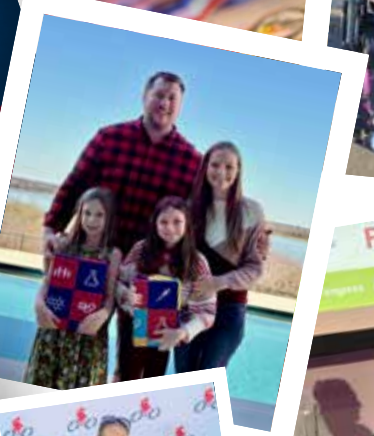
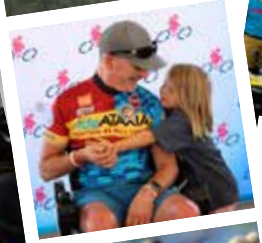
Donor Impact Report 2025

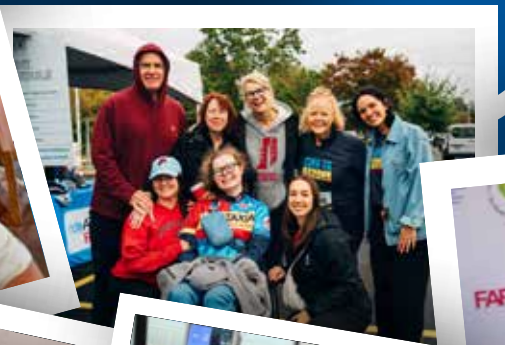
FARA Friedreich's Ataxia Research Alliance

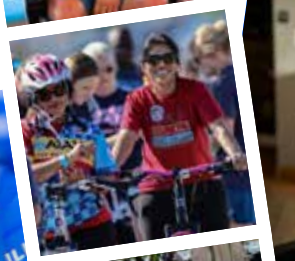














2025 BOARD OF DIRECTORS

Ronald J. Bartek
President / Director / Co-Founder

Paul Avery
Chairman of the Board

Ruth Acton
Treasurer / Director

Maureen Juip
Secretary / Director

Sanjay Bidichandani, MBBS, PhD
Scientific Director

Brigid T. Brennan, Esq.
Director / General Counsel / Advocacy

Alex Fielding
Director

Jennifer L. Good
Director

Thomas Hamilton
Director

Holly Hedrick, MD, FACS
Director

Derek Hennecke
Director

Warren Huff
Director

Stephen Klasko, MD, MBA
Director

Katherine Mathews, MD, FAAN
Director

James McArthur, PhD
Scientific Director

Tony Plohoros
Director

Patrick Ritschel
Director

James Rusche, PhD
Scientific Director

OUR APPROACH

Driven by our promise to treat and cure FA through research, we work collaboratively and with urgency to build strong relationships, expand knowledge, and remove uncertainty.

OUR HISTORY

FARA was founded in September 1998 by patient families and three of the world's leading FA scientists. We have dedicated ourselves to changing the course of FA.

Dear friends,

As we reflect on the past year, we are filled with gratitude for this community and everything we have accomplished together in our pursuit of treatments and a cure for Friedreich's ataxia (FA).

This was a year of meaningful discovery. In a remarkable convergence, two independent FARA-funded research labs uncovered a previously unknown connection between frataxin (the protein controlled by the FXN gene) and ferredoxin 2 (controlled by the FDX2 gene). This finding is important because it opens entirely new possibilities for therapy. We have long believed that curing FA will require multiple therapies working together. Discoveries like this one expand the possibilities of what that combination could look like.

Science is accelerating and so is our progress. In 2025, we invested more than $9 million in FA research, fueling projects at every stage of discovery and development.

One of FARA's major research initiatives has been TRACK-FA, the world's largest neuroimaging study of FA. Clinic visits have been completed, and the data is already yielding insights into how FA affects both neurodevelopmental and neurodegenerative pathways, helping scientists pinpoint where and when future therapies may have the greatest impact.

FARA has also built the global clinical infrastructure that moves research into the clinic. The FA Global Clinical Consortium connects leading clinical sites around the world, creating the coordinated network that makes large, rigorous studies possible.

That foundation is also enabling clinical progress. Multiple clinical trials are enrolling participants, including children as young as two years old, across an unprecedented range of therapeutic mechanisms: improving mitochondrial function and reducing oxidative stress, frataxin protein replacement, increasing gene expression, and gene addition therapies. The pipeline has never been more diverse.

FARA's role remains essential. By funding early-stage ideas and rigorously advancing them, we help de-risk new approaches and move them closer to the people who need them. We also continue to advocate nationally and globally, keeping FA visible, funded, and prioritized.

None of this happens without you. Each person reading this report is part of something much larger than any single gift or gesture. Your generosity, combined with the contributions of many others in this community, drives these breakthroughs forward. It truly takes all of us, and we are deeply grateful for every one of you.

With gratitude,

Jennifer Farmer, Chief Executive Officer

Ronald J. Bartek, President

2025 MILESTONES

INVESTED $9M+ IN RESEARCH to support our mission to slow, stop, reverse, and cure FA

STRENGTHENED THE FA TREATMENT PIPELINE with novel, diverse therapeutic approaches

COMPLETED VISITS FOR TRACK-FA the world's largest neuroimaging study in FA

EXPANDED NATURAL HISTORY DATA collection across the FA Global Clinical Consortium to accelerate clinical trials

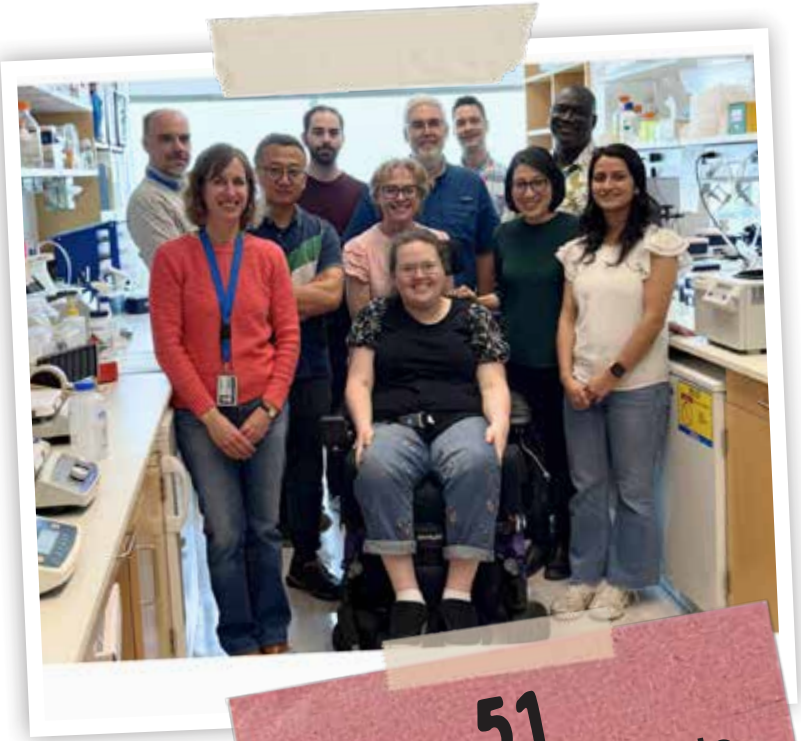
EDUCATED THE GLOBAL FA COMMUNITY on key research initiatives and participation opportunities

CONVENED RESEARCHERS for the first Clinical Trials in Inherited Ataxias Conference to help advance safe and effective therapies

FUELED NEW DISCOVERIES at FARA-funded FA research centers

BROAD INSTITUTE · Children's Hospital of Philadelphia Friedreich's Ataxia Program · Penn

RESEARCH GRANT PROGRAM



51
Total funded grants

22
New grants

10
Countries

$9M+
Research funding

FARA's grant program is a competitive funding mechanism driving research across the full spectrum of Friedreich's ataxia, from basic discovery to preclinical development and clinical research.

