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.
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,

Jennifer Farmer  
Chief Executive Officer

Ron Bartek  
President

Jennifer Farmer  
Chief Executive Officer
G treat and cure F 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
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.
**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.

**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.”
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.

| COLLABORATIVE CLINICAL RESEARCH NETWORK |

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

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### Growing the FA Research Community - IARC by the Numbers

<table>
<thead>
<tr>
<th>Category</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Countries Represented</td>
<td>21</td>
</tr>
<tr>
<td>Attendees from Academia and Regulatory</td>
<td>150</td>
</tr>
<tr>
<td>Attendees from Industry</td>
<td>140</td>
</tr>
<tr>
<td>Junior Investigators</td>
<td>100</td>
</tr>
<tr>
<td>Patient Advocacy Organizations</td>
<td>17</td>
</tr>
</tbody>
</table>
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.
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.
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.
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

#### $1.3M RAISED

<table>
<thead>
<tr>
<th>Event Name</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Burrows-Hill Foundation: A Night to Fight Friedreich’s Ataxia</td>
<td>Annapolis, MD</td>
</tr>
<tr>
<td>Cure FA Soirée</td>
<td>Edmond, OK</td>
</tr>
<tr>
<td>Hope for ToMORROW Towson</td>
<td>Towson, MD</td>
</tr>
<tr>
<td>Opening Night Movie Fundraiser (2019: Star Wars: The Rise of Skywalker)</td>
<td>Southfield, MI</td>
</tr>
<tr>
<td>Pull for a Cure</td>
<td>Land O Lakes, FL</td>
</tr>
<tr>
<td>The Race for Matt &amp; Grace</td>
<td>Providence, RI</td>
</tr>
</tbody>
</table>

#### $25,000 - $50,000

<table>
<thead>
<tr>
<th>Event Name</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>Century 21 King Charity Golf Classic</td>
<td>Rancho Cucamonga, CA</td>
</tr>
<tr>
<td>Friends of Jerod: Reverse Draw &amp; Live Auction</td>
<td>Bakersfield, CA</td>
</tr>
<tr>
<td>Huffman &amp; Huffman FORE! FARA Golf Tournament</td>
<td>Virginia Beach, VA</td>
</tr>
<tr>
<td>Loving Life: An Evening to Cure Friedreich’s Ataxia</td>
<td>Branford, CT</td>
</tr>
<tr>
<td>N.J. Seaside Stride</td>
<td>Seaside Park, NJ</td>
</tr>
<tr>
<td>Swing Away at FA</td>
<td>Dawsonville, GA</td>
</tr>
<tr>
<td>Team Alison Price</td>
<td>Wake Forest, NC</td>
</tr>
<tr>
<td>USI vs Notre Dame Baseball Exhibition Game</td>
<td>Evansville, IN</td>
</tr>
</tbody>
</table>

#### $10,000 - $24,999

<table>
<thead>
<tr>
<th>Event Name</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fuzzy Buzzy Golf Tournament</td>
<td>Windham, NH</td>
</tr>
<tr>
<td>Mother’s Day 5K Race for Christina</td>
<td>Richboro, PA</td>
</tr>
<tr>
<td>Pizza Port Golf Tournament</td>
<td>Encinitas, CA</td>
</tr>
<tr>
<td>Rocky Mountain Bird &amp; Birdie</td>
<td>Brighton, CO</td>
</tr>
</tbody>
</table>

#### Screening of "The Ataxian" Ketchum, ID

#### Sparky’s Memorial Day Golf Tournament

#### Watertown, SD

#### Team Donovan: Westchester Triathlon

#### Rye, NY

#### 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

#### *Listed as fundraising gross

#### +Funds represented in FARA Energy Ball total
FINANCIALS

SOURCES OF FUNDING

55% Special Events (Energy Ball, rideATAXIA, Grassroots)

