Dear Friends,

Thank you very much for your support and commitment to FARA, which has enabled us to make meaningful progress towards treatments and a cure for Friedreich’s Ataxia (FA). As September 29, 2018 marked the twentieth anniversary of FARA’s founding, the end of 2018 provided an opportunity to reflect on both the progress of the previous twelve months as well as the last twenty years. As we draw closer to truly meaningful therapies for FA, we considered all of the extraordinary people and milestones that have helped us reach this point. When FARA was founded, it was an all-volunteer organization consisting of an eleven-member working board. Our first grant was for $14,000 and our budget for that first year was $100,000. Since that time, your commitment has fostered growth of our research program, engagement of our community and of our government and industry partners, and strengthening of our organization. The timeline on the right shows some of the important milestones along our journey to treatments and a cure for FA.

FARA’s accomplishments in 2018 demonstrate just how far we’ve come on that timeline. We awarded more than $6 million in grants to advance very promising scientific research. With the active participation of the FA patient community, we continued to expand and refine the world’s largest FA patient registry, largest FA clinical research network and largest FA natural history database, into which we began to recruit additional pediatric patients so as to enable their more extensive participation in clinical trials. We continued to build and nurture our first-rate relationships with all our partners in this concerted effort to treat and cure FA. For example, we awarded a record number of research grants to academic investigators around the world, continued to strengthen our collaboration with key government partners such as the National Institutes of Health (NIH) and the Food and Drug Administration (FDA), and grew our very productive partnerships with the biopharmaceutical industry to about two dozen companies. To help tremendously with the important patient-to-patient communications and those between our patients and our academic, government and industry partners, we have expanded the highly successful Ambassador Program to include over 65 very active patient ambassadors. This report will provide you a detailed look at these programs and accomplishments.

We are deeply grateful for your past support and continued commitment - the key to the tremendous progress in FA research. We hope you are as proud as we are of all we are accomplishing together. Our ability to come together - researchers, pharma representatives, government agencies, patients, families and friends - is the most powerful driver of our work. With every new meaningful milestone, we are proving -Together, we will treat and cure FA.

Thank you very much,

Ron Bartek
President

Jennifer Farmer
Executive Director
1981 Clinical Diagnostic Criteria established
1996 Disease-causing gene mutation identified
1998 FARA was founded
1999 FARA hosts first FA scientific conference
2001 First animal model of FA was created
2004 FA Natural History study launched
2006 FARA Patient Registry was launched
2008 Small molecules increase frataxin (reverse gene silencing) in FA mouse model
2010 Creation of novel models derived from FA patient cells
2011 FARA hosts 4th FA Scientific Conference
2014 Gene therapy shown to reverse FA cardiac disease in a mouse model & 3 New Pharmaceutical Companies Formed to advance gene therapy
2016 FA Natural History Study Reaches 800 Participants
2017 FARA brings patient voice to the FDA in FA Patient Focused Drug Development Meeting
2018 Gene therapy shown to reverse FA neurological disease in mouse model
Completed enrollment for a phase II & a phase III with >175 participants
2019 Gene therapy shown to reverse FA cardiac disease in human patients
2020 Oncolytic virotherapy shown to improve clinical outcomes in FA patients
2021 FARA launches clinical trial for FA gene therapy
2022 FARA launches partnership with leading biotech companies to advance novel treatments

>1050 PARTICIPANTS IN NATURAL HISTORY STUDY

>3500 IN GLOBAL PATIENT REGISTRY

FA TREATMENT PIPELINE
7 treatment approaches with >11 candidates in development or clinical trials

>50 FA PATIENT Cell Lines Available for Research

>20 BIOTECH & PHARMA companies engaged in FA research advancing novel treatments

FARA FUNDING
>6M IN RESEARCH ANNUALLY
In 2018, FARA provided $6.1m for basic, translational, and clinical research grants, our largest amount of research funding in a year ever.