In 2025, FARA committed more than $9 million to support a broad portfolio of studies such as advancing understanding of disease biology, strengthening tools for drug development, and helping move potential therapies closer to patients.

A central part of FARA's strategy is providing early, catalytic funding. Many grants support proof-of-concept work, enabling investigators to generate the data needed to de-risk new ideas and position them for larger follow-on funding from federal agencies, foundations, and industry partners. These early investments often act as a springboard, moving individual projects forward while strengthening the broader pipeline of potential treatments. All of the candidates in the FA treatment pipeline reflect insights from earlier FARA-funded research.

This approach also plays an important role in growing and sustaining the FA research field. FARA continues to invest in early-career investigators while drawing new scientists into the space. In 2025, the organization received more than 100 applications from researchers across disciplines and geographies, with nearly half new to FARA or to FA research, an encouraging sign of the field's continued expansion and increasing reach.

Underlying all of this is a clear sense of urgency. FARA has expanded its support for high-risk, high-reward science, funding six Award for Innovative Mindset grants focused on bold ideas. These projects may fall outside traditional funding pathways, but they hold the potential to open new directions and accelerate progress in meaningful ways.


Molecular and Cellular Mechanisms of Cardiac Fibrosis in Friedreich's Ataxia

Giovanni Manfredi, MD, PhD, Weill Cornell Medicine;

Mark Payne, MD, Indiana University

Heart disease is a leading cause of early death in FA. When frataxin is lost in heart tissue, it triggers a cascade that includes inflammation and fibrosis (the excessive buildup of collagen that stiffens the heart and impairs its ability to fill with blood), and leads to progressive cell death. Cardiac fibrosis may also contribute to the arrhythmias commonly seen in FA cardiomyopathy.

This project focuses on cardiac fibroblasts, the cells responsible for collagen production, to understand what activates them in the FA heart and identify targets for therapy. The goal is to find ways to slow or stop the fibrosis that drives FA heart disease progression.

This grant is co-sponsored by the Muscular Dystrophy Association.



Pre-Clinical Assessment of Protein Replacement Therapy in the Central Nervous System of Friedreich's Ataxia Mouse Models

Macarena Sánchez Navarro, PhD, Consejo Superior de Investigaciones Científicas (CSIC);

Jordi Magrané, PhD, Weill Cornell Medicine;

Joaquim Ros, PhD, Universitat de Lleida

This project evaluates a novel frataxin protein replacement strategy designed to overcome the blood–brain barrier, one of the challenges in treating Friedreich's ataxia. By pairing frataxin with a specialized shuttle peptide, the research team aims to improve delivery of frataxin to the brain. The safety, distribution, and therapeutic potential of this strategy are being tested in two FA mouse models, with the goal of preventing or even reversing neurological damage.

Does Frataxin Deficiency Disrupt GLUR2 Trafficking in the Cerebellum via Defects in Palmitoylation?

Elizabeth Mercado-Ayon, University of Pennsylvania

This research investigates how frataxin deficiency alters synaptic signaling in the cerebellum. Focusing on the AMPA receptor subunit GluR2, the project tests whether impaired modifications of this receptor disrupt its trafficking and stability. Defining these mechanisms may reveal new targets to protect cerebellar neurons and address neurological symptoms in FA.

>> Learn more about research grants awarded by FARA at curefa.org/funded-grants

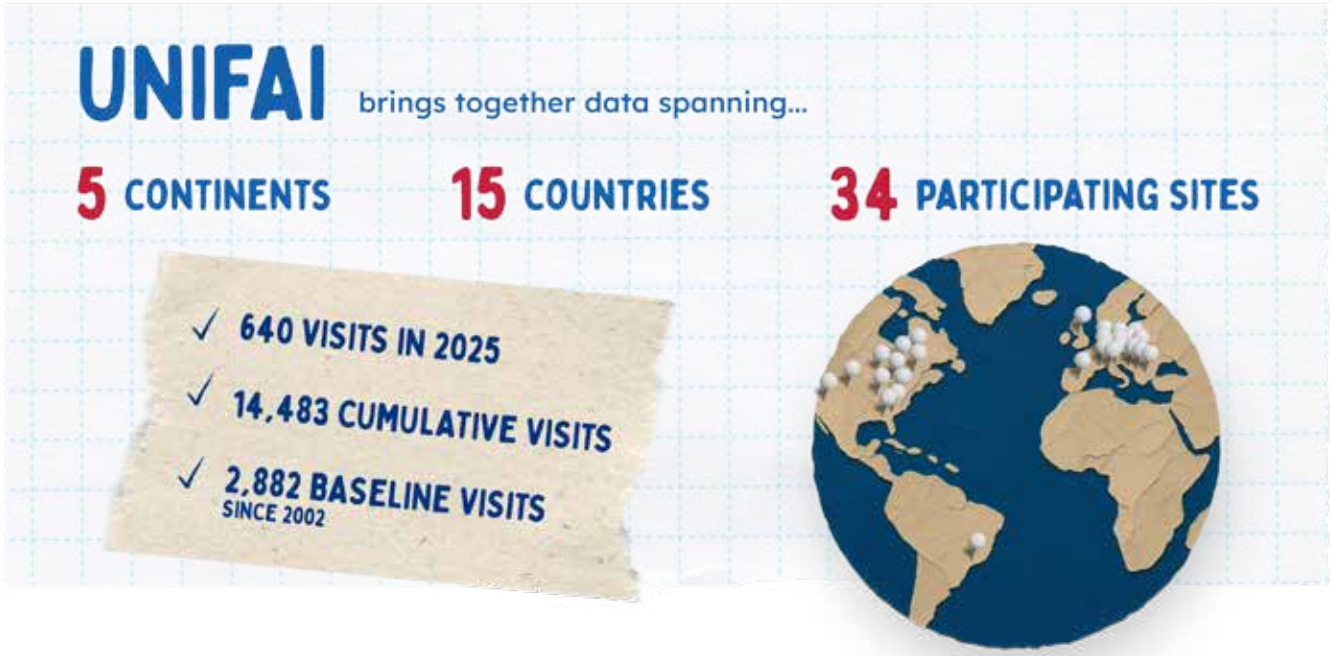
FA Global Clinical Consortium (FA GCC) & UNIFAI Natural History Study

One of FARA's most powerful global investments is the FA Global Clinical Consortium (FA GCC), a coordinated international network of clinics built to accelerate clinical trial readiness and therapeutic development for Friedreich's ataxia.

