WE BELIEVE TRANSFORMATIVE CHANGE LIES AT THE INTERSECTION OF PEOPLE AND SCIENCE.

WE WORK IN COLLABORATION AND WITH A SENSE OF URGENCY TO BUILD STRONG RELATIONSHIPS, EXPAND KNOWLEDGE, AND REMOVE UNCERTAINTY.

WE'VE MADE A PROMISE TO TREAT AND CURE FA THROUGH RESEARCH.

2019
Annual Report

FARA Friedreich's Ataxia Research Alliance

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Dear Friends,

We lead with FARA's Why statement on the cover of this publication because amidst the building momentum and research growth of the past year, it is important to revisit the fundamental truths that drive our work. The foundation of FARA's effort is rooted in people and science, and our role is to help marshal and focus efforts to achieve treatments and a cure for FA. To that end, FARA's leadership undertook to reframe the organization's strategic priorities and activities into the following four essential pillars-

Attracting & Facilitating Collaboration in the Community: We assemble all stakeholders- researchers, physicians, patient families, industry and government partners - to share insights, new research and build partnerships that unite us as one well-aligned and stronger FA community. This past year, FARA cohosted the largest International Ataxia Research Conference with our international advocacy partners for over 400 attendees. This collaborative model is critical in accelerating real-time knowledge and data sharing as one global FA community.

Deploying Financial Resources: We deploy financial resources through a competitive, peer reviewed research grant program as well as FARA directed research. Last year, $6M in research funding was deployed for more than 30 projects, including Institutional Programs such as the Center of Excellence at the Children's Hospital of Philadelphia. Going forward, FARA will continue to fund research proposals through our traditional grant program, but will also fund more FARA directed projects at institutions with expertise in a focused research area or key projects identified by our Scientific Advisory Board.

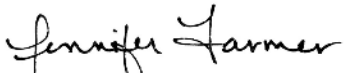
Creating Domain Resources: We build resources that help advance all therapies in the field. Examples of domain resources created over the last year include the FA Global Patient Registry, the FA-Integrated Clinical Database, and bio and cell repositories.

Sharing Knowledge & Know-How: We believe that sharing the knowledge from our grant program, research conferences, academic and industry partners, and patient families optimizes our pace and enables the efficient use of resources. Much of FARA leadership's time is invested in ensuring that our pharma partners have the information they need to advance their programs to clinical trials. We also know that an educated patient community is essential for informed participation in research. This past year we cohosted three educational symposiums, an ambassador training, as well as a video series about FARA funded research.

We believe these strategic focus areas are the cornerstones of FARA's work. They provide the tools, the knowledge and the collaborative relationships that advance therapeutic candidates in the treatment pipeline. This progress is evident in the number of treatment approaches in trial phases over the last year. Thank you for your continued generous support. You allow us to be forward thinking, act with a sense of urgency, and keep the promise we've made to treat and cure FA.

With our gratitude,

Ron Bartek *President*



Jennifer Farmer *Chief Executive Officer*

ATTRACTING & FACILITATING COLLABORATION

DEPLOYING FINANCIAL RESOURCES

CREATING DOMAIN RESOURCES

SHARING KNOWLEDGE & KNOW-HOW

GOAL/MISSION
Treat and cure FA by marshalling and focusing global resources and relationships.

MARSHAL
Bring together funds and people

FOCUS
Direct and deliberate action, aligned with strategy and a deep and diverse pipeline