FARA research funding continues to grow, which entices new outstanding investigators to apply their expertise to developing promising treatments for FA and to share their findings with the FA research community. During 2018, FARA received 37 letters of intent (LOIs) and invited 26 investigators to submit full research grant applications. Following the peer-review process, 17 were awarded funding. The successful investigators were from 8 different countries and 8 of them (3 of whom were junior investigators) had not previously submitted applications to FARA. Several of these grants were co-funded with our FA advocacy group partners. Continuation funds for a second year were given to an additional 18 research projects. FARA also provided 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 the investigators who provide rigorous peer review of grant applications submitted to FARA. Their voluntary contribution of time and effort is essential for ensuring the high quality of FARA-funded research projects.

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.
Two of the 2018 new FARA investigators were Dr. Michael Green and Dr. Jon Watts, both from the University of Massachusetts Medical School. Because of their FARA awards, Dr. Green and Dr. Watts are now communicating regularly with one another about their FA studies. While their approaches are different, they are both working with FA cell and mouse models to identify compounds that reverse the silencing effect of the GAA repeat expansion, and lead to increased frataxin levels and improved mitochondrial function.

The goal of Dr. Green’s project “Systematic identification of pharmacological activators of the repressed FXN gene to treat Friedrich Ataxia” is to first identify proteins that are involved in the repression of FXN when the repeat expansion is present, and then find compounds that block the function of these proteins. So far this approach has detected several compounds that increase FXN expression in FA neurons and cardiomyocytes, which is promising.

Dr. Watts’ project “Activating frataxin expression in animals using chemically modified oligonucleotides” builds on studies by his collaborator, Dr. David Corey at the University of Texas Southwestern Medical Center, who is also a FARA-funded investigator. Dr. Corey treated FA cells with repeat-targeted oligonucleotides (short nucleotide sequences) and showed that frataxin expression was increased. To follow up, Dr. Watts is synthesizing oligonucleotides and optimizing them for delivery to the central nervous system and the heart. He will then examine the effect of these compounds in FA mouse models. Grant funding for this project was made possible by The Crisp Family Fund.

The ongoing studies by Dr. Green and Dr. Watts will potentially lead to the development of two new types of drugs for treating FA.
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 treatments and clinical care for individuals with Friedreich’s ataxia.

The CCRN is actively:
- Identifying and validating clinical outcome measures and biomarkers in FA that are necessary for clinical trials
- Facilitating the implementation and delivery of clinical trials
- Sharing data and resources to advance treatments for FA
- Defining best clinical practices for FA and providing the highest level of clinical care for patients

At each clinical research center, there is a team of researchers, physicians and health care providers dedicated to FA. All recent FA clinical trials have been conducted through the CCRN.

CCRN in FA Supplemental Activities
In addition to the primary natural history and outcome measure study, sites participated in and fully enrolled two industry-sponsored clinical trials and launched a more detailed neurological natural history study in children with FA.

- **Phase 2, Part 2 Clinical Trial: MOXIe, RTA-408 Capsules in Patients with Friedreich’s Ataxia**, Sponsor: Reata Pharmaceuticals, ClinicalTrials.gov Identifier: NCT02255435
- **Phase 2 Clinical Trial: Efficacy, Tolerability and Pharmacokinetics of Multiple Doses of Oral TAK-831 in Adults with Friedreich Ataxia**, Sponsor: Takeda, ClinicalTrials.gov Identifier: NCT03214588
- **Neurological Measures of Progression in Children with FA**
  Enrolling 100 children with FA and evaluating the progression of neurological function at 6-month intervals for 3 years at Children’s Hospital of Philadelphia, University of Florida, University of California Los Angeles, Sponsors: Food and Drug Administration and FARA

**Natural History & Outcome Measure Study**

>1050 Subjects Enrolled
40% of individuals in the study are children

>4550 Completed Visits in the Database
69% had onset of FA symptoms before 14yrs of age
The TAK-831 study was fully enrolled and completed two months ahead of Takeda’s schedule and we believe this was only possible because FARA’s direct support that has facilitated the commitment and organization of the physicians and coordinators in the CCRN in FA, and recruitment and engagement of the FA patient community in research.