In 2025, the FA GCC included more than 30 clinical research sites worldwide. This expanding infrastructure strengthens trial start-up efficiency, harmonizes data collection across countries, fosters collaboration among leading FA experts, and supports the collection of real-world evidence as new therapies emerge. Through ongoing site engagement, training initiatives, and global partnerships, FARA ensures the FA community is prepared for the next wave of clinical trials.

At the heart of this effort is the UNIFAI Natural History Study, which provides the longitudinal data needed to understand how FA progresses over time. UNIFAI informs trial design, endpoint selection, and biomarker development while offering critical context for interpreting clinical trial outcomes.

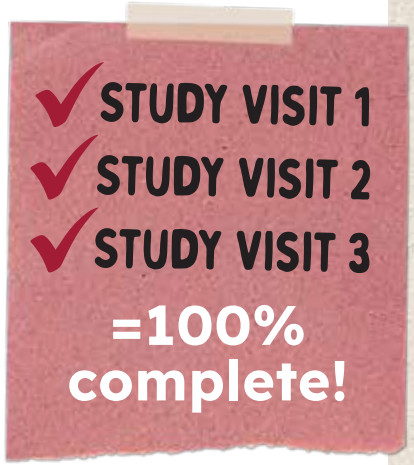
Because of your support, this integrated global network is not just preparing for future treatments, it is actively accelerating them.

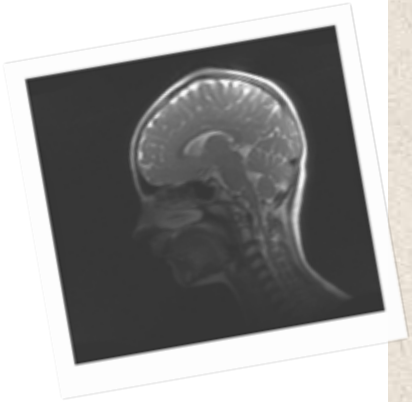


TRACK-FA: Largest Global FA Neuroimaging Study

2025 was a milestone year for TRACK-FA, the largest global neuroimaging study ever conducted in Friedreich's ataxia. All study visits have now been successfully completed. This year marked publication of the first TRACK-FA cross-sectional paper, which is a major scientific achievement and a powerful testament to the strength of international collaboration.

This milestone would not have been possible without the extraordinary commitment of the global FA community. Hundreds of children and adults volunteered their time, traveled to study sites, and returned year after year to ensure this research could move forward. Thanks to their dedication, TRACK-FA is generating critical data to identify imaging biomarkers that can accelerate clinical trials and improve how we measure the impact of treatments.






Neuroimaging Biomarkers for Friedreich Ataxia: A Cross-Sectional Analysis of the TRACK-FA Study

Clinical Trials in Inherited Ataxias Conference (CTAX)

In November 2025, FARA helped launch CTAX, the first conference dedicated exclusively to clinical trials in inherited ataxias. Held in Amsterdam, the invitation-only meeting brought together 120 clinicians, researchers, patient advocates, industry sponsors, and regulators from around the world.

Launched at a pivotal moment for the field, CTAX builds on the momentum of the first approved therapy for Friedreich's ataxia and a growing pipeline of treatments for FA and spinocerebellar ataxias. This meeting created a forum focused on developing strategies to accelerate safe and effective therapies worldwide.

Participants discussed lessons from recent trials, how natural history data can inform study design and regulatory decisions, biomarker development, clinical outcome assessments and patient-reported outcomes, and trial designs for pediatric and presymptomatic populations.

By convening regulators, industry sponsors, clinicians, and patient advocates in one room, CTAX strengthened global coordination and reduced barriers to progress.

Through this collaboration, FARA is helping to shape not only research but also the global framework for how ataxia treatments are developed, evaluated, and delivered to patients.

FRIEDREICH'S ATAXIA CENTER OF EXCELLENCE (COE)

at the Children's Hospital of Philadelphia and the University of Pennsylvania

Children's Hospital of Philadelphia
Friedreich's Ataxia Program

Penn
University of Pennsylvania

Since its founding, the FA Center of Excellence at Children's Hospital of Philadelphia and the University of Pennsylvania has demonstrated what is possible when basic scientists and clinicians work side by side.

This deeply integrated partnership has generated more than 115 publications and contributed meaningful insights that continue to shape the field.

In 2025, that momentum continued, with COE investigators advancing work across a wide range of focus areas, including cerebellar dysfunction, frataxin biology, inflammation in FA, lipid dysregulation, biomarker discovery and assay development, natural history studies, and numerous interventional trials.

The COE has also become an important hub for the collection and sharing of repository samples, further strengthening its role as a resource for the broader research community.

FARA is proud to support this one-of-a-kind research engine, made possible through the generous partnership of the CureFA Foundation and the Hamilton and Finneran families.

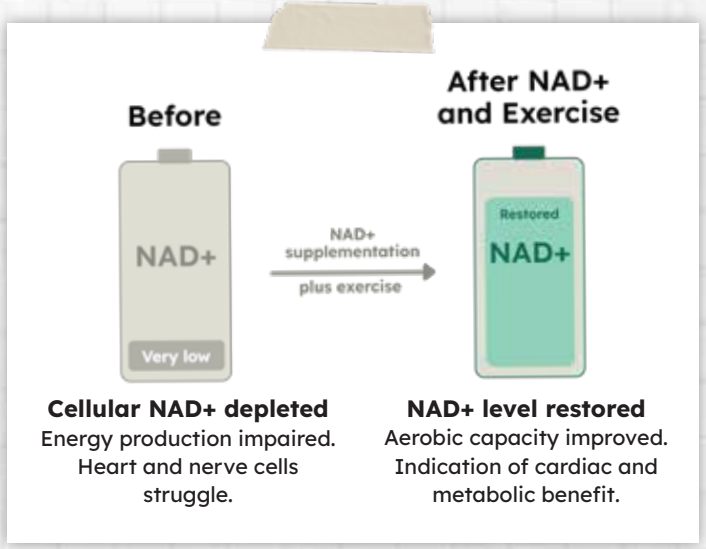
COE investigators: Dr. Ian Blair, Dr. Kim Lin, Dr. Dave Lynch, Dr. Shana McCormack, Dr. Clementina Mesaros, and Dr. Rob Wilson

NAD+ and exercise research offer new insights for managing Friedreich's ataxia

NAD+ is a cellular metabolite that declines in some diseases and may be related to aging. COE researchers showed that boosting NAD+ improved heart function and survival in FA mouse models.

That finding prompted a clinical trial to test whether an NAD+ supplement combined with structured exercise could improve aerobic capacity in people living with FA. It did. The results were published in the esteemed journal *The Lancet Neurology* and the FA Clinical Management Guidelines are being updated to reflect these findings.

What made this study distinctive was its breadth. It examined cardiac, neurological, and metabolic outcomes simultaneously. Samples collected during the trial are now being analyzed by the COE's biomarker team, which is turning a single study into a platform for multiple discoveries.