41% Contributions & Program Income

4% Investment

WHERE YOUR MONEY GOES

86% Research & Programs

12% Fundraising

2% General & Administrative
# Statements of Financial Position

## December 31, 2019 and 2018

## Assets

<table>
<thead>
<tr>
<th></th>
<th>2019</th>
<th>2018</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Current Assets</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cash &amp; Cash Equivalents</td>
<td>$1,821,067</td>
<td>$2,162,521</td>
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<tr>
<td>Contributions Receivable</td>
<td>191,637</td>
<td>195,821</td>
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<tr>
<td>Prepaid Expenses</td>
<td>35,477</td>
<td>37,323</td>
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<tr>
<td>Investment in Securities</td>
<td>2,128,027</td>
<td>1,620,731</td>
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<tr>
<td><strong>Total Current Assets</strong></td>
<td><strong>4,176,208</strong></td>
<td><strong>4,016,396</strong></td>
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<tr>
<td><strong>Computer Equipment</strong></td>
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<td></td>
</tr>
<tr>
<td></td>
<td>120</td>
<td>506</td>
</tr>
<tr>
<td><strong>Other Assets</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Investment in Common Stock*</td>
<td>10,915</td>
<td>1,091,500</td>
</tr>
<tr>
<td><strong>Total Assets</strong></td>
<td><strong>$4,187,243</strong></td>
<td><strong>$5,108,402</strong></td>
</tr>
</tbody>
</table>

## Liabilities & Net Assets

<table>
<thead>
<tr>
<th></th>
<th>2019</th>
<th>2018</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Current Liabilities</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Accounts Payable</td>
<td>$385,252</td>
<td>$130,166</td>
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<tr>
<td>Deferred Revenue</td>
<td>9,074</td>
<td>-</td>
</tr>
<tr>
<td><strong>Total Current Liabilities</strong></td>
<td><strong>394,326</strong></td>
<td><strong>130,166</strong></td>
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## Net Assets

<table>
<thead>
<tr>
<th></th>
<th>2019</th>
<th>2018</th>
</tr>
</thead>
<tbody>
<tr>
<td>Without Donor Restrictions</td>
<td>3,668,941</td>
<td>4,914,855</td>
</tr>
<tr>
<td>With Donor Restrictions</td>
<td>123,976</td>
<td>63,381</td>
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<tr>
<td><strong>Total Net Assets</strong></td>
<td><strong>3,792,917</strong></td>
<td><strong>4,978,236</strong></td>
</tr>
</tbody>
</table>

## Total Liabilities & Net Assets

|                                | **$4,187,243** | **$5,108,402** |

# Statements of Activities

## Years Ended December 31, 2019 & 2018

## Net Assets Without Donor Restrictions

<table>
<thead>
<tr>
<th></th>
<th>2019</th>
<th>2018</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Revenue &amp; Support</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Contributions &amp; Program Income</td>
<td>$1,691,858</td>
<td>$1,019,316</td>
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<tr>
<td>Special Events</td>
<td>4,556,102</td>
<td>5,133,236</td>
</tr>
<tr>
<td>Investment Return</td>
<td>339,096</td>
<td>(71,107)</td>
</tr>
<tr>
<td><strong>Total Revenue &amp; Support</strong></td>
<td><strong>8,163,896</strong></td>
<td><strong>8,617,810</strong></td>
</tr>
<tr>
<td><strong>Expenses</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Program Services</td>
<td>7,168,645</td>
<td>6,808,975</td>
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<tr>
<td>Fundraising</td>
<td>990,849</td>
<td>986,105</td>
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<tr>
<td>General &amp; Administrative</td>
<td>169,731</td>
<td>116,177</td>
</tr>
<tr>
<td><strong>Total Expenses</strong></td>
<td><strong>8,329,225</strong></td>
<td><strong>7,911,257</strong></td>
</tr>
<tr>
<td><strong>Impairment on Investment in Common Stock</strong>*</td>
<td>1,080,585</td>
<td>-</td>
</tr>
<tr>
<td><strong>Change in Net Assets Without Donor Restrictions</strong></td>
<td>(1,245,914)</td>
<td>706,553</td>
</tr>
</tbody>
</table>

## Net Assets With Donor Restrictions

<table>
<thead>
<tr>
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<th>2018</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contributions</td>
<td>1,637,435</td>
<td>2,278,264</td>
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<tr>
<td>Net Assets Released from Restrictions</td>
<td>(1,576,840)</td>
<td>(2,536,365)</td>
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## Change in Net Assets With Donor Restrictions

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
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</thead>
<tbody>
<tr>
<td><strong>Change in Net Assets</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(1,185,319)</td>
<td>448,452</td>
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## Net Assets at Beginning of Year

<table>
<thead>
<tr>
<th></th>
<th>2019</th>
<th>2018</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Net Assets</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Without Donor Restrictions</td>
<td>4,978,236</td>
<td>4,529,784</td>
</tr>
<tr>
<td>With Donor Restrictions</td>
<td></td>
<td></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>

## Total Liabilities & Net Assets

|                                | **$4,187,243** | **$5,108,402** |

*Write down of common stock in a privately held entity. Refer to FARA 2019 Financial Statements at https://curefa.org/financials.*
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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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$525K+

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