- Hao Wang, PhD Senior Scientific Director, Clinical Neuroscience-CNS TAU, Takeda
The FA Center of Excellence (COE) is a multi-disciplinary, translational research and clinical care center devoted to Friedreich’s ataxia. 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 in March 2014, with a gift (over 3 years) to Penn Medicine/Children’s Hospital of Philadelphia, presented by FARA in partnership with the Hamilton and Finneran families. In 2017, that funding commitment was renewed for an additional three years. The Center not only supports work with the teams outlined below, but also fosters efficient collaboration and synergy across them.

**Translational and Clinical Neuroscience Research – Dr. David Lynch**
- >450 individuals with FA visit Dr. Lynch and team annually to participate in research and receive clinical care
- Served as Principal Investigator for two industry sponsored clinical trials
- Explored FA research in cell and animal models including:
  - Studying how frataxin deficiency leads to cellular changes in neurons which correspond to the symptoms of FA
  - Examining proteins that interact with frataxin in neurons to promote stability
  - Testing drugs and treatment approaches in animal models

**Biomarker Discovery – Dr. Ian Blair**
- Developed a new and improved frataxin assay (measurement of the essential protein that is deficient in FA) for both pre-clinical and clinical development.
- Further optimized the frataxin assay to allow for more accurate measurement of frataxin in patient cells (blood, skin and muscle)
- Discovered a novel isoform of frataxin in red blood cells, called frataxin isoform E

**Drug Discovery – Dr. Robert Wilson**
- Developed a zebrafish model of FA to facilitate screening and testing of drugs
- Developed and characterized FA cardiomyocytes derived from patient cells to test drug candidates in disease relevant cells
- Evaluating p38 MAP kinase inhibitors, inhibitors of ferroptosis and DNA damage and repair as therapeutic candidates

**Cardiac Research and Clinical Care – Dr. Kimberly Lin**
- Discovery of biomarkers and endpoints for future clinical trials, novel approaches to treatment and improved clinical outcomes
- Completed studies include:
  - Cardiac MRI
  - Evaluation of >15 cardiac specific blood biomarkers
  - Validation of exercise tolerance test (currently being used in clinical trials)
- Ongoing studies include:
  - Retrospective and prospective analysis of cardiac clinical outcomes and risk factors
  - Evaluating the feasibility and utility of cardiac imaging study using spectroscopy

**Metabolism, Diabetes, and Exercise – Dr. Shana McCormack**
- Expanded the clinical research and care of FA to include:
  - Growth and development
  - Diabetes management
  - Evaluation of muscle specific biomarkers
  - Studies of exercise and nutrition

In 2018, the COE Investigators published 14 scientific journal articles. There were results of 3 clinical trials reported, 2 review articles, 2 publications on frataxin, 2 novel therapeutic target papers, 2 biomarker studies reported, 1 paper evaluating vision loss in FA, and several papers looking at mechanism of disease in cell and animal models.
Biomarkers are defined by the FDA as “characteristics that are objectively measured and evaluated as an indicator of normal biological processes, pathogenic processes, or pharmacologic responses to a therapeutic intervention”. The use of well-defined biomarkers can accelerate therapy development by telling us more quickly if a therapy does what it is expected to do, and gives us an indication if it might work. This saves time and money, and encourages pharmaceutical companies to look into potential FA therapies.

- FARA has looked into many different possible biomarkers that could be used for various use cases (i.e. for different drugs, different types of therapy, therapies targeting different systems).
- FARA holds meetings at least annually since 2015 to drive collaboration and prioritize studies that will help develop biomarkers that are seen as most needed and most promising.
- FARA funds grants to groups looking to develop new biomarkers, or gather more data to support their use.
- FARA works with industry and non-profit partners to run protocols to test potential new biomarkers.
- FARA brings together groups interested in related biomarkers to leverage funds and data to develop biomarkers quickly and effectively.