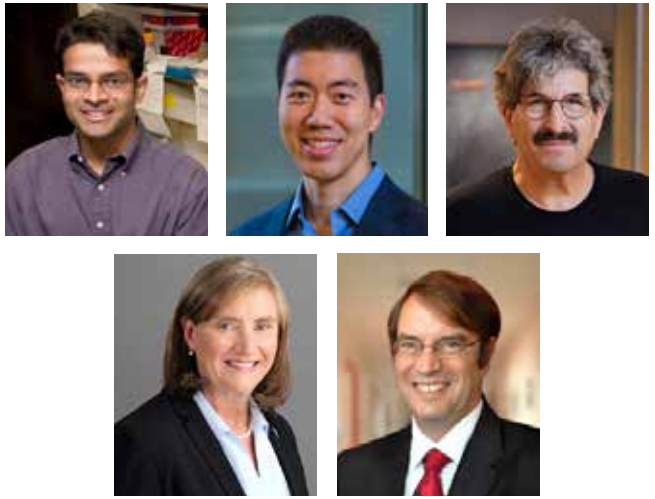
THE FRIEDREICH'S ATAXIA ACCELERATOR (FAA)

at the BROAD Institute of MIT and Harvard

BROAD INSTITUTE

At the Friedreich's Ataxia Accelerator, world-class researchers are making fundamental discoveries about FA biology, which are revealing entirely new avenues for treatment.

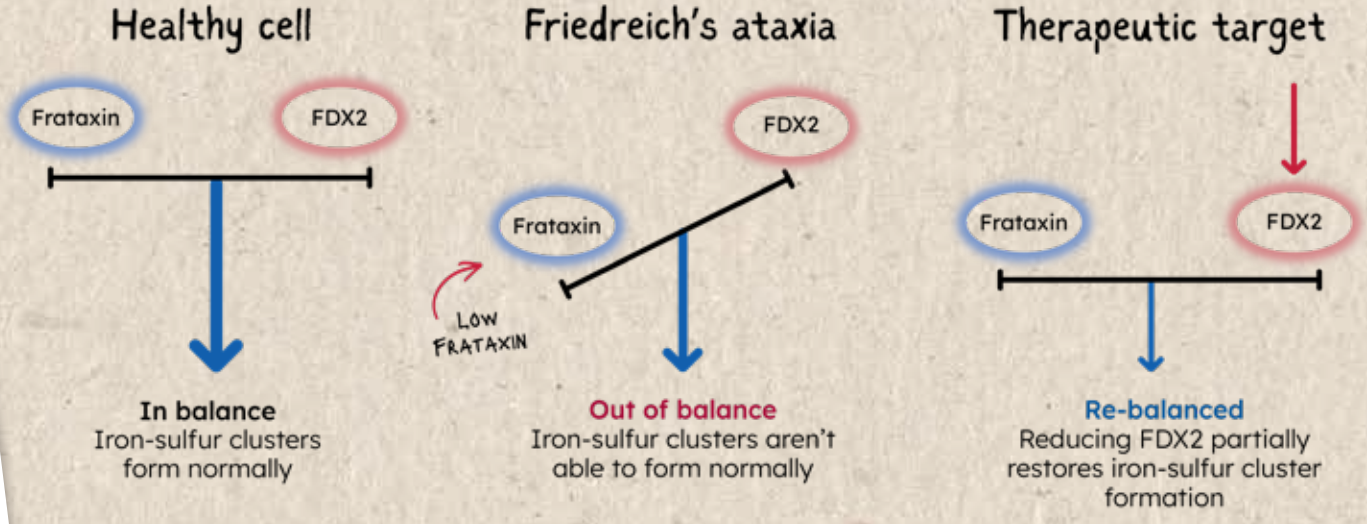
Led by Dr. Vamsi Mootha, the Friedreich's Ataxia Accelerator (FAA) at the Broad Institute of MIT and Harvard brings together an exceptional team of investigators united by a shared sense of urgency. In 2025, that work produced a landmark discovery: FAA researchers identified FDX2 as a novel therapeutic target in FA. This is the kind of foundational science the FAA was built for. The team doesn't simply apply existing approaches to FA, but instead they uncover new biology that opens doors no one knew were there. FARA is grateful to the CureFA Foundation and EndFA for their partnership in making this work possible.



FAA investigators: Dr. Vamsi Mootha, Dr. David Liu, Dr. Gary Ruvkun, Dr. Christine Seidman, Dr. Jonathan Seidman

A New Target in the Fight Against FA

What began as a discovery about hypoxia and cell survival has led FAA researchers to an entirely new understanding and a novel potential approach to treating FA. Frataxin protein levels are low in FA cells, while FDX2 protein levels remain normal. The FAA team discovered that this excess FDX2 actively blocks iron-sulfur cluster production when frataxin is low and that reducing FDX2 levels can partially restore production. Published in *Nature* in December 2025, this finding introduces a new therapeutic target in FA.



Discovery published in Nature, December 2025. Funded by FARA in partnership with the CureFA Foundation and EndFA.

ADVOCACY

The year 2025 brought significant changes to federal agency funding and structure, and the FA advocacy community rose to every challenge, ensuring their voices were heard and their priorities advanced.

Here's a look back at the major milestones and achievements:

Rare Disease Week on Capitol Hill

In February, FA advocates joined nearly 1,000 participants for Rare Disease Week in Washington, D.C., engaging in over 300 Congressional meetings. FARA Ambassadors and FA families represented the community alongside FARA leadership, ensuring FA had a strong presence during this critical event.

Protecting Research Funding

When Congress cut funding for the Congressionally Directed Medical Research Programs (CDMRP) by 57%, FARA mobilized quickly. Advocates educated lawmakers on the importance of CDMRP and submitted appropriations requests to keep "hereditary ataxia" eligible for FY26 funding, helping secure vital resources for FA research.

United Against Ataxia Hill Day

The 7th Annual Hill Day, hosted virtually with the National Ataxia Foundation, saw record participation: 169 advocates from 38 states attended 99 Congressional meetings. Key priorities included restoring CDMRP funding, supporting FDA and NIH budgets, reauthorizing the Rare Pediatric Disease PRV program, and advancing legislation like the Accelerating Kids' Access to Care Act.

National Recognition

The U.S. Senate unanimously passed S.Res. 447, designating September 25, 2025, as National Ataxia Awareness Day. This resolution elevates awareness and understanding of ataxia nationwide.

New Advocacy Resources

FARA's advocacy team created new resources for FA community advocates. The FA and Speech Toolkit provides advocates with information on public speaking and FA's impact on speech, and the Proclamation Toolkit provides guidance for requesting state or local proclamations. FARA also co-authored a paper with the Alliance for Patient Access, which outlines the challenges patients and providers face when dealing with FA.

Engagement Across the Rare Disease Community

FARA staff represented FA at major events, including the NORD Breakthrough Summit, World Orphan Drug Congress, BIO Patient Summit, and AMCP Nexus Conference. Leadership spoke on critical policy issues, emphasizing pediatric inclusion in clinical trials and the importance of patient voices in decision-making.

State-Level Advocacy

FA advocates also made an impact locally by meeting with legislators, securing proclamations, providing testimony, and raising awareness through media outreach.

2025 was a year of resilience and progress. By sharing their lived experiences, FA advocates drove meaningful change. FARA is deeply grateful for this commitment and looks forward to building on this momentum in 2026.

COMMUNITY EDUCATION & ENGAGEMENT

FARA believes that transformative change happens at the intersection of people and science. FARA's community education and engagement initiatives are where people and science meet.

Given the rarity of Friedreich's ataxia, most people have never heard of the condition before being diagnosed. Their local doctors are unlikely to be FA specialists. That's why FARA's community education matters; it connects people with the latest science, clinicians who know FA, and each other.