RESEARCH GRANT PROGRAM

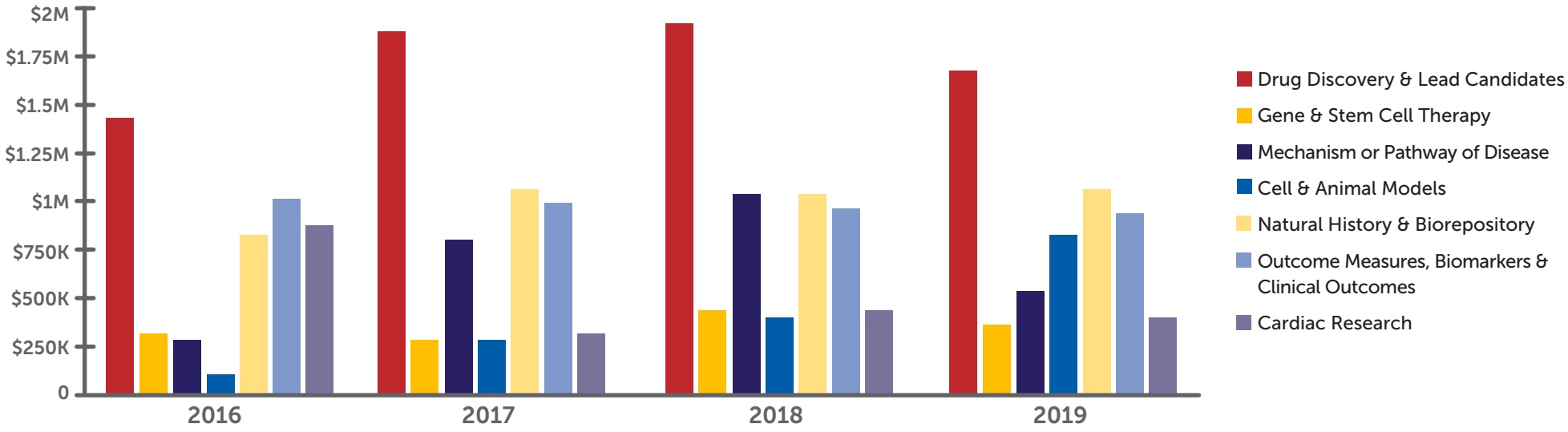
In 2019, the FARA research grant program provided over $6 million to advance FA research. Our goal remains to advance therapeutic development by funding projects related to basic, translational and clinical research. The program funds both established and new investigators in the FA field, both in academic and industry settings and promotes collaborations. Scientists submit applications to FARA to request financial support for their research. These applications undergo peer-review from other researchers, ensuring that the FARA grant program is rigorous and competitive. In addition, FARA reaches out directly to scientists who help address key gaps, questions or resources needed by our research community. FARA also provides ongoing support for the Collaborative Clinical Research Network in FA (CCRN), the FA Center of Excellence, biomarker development consortia and clinical research infrastructure to facilitate clinical trials.

Our sincere thanks goes to all FA researchers and especially the scientists who volunteer their time to provide rigorous peer review of grant applications submitted to FARA.

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 Grants by Strategic Initiative

2016-2019



Featured Drug Discovery Project: One of the new FARA-funded investigators is **Dr. Benoit D'Autréaux** from the University of Paris-Saclay, France. Dr. D'Autréaux's project entitled "Cell-free high throughput screening assays for the discovery of compounds replacing frataxin in FA" focuses on the development of a biochemical assay to measure whether a chemical compound can bypass the need for frataxin in Fe-S cluster formation. Dr. D'Autréaux plans to use this assay to randomly screen large chemical libraries to identify novel therapeutics for FA.

Featured Biomarker Research: FARA has awarded **Dr. Odelya Pagovich**, from Weill Cornell Medical College, a grant for her study entitled "Corneal Confocal Microscopy Quantitative Imaging of Corneal Nerves as a Biomarker of Neurologic Disease in Friedreich's Ataxia." Using corneal confocal microscopy (CCM), a non-invasive examination of the number and structure of nerves in the cornea, Dr. Pagovich will examine whether CCM correlates with the progression of disease over time and whether changes in corneal nerve morphology occur before the clinical manifestations. This measure could help test novel treatments in individuals with FA, and determine if drugs are reaching the neurons.

DESIGN THERAPEUTICS

Kyle Bryant Translational Research Award: Design Therapeutics, a biotechnology company based in California, is advancing the discovery of **Dr. Aseem Ansari** from St. Jude Children's Research Hospital, Memphis (a prior FARA grant recipient) demonstrating that a synthetic transcription elongation factor (Syn-TEF) can restore frataxin expression in cells derived from FA patients. These Syn-TEFs are able to overcome the repressive roadblocks provided by the expanded GAA repeats and restore transcription of the FXN gene, allowing for more frataxin protein to be produced in the cell. In 2019, Design Therapeutics was awarded the Kyle Bryant Translational Research Award for the project "Advancing Syn-TEFs as a therapeutic candidate for Friedreich's ataxia."

COLLABORATIVE CLINICAL RESEARCH NETWORK

The Collaborative Clinical Research Network in Friedreich's Ataxia (CCRN in FA) is an international network of clinical research centers that work together to advance our understanding of the natural history of FA, conduct clinical trials, and provide clinical care for individuals with Friedreich's ataxia. At each clinical research center, there is a team of researchers, physicians, and health care providers dedicated to FA. In 2019, the CCRN in FA added two new sites, one in Auckland, New Zealand and one in Montreal, Canada, expanding the total number of sites to twelve centers spanning four countries. The CCRN in FA has collected natural history data in more than 1,100 individuals with FA.