### FARA Funded Biomarker Studies

<table>
<thead>
<tr>
<th>Discovery</th>
<th>Quantification</th>
<th>Verification</th>
<th>Assay Optimization</th>
<th>Validation</th>
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<tbody>
<tr>
<td><strong>DISEASE MONITORING (NEURO)</strong></td>
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<tr>
<td>New Mass Spectroscopy</td>
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<tr>
<td>Assay for Frataxin</td>
<td></td>
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<tr>
<td>Motor Evoked Potentials</td>
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<tr>
<td>Meissner Corpuscles</td>
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<tr>
<td>Quantitative Sensory Testing</td>
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<tr>
<td>Brain/ Spinal Imaging</td>
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<tr>
<td><strong>DISEASE MONITORING (CARDIAC)</strong></td>
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<tr>
<td>Cardiac imaging</td>
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<tr>
<td>Blood based markers</td>
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<tr>
<td><strong>RESPONSE BIOMARKERS</strong></td>
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<tr>
<td>Measures of metabolism</td>
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<tr>
<td>Exercise recovery</td>
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**Intended Use:**
- To measure how much frataxin is produced by a genetic or protein therapy.
- To provide evidence whether a therapy is likely to slow or stop neurological disease progression.
- To provide evidence whether a therapy is likely to slow or stop cardiac disease progression.
- To quickly provide evidence whether a therapy is likely to impact muscle disease and other systemic features.
The FARA patient registry is undergoing a transformation to a more updated system, which will be easier for patients to enter data, allow increased functionalities, and to convert it into the Friedreich’s Ataxia Global Patient Registry. A contract was signed in June of 2018 with Pulse Infoframe, Inc. (London, Ontario) to initiate the transition of the current FARA patient registry to a new, more streamlined platform suitable for an international audience. A global steering committee is guiding the development of the new registry, including developing governance procedures, informed consent documents, and updated questionnaires, as well as working towards increased globalization with translation into multiple languages. The new platform allows FARA and the global FA community to expand on the data collected from patients and caregivers, to provide better insight for our work with researchers and pharmaceutical partners into the experiences that the worldwide patient populations have with FA, and to facilitate effective communication to FA patients about open studies and clinical trials. The platform offers the opportunity to collect patient experience data longitudinally across time in a more detailed and robust manner as compared to the current registry, and to administer time-limited questionnaires to inform specific research questions. It also offers improved data privacy standards. The expected launch of the new FA Global Patient Registry is summer of 2019.

FA GLOBAL PATIENT REGISTRY

>3,500 Registry Enrollments
~300 new registrants/ year

>65 Countries Represented

TOP 5
US, UK, Brazil, Canada, & Australia

>70% enrollments
FARA Ambassadors have been active in 2018, increasing FA awareness in academic and pharmaceutical arenas. This year provided the following opportunities for advocacy and education:

**Genetic Counseling Program Outreach**
Ambassadors spoke about their diagnostic journey at nine genetic counseling programs throughout the U.S., including programs in California (2), Georgia (1), Maryland (2), Massachusetts (2), and Pennsylvania (2). Genetic counseling students find that hearing patient stories enhances the education they receive in their coursework and in clinical rotations. Presentations by FA Ambassadors allow for honest communication exchange about living with a rare disease. Awareness of FA patients’ clinical and personal experiences provides expanded perspectives for genetic counseling students as they embark on their careers.

**Patient Panels at Pharmaceutical Companies**
Ambassadors and other patient/caregiver advocates continue to be involved with patient panel presentations at pharmaceutical companies with active FA drug or gene therapy development pipelines. The purpose of the patient panel is to provide company employees with the unique insight into how patients living with FA adapt. Each panel is comprised of patients at various stages of disease for a continuum of the natural history of FA. Feedback from pharmaceutical partners has been positive, as researchers understand concretely the urgency for treatments and a cure.