In 2025, FARA hosted four half-day research receptions across the country in Phoenix, Charlotte, Oklahoma City, and Tampa, plus a full-day symposium outside Philadelphia, bringing together more than 500 attendees. Each event featured clinical management sessions covering cardiac care, speech, exercise, and day-to-day living. Pharmaceutical and biotech companies developing FA therapies also presented directly to the community. They explained the mechanism of their potential therapy, what their trials involve, who is eligible, and what participation looks like. These conversations help families evaluate whether a trial is right for them, based on information about potential benefits and risks.

Beyond the science, attendees truly appreciated connecting with others in the community who understand FA in a way few others can.

Educational Resources

An informed community is a stronger partner in research. In 2025, FARA developed new educational resources on tissue donation, FA-related cardiac disease, and emerging genetic therapies, and shared them at the in-person research receptions and symposium, as well as at Community Conversations webinars.

Have you heard about gene therapy for FA? Watch this short video to learn more.

The Ambassador Program

FARA Ambassadors strengthen connections among FA families, researchers, and donors worldwide. Ambassadors are individuals living with FA, and they are often among the first to volunteer to complete surveys, provide feedback on pilot projects, and participate in awareness and advocacy initiatives. As connectors between FARA and the broader FA community, they send personalized thank-you cards to donors, host virtual hangouts for adults and teens living with FA, and keep the patient perspective central to both basic science and clinical research.

Bringing the FA Voice to the People Developing Therapies

FARA coordinates visits to industry and academic labs so that researchers and companies developing new treatments can learn more about the lived experience of FA. In 2025, more than 70 individuals with FA and caregivers participated in engagement events with pharmaceutical partners, academic researchers, and future clinicians.

A college student explained what it's like to navigate campus in a wheelchair while managing fatigue and speech changes. A mother spoke about weighing the risks of a gene therapy trial for her child. These conversations give a clearer understanding of what FA looks like day to day, and shape the endpoints researchers prioritize, how they design protocols, and the outcomes they measure. It's not just about building connection. It's about making better science.

GRASSROOTS FUNDRAISING

In 2025, the Friedreich's ataxia community hosted 25 grassroots events and raised an incredible $1.6 million. From coast to coast and throughout the year, supporters channeled creativity and commitment into meaningful resources for FA research.

The year began in Fort Lauderdale, FL, with Runway to the Cure, where more than 200 guests gathered for dinner and dancing in a private airplane hangar — an unforgettable evening hosted by the Maugee family. Spring followed with the sold-out NJ Seaside Stride in Seaside Park, NJ, featuring its signature boardwalk stroll and a competitive basket auction.

Summer brought record-setting success at the Cure FA Soirée in Oklahoma City, led by the Gehr family and their organizing committee. With 365 attendees, including 38 FA families, the evening featured live musical performances and raised an astounding $595,000 in one night.

As fall leaves turned, the Race for Matt & Grace committee hosted its signature 5K run and one-mile walk. Later in the season, six members of Team FARA took on the TCS New York City Marathon, raising more than $150,000 collectively. Just after Thanksgiving, the Juip family hosted a magical movie screening in Livonia, MI.

Each of the 25 grassroots events was uniquely shaped by the community that hosted it, and they all reflected incredible generosity and support.

Thank you to the donors, hosts, and participants who made 2025 a year of remarkable impact for the FA community.

2025 Grassroots Campaigns ($5,000+)

$595,000

The Cure FA Soirée
Oklahoma City, OK

$100,000+

Burrows Hill Foundation: Night to Fight FA
Annapolis, MD

Pull for a Cure
Land O' Lakes, FL

Race for Matt & Grace
Providence, RI

Runway to the Cure
Fort Lauderdale, FL

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

$50,000-$99,999

BBQ Love Fest
Tampa, FL

Juip Family | FBMJ Movie Fundraiser
Livonia, MI

New Jersey Seaside Stride
Seaside Park, NJ

$20,000-$49,999

Epic Game Day
Henderson, NV

Fuzzy Buzzy Golf Tournament
Windham, NH

Morrow Lacrosse Challenge
Baltimore, MD & High Point, NC

The Smith Family
Alabama

$10,000-$19,999

#CureFA Baseball Game
Terre Haute, IN

Fine Arts for Friedreich's Ataxia
Sioux Falls, SD

Golf Ataxia
Commerce Township, MI

Tee It Up Flower Fundraiser
Grandview Heights & Marble Cliff, OH

The Leonard Family
Virginia

$5,000-$9,999

Barbells for Boston Strong
Huntsville, TX

The Bode/Caruso Family
Connecticut

The Claxton Classic
Pasadena, MD

Lauderdale-By-The-Sea Mural
Fort Lauderdale, FL

Killeen Family Team FARA Trek
France

Poker Run to Cure FA
Vian, OK

The Stacks Family
Georgia

The Stoneham Open
Portsmouth, NH

Swing for a Cure
Uniontown, OH

Teeing Up for Tye
Salado, TX

Worcester Central School Varsity Leadership Club: Chuck a Duck
Worcester, NY

rideATAXIA

rideATAXIA is more than a series of bike rides. It's a nationwide movement bringing people of all abilities together to be active and move FARA's mission forward.

In 2025, rideATAXIA continued to grow not just in reach, but in impact. Across four FARA-hosted and nine volunteer-led Hometown rides, new FA families and longtime supporters came together to ride and raise over $1.3M. At rideATAXIA Philly, for example, nine new FA families joined the effort, exemplifying the passion and purpose that define these gatherings.

The momentum was also evident in the continued growth of rideATAXIA Hometown. Launched just three years ago as a grassroots initiative, the program began with a handful of local trail-rides and has since expanded into a multi-community network. Since its first season, both participation and fundraising have more than tripled, with hundreds of riders and walkers now coming together annually to raise over $350,000 in support of FA research. rideATAXIA Hometown Boston saw participation increase several-fold through strong collaboration between the FA community and biotech and pharmaceutical partners, while Hometown Chico more than doubled its fundraising within just a few years.

No matter where they took place, rideATAXIA events were built on the same foundation: people showing up for one another and for FA research.

In 2025, rideATAXIA hosted:

4 National events

9 Hometown events across the country

THE FARA ENERGY BALL

For the 17th consecutive year, the Tampa community built on a powerful tradition, raising $1.7M at the FARA Energy Ball to drive FA research forward. Over the years, the Energy Ball has steadily grown its impact, expanding what's possible for FA research at FARA and the USF Health Ataxia Research Center.

That commitment was unmistakable as more than 400 guests gathered at the Tampa Marriott Water Street for this year's "Race for a Cure" Kentucky Derby–themed gala. With lively music, dancing, and vibrant décor, the evening struck a balance between celebration and purpose.

One of the most powerful moments came during Fund-A-Cure, when donors enthusiastically raised their hands to pledge critical support for FA research. In a rare disease community where funding is never guaranteed, seeing so many people step forward so generously was deeply moving and a powerful reminder that no one is facing this fight alone.

The 2025 Energy Ball celebrated how far this community has come, while reaffirming a shared commitment to keep pushing forward together toward effective treatments and a cure.