***Auckland City Hospital, Auckland, New Zealand** Dr. Richard Roxburgh	***CHUM: Hospital Notre-Dame, Montreal, Canada** Dr. Antoine Duquette
University of California Los Angeles, CA Dr. Susan Perlman	**University of Florida, Gainesville, FL** Dr. Sub Subramony
University of Colorado, Denver, CO Dr. Lauren Seeberger	**University of South Florida, Tampa, FL** Dr. Theresa Zesiewicz
University of Iowa, Iowa City, IA Dr. Kathy Mathews	**Children's Hospital of Philadelphia, PA** Dr. David Lynch
Ohio State University, Columbus, OH Dr. Chad Hoyle	**Sick Kids, Toronto, Canada** Dr. Grace Yoon
Emory University, Atlanta, GA Dr. George Wilmot	**Murdoch Children's Research Institute, Melbourne, Australia** Dr. Martin Delatycki
Data Coordination Center, University of Rochester, NY Ms. Cindy Casaceli	**Clinical Data Sciences, Basel, Switzerland** Biostatistician, Christian Rummey

*New sites

The C-PATH Initiative

FARA initiated a project with Critical Path (C-Path) Institute's Data Collaboration Center to develop an aggregated database of clinical data for FA that can be shared and utilized by existing FA researchers. Four de-identified datasets from previous clinical trials as well as FA-natural history and clinical outcome measure datasets were aggregated into a single database in a scientifically rigorous manner. In 2019, this data was shared with >6 research organizations (academic and industry) to assist in designing clinical trials.

CENTER OF EXCELLENCE

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

27 Dedicated Clinicians, Scientists, Lab Techs, and Coordinators

>550 Research & Clinical visits for Neuro & Cardiac Care

Exercise Equipment Purchased for Clinical Trials

>11 Collaborative Research Projects with Industry & Academic Scientists

Testing Novel Drugs & Therapeutic Approaches in Cell & Animal Models with Industry Partners

3 Current Ongoing Clinical Trials

10 Manuscripts Published

Established in 2014, with support from FARA, the CureFA Foundation, and the Hamilton and Finneran families, the FA Center of Excellence (COE) is dedicated to fostering Friedreich's Ataxia research. Its mission is to expedite basic science and drug discovery to treatments and to dedicate resources to clinical research and care in order to further understand the disease, inform drug development, and improve outcomes for individuals living with FA. The Center was established to support the work within the teams outlined below and also to foster efficient collaboration and synergy across them.

The Center Maintains Four Core Research Facilities:

Translational and Clinical Research: Informing, leading and conducting FA clinical trials through interrogating natural history data, and developing and validating clinical endpoints and patient-reported outcomes. *(Dr. David Lynch)*

Drug Discovery: Identifying novel drug targets through high-throughput screening; testing and validating these targets in models of disease, with a focus on quick translation to human studies; and working to improve industry-academic partnerships to enable rapid and efficient development of promising drug candidates. *(Dr. Robert Wilson)*

Biomarker Discovery: Working to identify and develop blood biomarkers of FA disease progression, cardiac risk and therapeutic gain with treatment intervention in FA patients. *(Dr. Ian Blair)*

Cardiometabolic Investigations: Implementing clinical trials, leveraging ongoing natural history studies, and investigating novel research techniques to better understand and treat the cardiometabolic complications of FA. *(Drs. Kimberly Lin and Shana McCormack)*

KEY MILESTONES

ADVANCEMENT OF TREATMENTS IN FA

Performed four early-stage and three pivotal trials in the past six years.

DEVELOPED NEW FRATAXIN ASSAY FOR FA TRIALS

Developed both immunological and mass-spectrometry-based methodologies for measuring the key biomarker in FA, frataxin. This is now being employed in multiple clinical trials, and in aiding therapeutic development at pharmaceutical companies. In addition, this approach has identified multiple forms of frataxin, providing new information on the pathogenesis of the disease.

NEW BIOMARKERS OF FA

Identifying markers of disease in specific tissues or organs, is a crucial component of testing therapies. Biomarkers being tested and developed include molecular or metabolic signatures, system-based markers such as motor evoked potentials, and cardiac, muscle and neuroimaging methodologies.

CLINICAL PHENOMENOLOGY OF FA

By evaluating and treating the largest cohort of individuals with FA in the world, the COE has identified and scientifically evaluated novel aspects of the FA phenotype. This directly improves management and therapy in FA and facilitates a more holistic approach to the disorder, including specific understanding of vision and glucose homeostasis in FA.