**Rare Disease Week Advocacy**
Each year, at the end of February, a small Ambassador group attends events in Washington, D.C. for Rare Disease Week where training is provided on advocating at the government level for legislation that supports and promotes rare diseases. The events are sponsored by EveryLife and Rare Disease Legislative Advocates (RDLA) and include a documentary on a rare disease, a legislative conference, and meetings with members of Congress on Capitol Hill. In 2018, “The Ataxian” was the featured documentary.

**Continuing Education**
Ambassadors are invited each October to participate in training by staff at FARA to further develop their knowledge of the treatment pipelines for FA. This training occurs in conjunction with rideATAXIA Philadelphia and the research symposium sponsored by Children’s Hospital of Philadelphia (CHOP). Training serves a broader purpose of bringing together our ever-growing Ambassador team to solidify the commitment to accelerate research by advocating for FA awareness.
The 2018 FARA Energy Ball marked the 10th year the Tampa Bay community joined together to raise funds to advance FA research for all children and adults living with FA. With the theme Journey to the Cure, the night honored the enduring commitment of veteran FA researchers, the strength of people living with FA and the steadfast support of donors. The table centerpieces were adorned with roadmaps, mini suitcases, passports and postcards as well as milestones highlighting FA research progress over the past ten years. It was a sold-out event with a delicious plated dinner, a competitive auction and an exhilarating live band.

Standout event moments included a powerful performance of Journey’s Don’t Stop Believin’, heartfelt tributes from Honorary Chairs Janell and Steve Griggs, CEO Tampa Bay Lightning, and a moving message of gratitude delivered to guests by Alison and Laurel Avery, whose family founded the event. This year’s Fund a Cure raised $530,000 in a matter of minutes from generous donors throughout the ballroom, which was then matched by the CureFA Foundation/the Hamilton and Finneran Families. This contributed to a record-breaking $2.5 million event total raised in support of FA research.
rideATAXIA is a nation-wide program of bike rides that welcomes people of all abilities to ride and to raise funds for FARA’s mission to treat and cure FA through research. In 2018, FARA hosted 6 rides and welcomed a total of 2300 participants in SoCal, Dallas, NorCal, Chicago, Philadelphia and Orlando. While all of our rides are individually successful, together they become essential to the progress of FA research raising over $1 Million this past year. The ride consists of routes for all abilities and a post-ride celebration with lunch from National Presenting Sponsor - Outback Steakhouse, music and an award ceremony. Each ride has its own unique personality and regional flavor. These characteristics are products of the amazing local partners and volunteer committees that work hard every year to provide a great experience for all participants and FAmilies that attend the ride.

rideATAXIA Chicago has a small town friendly vibe with a big city impact. Teams traveling from all over the Midwest - Illinois, Michigan, Indiana, Ohio and Iowa come to the small central Illinois community of Channahon to spend the day. These Teams are not just made up of immediate FAmilies but their communities that travel with them. During the day, all of the teams can be found setting up tents and cheering sections across the start and finish. Once all of their teammates are back, they celebrate by enjoying lunch provided by Outback Steakhouse, Carrabba’s Italian Grill and Bonefish Grill. This year Chicago had its most successful year yet with 20 Teams traveling to Channahon raising over $147,000 for FA research!

Team Cousins for Cure celebrating their first year at the ride raising over $26,000 and recruiting over 20 teammates from Michigan.
2018 was a record-setting year for the Grassroots Program, with over $1.5 Million raised! When the FARA team started the #StriveforOneFive campaign, it was considered to be extremely ambitious. But the dedication, creativity, and generosity of all involved in the grassroots fundraising program allowed us to exceed the $1.5 Million goal.

There were several new events among the 60+ events contributing. One noteworthy example includes the Cure FA Soirée in Edmond, OK where the Gehr family hosted an evening of live music and dinner. Another took place in Indiana, where the USI and IU Baseball teams faced off in a friendly exhibition game that drew hundreds of spectators. At Howell High School in Michigan, 14 senior students lived in their school and competed to raise funds to be the ultimate Senior Survivor.