FINANCIALS

STATEMENTS OF FINANCIAL POSITION

December 31, 2025 and 2024

ASSETS	2025*	2024*
CURRENT ASSETS		
Cash & Cash Equivalents	$2,797,211	$1,959,581
Restricted Cash	660,040	2,350,400
Contributions Receivable, Net	169,578	682,067
Prepaid Expenses	202,826	67,503
Investments	2,466,516	2,137,780
TOTAL CURRENT ASSETS	**6,296,171**	**7,197,331**
OTHER ASSETS	170,754	51,862
TOTAL ASSETS	**$ 6,466,925**	**$7,249,193**

LIABILITIES & NET ASSETS

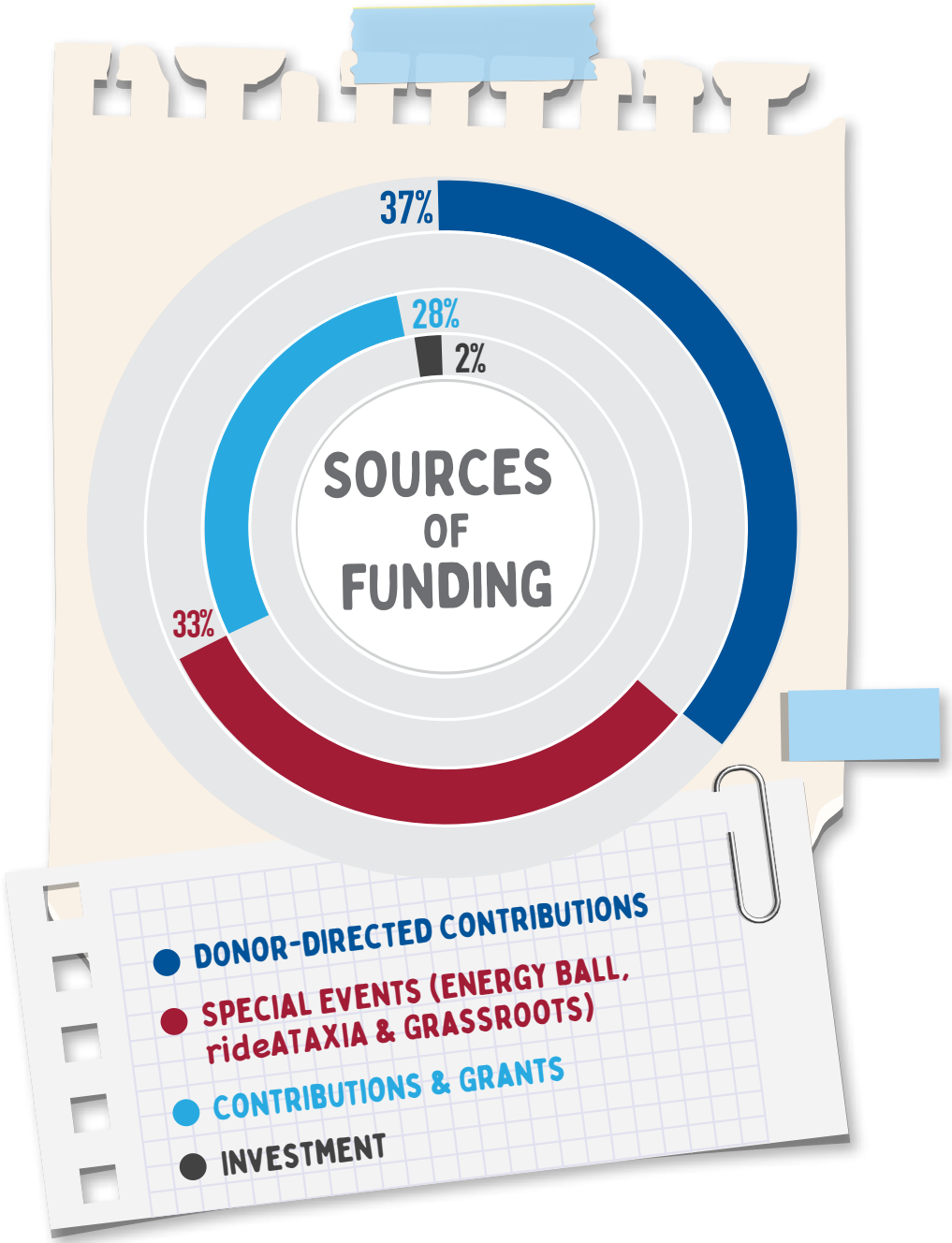
LIABILITIES		
Accounts Payable	$1,263,345	$689,951
Deferred Revenues	5,615	10,630
Lease Liabilities	178,465	49,940
TOTAL LIABILITIES	**1,447,425**	**750,521**
NET ASSETS		
Without Donor Restrictions	4,359,460	4,148,272
With Donor Restrictions	660,040	2,350,400
TOTAL NET ASSETS	**5,019,500**	**6,498,672**
TOTAL LIABILITIES & NET ASSETS	**$6,466,925**	**$7,249,193**

