273	339,096
Net Assets Released from Restrictions	3,874,860	1,576,840
TOTAL REVENUE & SUPPORT	**8,823,256**	**8,163,896**
EXPENSES		
Program Services	7,446,727	7,168,645
Fundraising	716,126	990,849
General & Administrative	198,984	169,731
TOTAL EXPENSES	**8,361,837**	**8,329,225**
IMPAIRMENT ON INVESTMENT IN COMMON STOCK*	(5,458)	(1,080,585)
CHANGE IN NET ASSETS WITHOUT DONOR RESTRICTIONS	**455,961**	**(1,245,914)**
NET ASSETS WITH DONOR RESTRICTIONS		
Contributions & Grants	8,331,353	1,637,435
Net Assets Released from Restrictions	(3,874,860)	(1,576,840)
CHANGE IN NET ASSETS WITH DONOR RESTRICTIONS	**4,456,493**	**60,595**
CHANGE IN NET ASSETS	4,912,454	(1,185,319)
NET ASSETS AT BEGINNING OF YEAR	3,792,917	4,978,236
NET ASSETS AT END OF YEAR	$8,705,371	$3,792,917

** Write down of common stock in a privately held entity. Refer to FARA 2020 and 2019 Financial Statements at https://curefa.org/financials.*

DONORS & CONTRIBUTORS

>$1 Million
Anonymous

$500,000-$999,999
CureFA Foundation *+

$250,000-$499,000
Anonymous

$100,000-$249,999
Brigid Brennan and Michael Henry
The Crisp Family Fund
Friedreich Ataxia Research Association (fara Australia) +
The Ritschel Family
Mary Alice Wheeler

$45,000-$99,999
Anonymous
Anonymous
The Burrows Hill Foundation
Kurt and Amy Hull
The Brad and Nancy Rex Family
Gavin and Laura Southwell

$25,000-$44,999
Amalie Oil Company
Jeff and Valerie Anderson
Anonymous
Chris T. Sullivan Foundation
McDaniel Charitable Foundation
Roger Klauber Family Foundation
Vanguard Protex Global
The Villages- Rick and Tracy Dadeo
Cara Wiechens
Bill and Heidi Wright

* Center of Excellence Funder | + Grant Co-Funder

DONORS & CONTRIBUTORS

$10,000-$24,999

Robert and Shelley Barnes
Ron and Raychel Bartek
Benefytt
Thomas Bradley
Paul and Gloria Burke
Coastal Alehouse Management
Jodi Cook and Michael Tardugno
The Corbett Family Charitable Foundation
Corporate Creations Foundation Inc.
Dan Kirkland Wells Foundation
Harvey and Sharon Dean
Candy and Eddie DeBartolo and Family
Simon and Lucia Dolan
David Donofrio
El Dorado Holdings
Foley, Baron, Metzger & Juip PLLC
Justin and Allison Gerbereux
The Glenmede Trust Company
Grill & Provisions Company
Derek and Marcy Hennecke
John and Madison Isner
Paul and Mary Jacobs
William and Victoria Krutzer
Roberta Lindsay
Damian and Trina Mandola
Thomas and Judith Marrow
Masonry Builders, Inc
Geronimo Mirano
National Organization for Rare Disorders
Patrick Henry Creative Promotions
Tony Plohoros
Raymond James Financial, Inc.
Doug and Kathy Rothschild
Bryan Sheffield
Drs. Joseph Staffetti and Theresa Zesiewicz
Pete and Jean Supron
Thomas A. & Mary S. James Foundation
Jason and Nancy Wilson
www.TheEventHelper.com
James Ziegler and Lori Usher

$5,000-$9,999

Francisco Alonso
Anonymous
Auburn High Volleyball
Barbara and Franklin Carson Family Foundation
Rick & Dixie Berman
Brent Boulay
Neil and Sally Braid
The Briar Foundation
Brown & Brown Insurance
Socorro Cavazos
Center for Neurologic Study
The Claxton Classic
Tony Cline
Confidio LLC
Lauren and Kier Cooper
CVS Corporation
Emily Davis
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