FARA’s many returning events also played a huge role in getting the program to our goal. The Burrows-Hill Foundation hosted their second Night to Fight FA, a reception and auction in Annapolis, MD, and generously gave their proceeds to FARA. The Race for Matt & Grace in Providence, RI kept their community engaged year-round with a full calendar of events. The Juip family hosted another premier movie screening in Southfield, MI – this time featuring Fantastic Beasts: The Crimes of Grindelwald. And Hope for toMORROW, an annual evening of food, drinks, auction and entertainment, in the Baltimore area increased their fundraising due in part to the introduction of mobile bidding and a give request generously supported by guests.

We are sincerely grateful to all of our tireless fundraisers and their communities of supporters for powering FARA’s research mission.
SOURCE OF FUNDING

61% Special Events (Energy Ball, rideATAXIA, Grassroots)

39% Contributions

WHERE YOUR MONEY GOES

86% Research & Programs

12% Fundraising

2% General & Administrative
# Financial Statements

## Statement of Financial Position

**Years Ended December 31, 2018 & 2017**

### Assets

#### Current Assets

<table>
<thead>
<tr>
<th></th>
<th>2018</th>
<th>2017</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cash &amp; Cash Equivalents</td>
<td>$2,162,521</td>
<td>$1,459,689</td>
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<tr>
<td>Contributions Receivable</td>
<td>195,821</td>
<td>358,567</td>
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<tr>
<td>Prepaid Expenses</td>
<td>37,323</td>
<td>8,402</td>
</tr>
<tr>
<td>Investment in Securities</td>
<td>1,620,731</td>
<td>1,933,814</td>
</tr>
<tr>
<td><strong>TOTAL CURRENT ASSETS</strong></td>
<td><strong>$4,016,396</strong></td>
<td><strong>$3,760,472</strong></td>
</tr>
</tbody>
</table>

#### Computer Equipment

- Net of accumulated depreciation of $6,629 (2018) and $6,129 (2017)
- **2018**: 506
- **2017**: 1,006

#### Other Assets

<table>
<thead>
<tr>
<th></th>
<th>2018</th>
<th>2017</th>
</tr>
</thead>
<tbody>
<tr>
<td>Investment in Common Stock</td>
<td>1,091,500</td>
<td>1,091,500</td>
</tr>
<tr>
<td><strong>TOTAL ASSETS</strong></td>
<td><strong>$5,108,402</strong></td>
<td><strong>$4,852,978</strong></td>
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</tbody>
</table>

### Liabilities & Net Assets

#### Current Liabilities


#### Net Assets

<table>
<thead>
<tr>
<th></th>
<th>Without Donor Restrictions</th>
<th>With Donor Restrictions</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>2018</strong></td>
<td>$4,914,855</td>
<td>63,381</td>
</tr>
<tr>
<td><strong>2017</strong></td>
<td>$4,208,302</td>
<td>321,482</td>
</tr>
<tr>
<td><strong>TOTAL NET ASSETS</strong></td>
<td><strong>$4,978,236</strong></td>
<td><strong>4,529,784</strong></td>
</tr>
</tbody>
</table>

### Net Assets Without Donor Restrictions

<table>
<thead>
<tr>
<th></th>
<th>2018</th>
<th>2017</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contributions</td>
<td>$1,019,316</td>
<td>$1,448,463</td>
</tr>
<tr>
<td>Grants</td>
<td>-</td>
<td>15,000</td>
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<tr>
<td>Special Events</td>
<td>5,133,236</td>
<td>4,540,268</td>
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<tr>
<td>Investment Return</td>
<td>-71,107</td>
<td>222,780</td>
</tr>
<tr>
<td>Net Assets Released from Restrictions</td>
<td>2,536,365</td>
<td>2,005,679</td>
</tr>
<tr>
<td><strong>TOTAL REVENUE &amp; SUPPORT</strong></td>
<td><strong>$8,617,810</strong></td>
<td><strong>$8,232,190</strong></td>
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</table>