MODEL SYSTEMS TO STUDY FA

COE investigators have established and characterized a range of FA models including cellular models (fibroblasts, lymphoblasts and iPSC derived cardiomyocytes) and whole organism models (zebrafish and mouse). These model systems are used to study the pathophysiology of FA, identify novel targets for treatment approaches and to test drugs and therapies.

CLINICAL OUTCOME MEASURES IN FA

Development and validation of clinical outcome measures, such as the modified Friedreich's Ataxia Rating Scale (mFARS), used as a primary endpoint in late-stage clinical trials, has informed clinical and regulatory paths.

INTERNATIONAL ATAXIA RESEARCH CONFERENCE

FARA, in partnership with Ataxia UK, fara Australia, and goFAR, hosted the International Ataxia Research Conference (IARC) on November 14-16, 2019. The IARC was a two and a half-day conference filled with 50 oral presentations, 200 poster presenters with selected flash talks, and a mentoring session for young investigators. Conference topics covered Mechanism of Disease, Therapeutic Approaches and Drug Discovery, Genetics of Disease, Neurophysiology and the Cerebellum, Cellular and Animal Models of Disease, Natural History, Biomarkers and Endpoints, Clinical Trials and Clinical Design. Attendees left energized from the dynamic exchange of ideas, new scientific insights, networking and plans for new collaborations.

MECHANISM OF DISEASE

Dr. Valentine Mosbach from the Puccio lab at IGBMC, in Strasbourg, France, provided new data on frataxin function and showed how studies on bacterial frataxin can identify strategies to bypass frataxin in human cells.

BIOMARKERS & ENDPOINTS

Dr. Louise Corben described a new tool to measure upper limb function in FA. This instrumented spoon is equipped with a motion capture device to assess impairment levels while the patient is engaged in a routine daily activity, such as feeding.

CLINICAL TRIAL & CLINICAL DESIGN

Dr. Wilson Bryan from the FDA spoke on the challenges of gene therapy approaches and gene therapy clinical trial design. Topics addressed in this session were the difficulties of clinical trial design in rare diseases, lessons learned from previous trials and how to avoid making the same design mistakes.

FOR MORE HIGHLIGHTS

For more conference highlights, visit iarc2019.org to view the IARC interview series hosted by Kyle Bryant and Randy Juip. The series includes 12 interviews with FARA staff and founders, members of the conference Scientific Steering Committee, leading FA researchers, and young investigators.