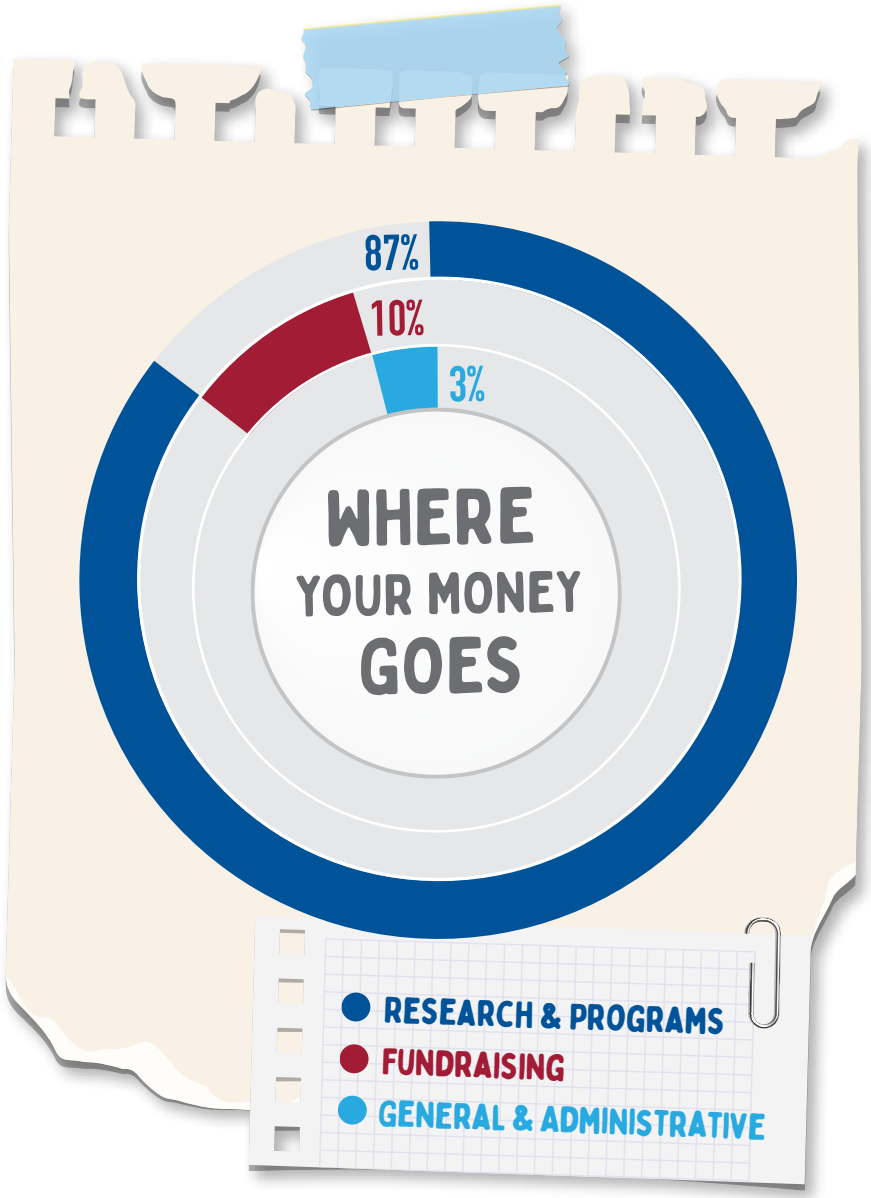
STATEMENTS OF ACTIVITIES

Years Ended December 31, 2025 and 2024

NET ASSETS WITHOUT DONOR RESTRICTIONS	2025*	2024*
REVENUE & SUPPORT		
Contributions & Grants	$3,781,458	$2,497,238
Special Events & In-kind Contributions	4,545,159	4,690,438
Investment Return	336,475	346,163
Net Assets Released from Restrictions	4,986,899	5,652,908
TOTAL REVENUE & SUPPORT	**13,649,991**	**13,186,747**
EXPENSES		
Program Services	11,638,582	12,740,598
Fundraising	1,313,965	1,349,672
General & Administrative	486,256	436,942
TOTAL EXPENSES	**13,438,803**	**14,527,212**
CHANGE IN NET ASSETS WITHOUT DONOR RESTRICTIONS	**211,188**	**(1,340,465)**
NET ASSETS WITH DONOR RESTRICTIONS		
Contributions & Grants	3,296,539	7,039,529
Net Assets Released from Restrictions	(4,986,899)	(5,652,908)
CHANGE IN NET ASSETS WITH DONOR RESTRICTIONS	**(1,690,360)**	**1,386,621**
TOTAL NET ASSETS		
CHANGE IN NET ASSETS	(1,479,172)	46,156
NET ASSETS AT BEGINNING OF YEAR	6,498,672	6,452,516
NET ASSETS AT END OF YEAR	$5,019,500	$6,498,672

**FARA and FARA Europe consolidated*


37%
28%
2%
33%
SOURCES OF FUNDING
DONOR-DIRECTED CONTRIBUTIONS
SPECIAL EVENTS (ENERGY BALL, rideATAXIA & GRASSROOTS)
CONTRIBUTIONS & GRANTS
INVESTMENT


87%
10%
3%
WHERE YOUR MONEY GOES
RESEARCH & PROGRAMS
FUNDRAISING
GENERAL & ADMINISTRATIVE

DONORS AND CONTRIBUTORS

$1 Million+

Anonymous
CureFA Foundation*

$500,000-$999,999

Anonymous
Stephen and Heather Fredette

$250,000-$499,999

Anonymous

$100,000-$249,999

The Avery Family Foundation
Brigid Brennan and Michael Henry
The Burrows Hill Foundation
The Crisp Family Fund
Rick and Tracy Dadeo
Nora Gallagher
Warren and Cecilia Huff
Kent and Emily McGaughy
Muscular Dystrophy Association*
Oak Foundation
Estate of Bernice G. Raymond
The Ritschel Family
The Rose Family Foundation
William and Catherine Rose

$50,000-$99,999

Amalie Oil Company
David and Gretchen Anderson
The Bradley Family
fara Australia (Friedreich Ataxia Research Association)*
McDaniel Charitable Foundation
The Brad and Nancy Rex Family
Karlye Waterman
Mary H. Whitney and The Cedar Street Home

$25,000-$49,999

Anonymous
The Bennett Family Foundation
Ryan and Nicole Best
The Boardman Family Foundation
Chris T. Sullivan Foundation
Emily Dadeo
Terry and Michele Edmonson
Friedreich's Ataxia Research Alliance Ireland*
James and Rebecca Frost
Alex Harllee
Dr. Stephen Klasko and Mrs. Colleen Wyse
Mr. and Mrs. Michael Klonoski
Chris and Michelle Ponte
Virginia Tyson
Michael and Jennifer Whitman Family Fund

* Research Co-Funding Organization

List reflects donors from FARA and FARA Europe consolidated activities

$15,000-$24,999

Anonymous
Alexander Bradley
David and Rhonda Calverley
The Dan Kirkland Wells Foundation
Michele Eleyet
Timothy Fredette and Sarah Vitelli
Derek and Marcy Hennecke
Kami Kim, MD and Thomas McDonald, MD
Roberta Lindsay
Elizabeth A. McDaniel
John and Karen McDonnell
Rodney and Karen Munsell
The Rothschild Family
John Shaffer
Don and Cheryl Smith
Southern Pine Timber Products, Inc.
Madhvi and Ramesh Subrahmanian – *in loving memory of Raja and Harish Kapadia*
Greg and Tammy Williams
Jason and Nancy Wilson
You For Two*

$10,000-$14,999

Joe and Louisa Altman
Anonymous
Matt and Jen Bello
Michael and Carol Bilder
Kathy Butler
CardioVascular Health
Coach Joy Cavagnaro Lewis Family
The Charlotte Boswell Health Foundation
The Corbett Family Charitable Foundation - Richard and Cornelia Corbett
Corporate Creations Foundation Inc.
Joseph Deeb
Duncan Real Estate, Inc
Foley, Baron, Metzger & Juip, PLLC
Fowler Family Fund
Adam K. Gehr and Virginia E. Miller
The Gehr Family
Carl and Joyce Greber
Steve and Janell Griggs
Huffman & Huffman Brothers-In-Law, PLLC
Sheila and Mike Ingram, El Dorado Holdings, Inc.
Duggan Jacobs
Paul and Mary Jacobs
Annemarie Krim and Steven Schwalbe
Kurt and Gina Conti Foundation
Eric and Caroline Maugee
Ted Miller and Daisy Housel-Miller Charitable Fund
Katie and Wilson Moore
Notis Professional Services
Tony Plohoros
Raymond James Financial, Inc.
George and Charlotte Robinson
Rock-N-Jock Charities
Roger Klauber Family Foundation
Martelia and Brandt Sakakeeny
Schlaifer Family Fund
Shumaker, Loop & Kendrick LLP
Jim Smith
Richard and Sheila Smith
Ryan Smith
Dr. Joseph Staffetti and Dr. Theresa Zesiewicz
The Stone Family Charitable Foundation
Theodore Swanson
Alex Taylor
Tito's Handmade Vodka
Patty and Deborah Waldeck
James Ziegler and Lori Usher