### Expenses

<table>
<thead>
<tr>
<th></th>
<th>2018</th>
<th>2017</th>
</tr>
</thead>
<tbody>
<tr>
<td>Program Services</td>
<td>6,808,975</td>
<td>6,603,594</td>
</tr>
<tr>
<td>Fundraising</td>
<td>986,105</td>
<td>924,169</td>
</tr>
<tr>
<td>General &amp; Administrative</td>
<td>116,177</td>
<td>93,217</td>
</tr>
<tr>
<td><strong>TOTAL EXPENSES</strong></td>
<td><strong>7,911,257</strong></td>
<td><strong>7,620,980</strong></td>
</tr>
</tbody>
</table>

### Change in Unrestricted Net Assets

- **2018**: $706,553
- **2017**: $611,210

## Consolidated Statement of Activities

**Years Ended December 31, 2018 & 2017**

### Net Assets Without Donor Restrictions

<table>
<thead>
<tr>
<th></th>
<th>2018</th>
<th>2017</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contributions</td>
<td>2,278,264</td>
<td>2,299,186</td>
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<tr>
<td>Net Assets Released from Donor Restrictions</td>
<td>-2,536,365</td>
<td>-2,005,679</td>
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<tr>
<td><strong>CHANGE IN TEMPORARILY RESTRICTED NET ASSETS</strong></td>
<td><strong>-258,101</strong></td>
<td><strong>293,507</strong></td>
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<tr>
<td><strong>CHANGE IN NET ASSETS</strong></td>
<td><strong>448,452</strong></td>
<td><strong>904,717</strong></td>
</tr>
</tbody>
</table>

### Net Assets at Beginning of Year

- **2018**: $4,529,784
- **2017**: $3,625,067

### Net Assets at End of Year

- **2018**: $4,978,236
- **2017**: $4,529,784
2018 DONOR LISTING

$1.5M & ABOVE
CureFA Foundation *

$250,000-$500,000
The Crisp Family Fund+
Patricia Finneran*
William B. Finneran*

$100,000-$249,999
Amalie Oil Company
The Avery Family Foundation
The Burrows Hill Foundation
Friedreich Ataxia Research Association+
Michael Henry and Brigid Brennan
Herbert Lampert
The Ritschel Family
Mary Alice Wheeler

$25,000-$49,999
Abundant Life Ministries - Tracy Mathews
Association Française de l’Ataxie de Friedreich (AFAF)+
Thomas Bradley
Ken and Elizabeth Burdick
Hugh Connerty
The Corbett Family Charitable Foundation
Florida Purchasing Agency - Eric and Caroline Maugee
Friedreich’s Ataxia Research Alliance Ireland+
Howell Public Schools - Senior Survivor 2018
Paul and Mary Jacobs
The Brad & Nancy Rex Family
Roger Klauber Family Foundation
Ed and Sandy Taylor
Vanguard Protex Global
Villa Restaurant Group

* Center of Excellence Funder  |  + Grant or Conference Co-Funder
### $10,000-$24,999
- Paul and Gloria Burke
- Barbara and Franklin Carson Family Foundation
- Jodi Cook
- 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
- Event Development Institute
- Exelon
- Friends of Jerod
- Fuzzy Buzzy
- Justin and Allison Gerbereux
- Hamilton Family Charitable Foundation
- Health Insurance Innovations
- Warren and Winifred Huff
- Robert and Katina Johnston
- Joseph and Teresa Kadow
- The Krutzer/Fisher Family Trust
- Live City
- Justin and Alyssa Owmary
- Tony Plohoros
- Mark and Carrie Pykett
- Race for Matt and Grace
- Hari and Shirisha Rao
- Raymond James Financial, Inc.
- Rocky Mountain Bird & Birdie
- Doug and Kathy Rothschild
- The James R. Ryan Foundation
- Carl and Julie Sahlsen
- Sioux Empire Community Theater
- Richard and Sheila Smith
- Southern Glazer’s Wine & Spirits
- Drs. Joseph Staffetti and Theresa Zesiewicz
- Bud Strange
- Synovus
- Tampa Bay Sporting Clays - Mike and Nicole Mejzrah
- Tampa General Hospital
- Michael and Susan Thomas
- Christopher and Goergeitte Tsavoussis
- USF Health
- Carol Wiiken
- William and Heidi Wright
- James Ziegler and Lori Usher