Growing the FA Research Community - IARC by the Numbers

21 Countries Represented

150 Attendees from Academia and Regulatory

140 Attendees from Industry

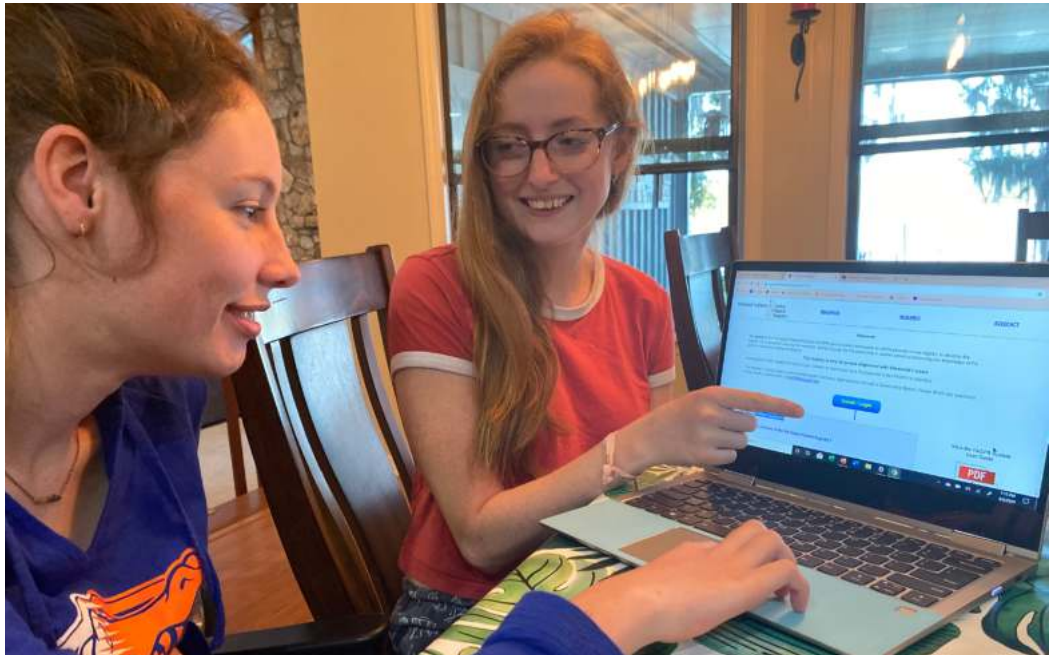
100 Junior Investigators

17 Patient Advocacy Organizations

FA GLOBAL PATIENT REGISTRY & ICD 10 CODE

Friedreich's Ataxia Global Patient Registry

The patient registry transitioned to a more updated system in Fall of 2019. A global steering committee guided the development of the new registry, including developing governance procedures, informed consent documents, and updated questionnaires. The registry is working towards increased globalization with translation into multiple languages. The new platform affords FARA and international advocacy partners equal responsibility in expanding robust data collection from patients. This data will provide better insight for researchers and industry into the lived experiences of the global FA community and facilitate effective communication to individual FA patients about eligibility for studies and clinical trials.



ICD-10 CODE SPECIFIC FOR FA

The ICD-10 coding system is used by healthcare providers to document medical services and diagnoses of patients. The World Health Organization manages the system, and the codes are used for epidemiology data. The codes are also used for billing and reimbursement through health insurance payers. FARA initiated a request to have FA designated under its own ICD-10 code, separate from cerebellar ataxia. An FA specific ICD-10 code allows for correct documentation of diagnosis prevalence, appropriate referrals to specialists, and appropriate payer coverage of medical care and of future FDA-approved treatments. FARA presented to the ICD-10 committee in September 2019, and the new code will be up for approval in the next code implementation cycle in October 2020.

AMBASSADOR PROGRAM

Our team of 75 FARA Ambassadors was active in 2019, increasing FA community support and awareness in government, academic and pharmaceutical arenas. Some of the highlights include:

Rare Disease Week Advocacy

At the end of February, a small group of Ambassadors attended events in Washington, D.C. for Rare Disease Week where training was provided on advocating at the government level for legislation that supports and promotes rare diseases. The events were sponsored by the EveryLife Foundation. The experience prompted one Ambassador, Mary Nadon Scott (top left), to continue her advocacy in the local Vermont offices of her U.S. Representative, Senators and Governor.

Patient Panels at Pharmaceutical Companies

Ambassadors and other FA advocates were involved with panel presentations at pharmaceutical companies with active FA drug or gene therapy development pipelines. The purpose of the patient panels was to provide employees with unique perspectives on living with FA. Each panel was comprised of patients at various ages and stages of FA for a comprehensive understanding of life with the condition. The positive interaction with patients allowed researchers to tangibly understand the urgency for treatments and a cure. In 2019, PTC Therapeutics, Agios, CRISPR Therapeutics, StrideBio, Voyager Therapeutics, AveXis, and Neurocrine BioSciences all hosted FA patient panels facilitated by FARA.

Continuing Education

In October, Ambassadors participated in training by FARA staff to further develop their knowledge of gene therapy development for FA. The training served a broader purpose of bringing together our ever-growing Ambassador team to solidify understanding of research processes and the power of the patient voice to inform and accelerate research for FA.

ENERGY BALL

THE FARA ENERGY BALL

The 11th FARA Energy Ball brought the Tampa Bay community together for an extraordinary night of entertainment and fundraising to advance FA research. The theme of the event was *A Night at the Opera to Cure FA*. While the event décor brought the sophistication of the Met at Lincoln Center, the energy in the room was straight out of a modern rock opera- complete with Queen's Bohemian Rhapsody pumping through the speakers. The event program was fashioned into a customized Playbill, including a "Cast List" that named all FA families in attendance. As Event Co-Chairs, Paul and Suzanne Avery read each name in the "Cast," the crowd responded with resounding applause.

As a result of the continued generous support from sponsors, auction donors, attendees and committee members, **the 2019 FARA Energy Ball raised an incredible $1.6 million**. Bravo!

rideATAXIA had a goal-shattering year in 2019, raising $1.6 Million. The program hosted six rides: SoCal, Dallas, NorCal, Chicago, Philly and Orlando, and launched the rideATAXIA Local Challenge; this gave individuals and teams who were not close to a rideATAXIA location the opportunity to participate in the program remotely. Whether they are pushing themselves physically or on the fundraising front, we are really proud of and grateful for all of our cyclists, teams, volunteers and donors. As one team, they are powering not only their bikes and trikes but also FA research.

rideATAXIA DALLAS

In its 9th year, rideATAXIA Dallas was paired with a patient symposium, bringing more FA families than ever to the ride.We were ready to ride and celebrate rideATAXIA Dallas's most successful fundraising year, but a menacing thunderstorm loomed in the distance. As the storm continued its approach, for the first time in the history of the ride, we had to cancel the outdoor event.

In this turn of events, we were able to see the true resilience and dedication of the community to dance in the midst of the storm, literally. Rallying together, the local committee was able to establish an indoor location with all the necessities and equipment to serve lunch. Our partners, Outback Steakhouse and Grub Burger Bar worked together to provide amazing burgers, chicken sandwiches and delicious milkshakes for the 350 participants who assembled to celebrate raising over $200,000 for FA research! This event showed the true power of the rideATAXIA community and that when we work together, we are unstoppable.

$1.3M RAISED

When FARA was founded in 1998, FAmily-led fundraising events were the primary source of funds for the organization's research initiatives. Thanks to the efforts of our many volunteer event planners across the country, the Grassroots Program remains a driving force in moving research forward, raising over $1.3 Million in 2019! Over 50 fundraising events - including dinners, concerts, movie screenings and endurance activities - all contributed to this overall total.

We are grateful to all of our volunteer fundraisers who use their time and talents each year to power FARA's research mission through Grassroots events.

2019 Grassroots Events

100K+

The Burrows-Hill Foundation: A Night to Fight Friedreich's Ataxia *Annapolis, MD*

Cure FA Soirée *Edmond, OK*

Hope for ToMORROW *Towson, MD*

Opening Night Movie Fundraiser (2019: Star Wars: The Rise of Skywalker) *Southfield, MI*