### $5,000-$9,999
- Carlos and Dorothy Alfonso
- AT & T Florida
- BASF Foundation USA
- Bellingham / Whatcom Fire Fighters Benevolent Foundation
- Valerie Bennett
- Richard and Dixie Berman
- Theresa Boots
- Neil and Sally Braid
- Joe and Maureen Brotherton - SOS Foundation
- James Buell
- Sheryl Cassidy
- Cecil A and Mabel Lene Hamman Foundation
- Mike and Lauretta Chrys
- Anne Marie Conway
- Kier and Lauren Cooper
- Tim and Jen Curci
- CVS Corporation
- Dan and Jackie Devine
- DMD Properties, Inc.
- Rob Eddy
- El Dorado Holdings
- Mark and Catherine Ensisio Family Foundation Inc
- Ava Forney
- Frederick Landscaping, Inc
- Paul and Suzanne Gabos
- Grain To Green
- Steve and Janell Griggs
- Gene and Judith Hedrick
- Huffman & Huffman
- Huron Valley Radiology
- John and Madison Isner
- Jabil Inc.
- Jumpin for Jazz, Inc.
- Kelly Integral Solutions LLC
- Joseph and Anna Kokolakis
- Laura Lee
- LG Family Foundation
- Roberta A. Lindsay
- James and Dawn Maddux
- McGehee Foundation
- Gail Moore
- Carol Novack
- Ben and Beth Novello
- O’Connor Management
- SNL Entertainment LLC
- Mark Payne
- The Ramazio Family
- Rock-N-Jock Charities
- James Rusche and Patricia Epperly
- Kenneth Saller
- Seminole Hard Rock Hotel & Casino Tampa
- F. Nicholas Shamma
- Tom And Kathy Shannon Family Foundation
- Rick and Lisa Silva
- SunTrust Bank
- Sutter Home Winery
- Carolyn A. Swatsler
- TD Bank
- Thomas Financial
- Barbara Thomason
- Joseph Thomure
- David Troyer
- USF Foundation
- Louis and Kelly Varsames
- Kristin Vogel
- Patricia Waldeck
- Bret Wienke
- Julie Wooley
- W. Dan Wright
- Paul and Avery Zaritsky
- Watertown School District
- Western Digital Corporation
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. Their support expands our capability to engage the FA community in research and advance science towards treatments and a cure. Collectively, these partners contributed more than $537,000 to our programs in 2018. Many contributions were made in the form of sponsorship of FARA events, education initiatives, and scientific conferences.

More than a quarter of these funds ($152,542) were contributions to our FA Biomarker Consortium. Biomarkers are biological measurements that in a relatively short timeframe can give us information indicating what result might be seen in a much longer study. In 2015, FARA, with its industry and academic partners, launched several multi-year studies to look for novel biomarkers for FA. Indicated by asterisks to the right, The FA Biomarker Consortium consists of contributors, along with FARA, that fund this work.

| CONTRIBUTED $537K+ |

- Adverum Biotechnologies
- BioElectron Technology Corp.
- BioMarin
- Cydan Development Inc
- Horizon Pharma USA, Inc.
- Minoryx Therapeutics
- Pfizer, Inc.
- PTC Therapeutics*
- Reata Pharmaceuticals
- Retrotope
- Stealth BioTherapeutics
- Takeda Pharmaceutical Company
- Voyager Therapeutics *