Pull for a Cure *Land O Lakes, FL +*

The Race for Matt & Grace *Providence, RI*

$25,000 - $50,000

Century 21 King Charity Golf Classic *Rancho Cucamongo, CA*

Friends of Jerod: Reverse Draw & Live Auction *Bakersfield, CA*

Huffman & Huffman FORE! FARA Golf Tournament *Virginia Beach, VA*

Loving Life: An Evening to Cure Friedreich's Ataxia *Branford, CT*

N.J. Seaside Stride *Seaside Park, NJ*

Swing Away at FA *Dawnsonville, GA*

Team Alison Price *Wake Forest, NC*

USI vs Notre Dame Baseball Exhibition Game *Evansville, IN*

$10,000 - $24,999

Fuzzy Buzzy Golf Tournament *Windham, NH*

Mother's Day 5K Race for Christina *Richboro, PA*

Pizza Port Golf Tournament *Encinitas, CA*

Rocky Mountain Bird & Birdie *Brighton, CO*

Screening of "The Ataxian" *Ketchum, ID*

Sparky's Memorial Day Golf Tournament *Watertown, SD*

Team Donovan: Westchester Triathlon *Rye, NY*

Team FARA: 100 Miles for Caroline *Auburn, AL*

Team FARA: FARAmones *Big Sur, CA*

Team FARA: Full Ascent *Mt. Kilimanjaro, Tanzania*

Team FARA: TCS NYC Marathon *New York, NY*

Welsh Bash in the Backyard *Harrisburg, PA*

$5,000 - $9,999

Charity Night at Oak & Ola *Tampa, FL +*

The Claxton Classic Golf Tournament *Glenn Dale, MD*

Commercial Contracting Corporation 5k Charity Walk *Auburn Hills, MI*

FA-Indy Walk/Run *Greenwood, IN*

FAmily Strides: FARA 5K Run/1 Mile Walk *St. Charles, MO*

Fine Arts for FA Showcase *Sioux Falls, SD*

Foxhound Run for FARA One Day Speed & Drive *Jarratt, VA*

Friedreich's Ataxia Awareness Day Luau *Gilroy, CA*

Lend Us Some Muscle *Worldwide*

Muscle Skate for Adriana & Luca *East Meadow, NY*

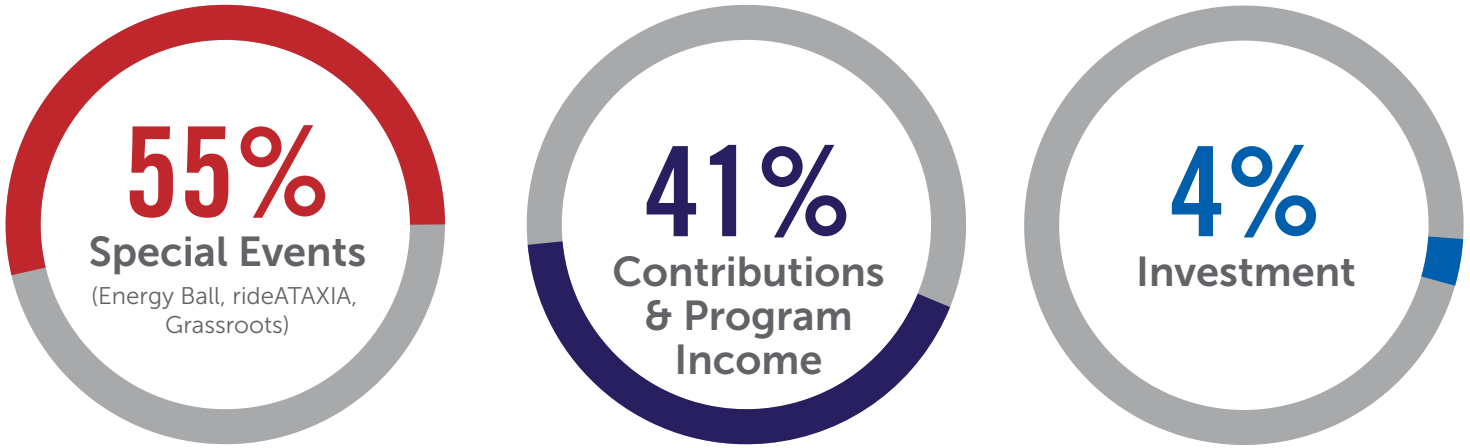
Show UR Rare #TeamJay *Pittsburgh, PA*

The Stoneham Open *Stoneham, MA*

**Listed as fundraising gross*

+Funds represented in FARA Energy Ball total

SOURCES OF FUNDING



WHERE YOUR MONEY GOES

FINANCIALS

STATEMENTS OF FINANCIAL POSITION

December 31, 2019 and 2018

ASSETS	2019	2018
CURRENT ASSETS		
Cash & Cash Equivalents	$1,821,067	$2,162,521
Contributions Receivable	191,637	195,821
Prepaid Expenses	35,477	37, 323
Investment in Securities	2,128,027	1,620,731
TOTAL CURRENT ASSETS	**4,176,208**	**4,016,396**
COMPUTER EQUIPMENT Net of accumulated depreciation of $7,015 (2019) and $6,629 (2018)	120	506
OTHER ASSETS		
Investment in Common Stock*	10,915	1,091,500
TOTAL ASSETS	**$4,187,243**	**$5,108,402**

LIABILITIES & NET ASSETS

CURRENT LIABILITIES		
Accounts Payable	$385,252	$130,166
Deferred Revenue	9,074	-
TOTAL CURRENT LIABILITIES	**394,326**	**130,166**
NET ASSETS		
Without Donor Restrictions	3,668,941	4,914,855
With Donor Restrictions	123,976	63,381
TOTAL NET ASSETS	**3,792,917**	**4,978,236**
TOTAL LIABILITIES & NET ASSETS	**$4,187,243**	**$5,108,402**

STATEMENTS OF ACTIVITIES

Years Ended December 31, 2019 & 2018

NET ASSETS WITHOUT DONOR RESTRICTIONS	2019	2018
REVENUE & SUPPORT		
Contributions & Program Income	$1,691,858	$1,019,316
Special Events	4,556,102	5,133,236
Investment Return	339,096	(71,107)
Net Assets Released from Restrictions	1,576,840	2,536,365
TOTAL REVENUE & SUPPORT	**8,163,896**	**8,617,810**
EXPENSES		
Program Services	7,168,645	6,808,975
Fundraising	990,849	986,105
General & Administrative	169,731	116,177
TOTAL EXPENSES	**8,329,225**	**7,911,257**
IMPAIRMENT ON INVESTMENT IN COMMON STOCK*	1,080,585	-
CHANGE IN NET ASSETS WITHOUT DONOR RESTRICTIONS	**(1,245,914)**	**706,553**
NET ASSETS WITH DONOR RESTRICTIONS		
Contributions	1,637,435	2,278,264
Net Assets Released from Restrictions	(1,576,840)	(2,536,365)
CHANGE IN NET ASSETS WITH DONOR RESTRICTIONS	**60,595**	**(258,101)**
CHANGE IN NET ASSETS	(1,185,319)	448,452
NET ASSETS AT BEGINNING OF YEAR	4,978,236	4,529,784
NET ASSETS AT END OF YEAR	$3,792,917	$4,978,236

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

DONORS & CONTRIBUTORS

>$400,000

CureFA Foundation *+

$300,000-$400,000

Patricia Finneran*
William B. Finneran*

$200,000-$299,000

David and Valerie Doremus+
Michael Henry and Brigid Brennan

$100,000-$199,999

Anonymous
Anonymous
The Burrows Hill Foundation to Fight Friedreich's Ataxia
The Crisp Family Fund+
The Ritschel Family
Mary Alice Wheeler

$50,000-$99,999

Anonymous
Abundant Life Ministries- Rick and Tracy Dadeo
Avery Family Foundation
Bloomin' Brands Inc
Friedreich Ataxia Research Association (fara Australia)+
www.TheEventHelper.com

$25,000-$49,999

Anonymous
Alfiero and Lucia Palestroni Foundation
Thomas Bradley
Chris T. Sullivan Foundation
David O. Kingston Foundation
Health Insurance Innovations
The Hennecke Family Foundation
Warren and Winifred Huff
Kurt and Amy Hull- Diversified Asset Funding
Paul and Mary Jacobs
McDaniel Charitable Foundation
The Brad & Nancy Rex Family
Rochester Area Community Foundation
Roger Klauber Family Foundation
Doug and Kathy Rothschild
Vanguard Protex Global
William and Heidi Wright

* Center of Excellence Funder | + Grant or Conference Co-Funder

DONORS & CONTRIBUTORS

$10,000-$24,999

Anonymous
Anonymous
Ataxia UK +
Barbara and Franklin Carson Family Foundation
Lucas and Jeremy Bourgeois-Knox
The Corbett Family Charitable Foundation
Corporate Creations Foundation Inc.
Shon and Sharyn Craig
Dan Kirkland Wells Foundation
Danker-Basham Foundation
Dean Family Foundation
Candy and Eddie DeBartolo and Family
Simon and Lucia Dolan
Herman and Tanya Fernandez
Fifth Generation Inc.
Friedreich's Ataxia Research Alliance Ireland +
John and Tracy Frost
Justin and Allison Gerbereux
goFAR +
H.G. Barsumian, M.D. Memorial Fund
The Krutzer/Fisher Family Trust
Roberta Lindsay
Lucky 13 Foundation
Maids Of Athena Grand Lodge
Thomas and Judith Marrow
Florida Purchasing Agency - Eric and Caroline Maugee
Metro Development Group LLC
Noble Energy
The Plohoros Family
The Rao Family
Raymond James Financial, Inc.
Brandt and Martelia Sakakeeny
Adam Snyder and Dr. Aarti Patel
Southern Glazer's Wine & Spirits
Drs. Joseph Staffetti and Theresa Zesiewicz
Karen Stiefel
Thomas A. & Mary S. James Foundation
Michael and Susan Thomas
Glenn Topping
Jonathan and Jordan Tubby
USF Health
White Rock Healing Arts
Jason and Nancy Wilson
James Wooten
James Ziegler and Lori Usher

$5,000-$9,999

A1 HR
Adrian Fernandez Insurance, Inc.
Frank and Anna Alfano
Francisco and Rhonda Alonso
Anonymous
Avonworth School District
Rakesh Bansal
Matthew and Jennifer Bello
Rick and Dixie Berman
Neil and Sally Braid
Joseph and Maureen Brotherton
Brown & Brown Insurance
Dennis and Pat Canaday
Cecil A and Mabel Lene Hamman Foundation
Compass Group
Anne Marie Conway
Kier and Lauren Cooper
CVS Corporation
Deutsche Bank Americas Foundation
Nicholas and Dana Di Iorio
David and Betty D'Onofrio
Cory Easton
Alexandre Emery
Express Scripts
Tim and Marcy Freed
Gabos Family Charitable Fund
Robert Giroux
Goldman Sachs Gives
Carl and Joyce Greber
Steve and Janell Griggs
Harding Family Foundation
Charles Harrison
Huffman & Huffman
I Plan It
Ineos Stryrolution America
Ingram Family Foundation
Jabil Inc.
Cathleen Jamieson
Robert and Katina Johnston
Joseph and Teresa Kadow
Mary Elizabeth Kennedy
Mr. and Mrs. Michael Klonoski
Mark and Catherine Ensio Family Foundation Inc.
Alyssa May
McGehee Foundation
Gail Moore
Thomas Pryma
Jennifer Ramirez
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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 $525,000 to our programs in 2019. Many contributions were made in the form of sponsorship of FARA events, education initiatives, and the International Ataxia Research Conference. Over a quarter of these funds ($165,000+) were comprised of contributions to our FA Biomarker Consortium, Core Programs and Services (such as the FA Global Patient Registry and the Collaborative Clinical Research Network), and honoraria for advisory board participation.

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