$5,000-$9,999

Robin Alexander
Allison P. and Andrew F. Cates Fund
The Alyssa and Tyler Harris Charitable Fund
Anonymous
Barbara and Franklin Carson Family Foundation
Ron and Raychel Bartek
Beebe Family Charitable Fund
Thomas and Mary Behm
Adam Besnard
Besnard Insurance
Big Timber Cattle Company, Inc.
Neil and Sally Braid
Brown & Brown, Inc.
Bob Buckhorn
Care4Lou*
Cecil A and Mabel Lene Hamman Foundation Inc.
Columbia Food Service Co., Inc.
Kier and Lauren Cooper
Harvey and Sharon Dean
Mr. and Mrs. Dan Devine
Adam Diasti
Nicholas and Dana DiIorio
Kieran and Kelly Doherty
Simon and Lucia Dolan
Dominic J Ruscetta Trust
Terry and Marilyn Downing
Jennifer and Alan Farmer
Herman and Tanya Fernandez
Fielding Manufacturing
Guy Fieri
Justin and Allison Gerbereux
Judson and Rosalind Gostin
Michael and Betty Halverson
Hal and Connie Harris
Harrison Charitable Fund
Diane and Tripp Hills
IED Family Foundation
Jackson Watts Moore, Jr. Family Foundation
Dr. Thomas Janssen
The John B & Ethel Templeton Fund
Neal and Libby Lacativo
Leon Max, Inc.
Keith and Tammy Leonard
Lopdrup Family Foundation
David Lynch and Laura Balcer
Mike and Ann Marshall
Martin and Kristen Segal Family Charitable Fund
McGehee Foundation
McKinney Health
Colin and Jessica Meyer
Carla Morgan
Patti and Scot Morrow
NFL Foundation Inc.
Carol and Daniel Novak
Joe Paolantonio
Linda and Steven Pellarin
Terry and Dianne Peschl
Beth And Adam Piekarczyk
Jim and Kaye Pollard
William Powers
Richard Randall and Joanna Rein
James and Akansha Rex
Lavonne Rodstein
James Rusche and Patricia Epperly
Mark and Cynthia Shaw
Rick and Lisa Silva
Mark Sing
Joe and Deanne Smith
Lauryn and Cope Smith
Lisa and Richard Sobieray
St. Mary Advocates, Inc.
Stellar Realty, Inc.
Vincent Stevens
Carolyn Swatsler
Tampa General Hospital
Thomas A. & Mary S. James Foundation
Thompson Family Fund
Tom And Kathy Shannon Family Foundation
USF Health
Vanguard Protex Global
Chris and Allison Viehbacher
Marc Viglio
Andreas Voss
Tom and Marianne Warren
Gene and Leslie Wiechens
Wilspec Technologies, Inc
Renek and Jo Wojtkowski
Jacqueline Woods
W. Dan and Pat Wright
William and Heidi Wright
Rick and Becky Young
Paul and Avery Zaritsky

The Bartek Legacy Circle

This celebrates donors who support the future of FARA with a gift from their estate.

Anonymous
Katarina Bell
Michael and Marissa Crawley
Sarah Gelbard
Mr. and Mrs. Michael Klonoski
Dawn and Kevin Lambert
Cait Monette
Chris and Anne Myers
Jalpa Pandya
Jacob B Sonke
Robert Shephard
Jean Melinda Woods

DONORS AND CONTRIBUTORS

The Pathway Donors

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

Ruth Acton
Jenny Adamson
Fabiola Aguilar
Anonymous
Jeremy Becker
Eric Bermudez
Richard Bircher
Alexandria Bode
Sam Bode
Stephen Bowen
Brigid Brennan and Michael Henry
Peter and Regina Brinkman
Leslie Brookman
Kyle Bryant
Juanita Buchanan
Patrick Byrne
Kevin Callanan
David Campbell
Karie Chard
Anne Christon
Jean Christopher
Craig Clark
Micah Constantine
Chris Cottrell
Pádraig Coyne
Michael and Marissa Crawley
Charles Davidson
Alex Dean
Felicia DeRosa
Joseph and Anne DeRosa
Maria Teresa Desanzo
Vincent and Mary Donnelly
Kit Durocher
Donna and Dan Egan
Nancy Ellis
Maureen Fahey
Alan and Jen Farmer
Herman and Tanya Fernandez
Kara Fick
Alex Fielding
Nadine Finnigan
David Fischer
Shauna Fitzgerald
Winford Fowler
Tim Fredette
John Gallagher
William Gambill
Virginia Gambrell
Roger and Julie Gates
The Gehr Family
Stephanie Gill
Laurie Green
Karthik Siddharth Gunda
Susie H
Sarah Hadley
Penny Haldeman
Michael and Charmaine Hamilton
Ryan and Elizabeth Hamilton
Kathy Hansen
Susan Harless
Hal and Connie Harris
Steve and Valerie Harris
Sue Hatton
Leon Havenga
Marilyn Heckler
Josef and Bonnie Hellegers
Nick and Michelle Herring
Ted Herring
Helena Hesselman
Anna Hesselman
Diana Holly
Dave Hollywood
Mekayla Holm
Roxanne Homayoun
Heather Hooper
Margaret Hopkins
Nicole Hopkins
Patrick Hopkins
Thomas Horan
Michelle Huebner
Barbara Hurford
Lisa-Marie Jackson
Rosemary Jeronimides and Christopher Bruneau
Jacek Jankowski
Randy and Maureen Juip
Nicole Kürten
Margaret Kearney
Anke Kelly
Amon Killeen
Madeline Killeen
John Kingsbury
John Lagedrost
John and Sandra Lagedrost
Jude and Lisa Lally
Sandra Lane
Hrysoula Lazaropoulos
Michael Lazaropoulos
Keith and Tammy Leonard
Robert Lewis
Marc and Maggie Likins
Alaina Maas
Angus and Judi Macpherson
Neil Macpherson
Armando Madrigal
Tom Marrow
Michael and Ann Marshall
Erin McInnis
Janine McInnis
Nancy McInnis
Brian McKeever
Caroline McMahon
Helen Meltzer-Krim
Lori Mersereau
Jerry and Melissa Meyer
Dwayne Miller
Gesa Mitchell
Grant Moak
Patricia Morrow
Ben and Kristin Morrow
Heidi Myers
Fred Nadon
Rodney and Pauline Nash
Mark Nicastre
Tara O'Mahony
Carlos Orozco
Christine Padgett
Jeff Pannell
John and Renee Papachriston
Patricia Patello
LaNell Payson
Susan Pelas
Todd Peters
Carol Plummer
William Pool
David and Laura Quirk
Zardasht Rad
Myriam Rai
William Ray
Megaera Regan
Michael and Lindsay Reklis
Robert Rhodes
Allison Rice
Paul and JoAnn Ryan
Thomas Sanders
John and Laurie Schatzber
Katharine Shadlock
Irene Shephard
Alexander Shirah
Pamela Shomette
Tracy and Herb Sims
Carol Singletary
Joseph Skubis
Karen Smaalders
Lauryn Smith
Steve Sommerville
John and Beth Spencer
Shelley Stainer
Rebecca and Lou Stazi
Anna Stepanova
Chandler Stevens
Leona Strait
Richard Stults
Michele Syme
Morgan Talevich
Shandra Trantham
Linda Trantham
Aaron Travers
Jenny and Ryan Turner
Monica Vargas
Ann Walker
Jean Walsh
Scott Werner
Kevin Whittlesey
Scott Wilbur
Megan Wolf

INDUSTRY SPONSORS

Biotechnology and pharmaceutical companies play an important role in advancing FARA's mission to treat and cure FA. In 2025, the companies listed on the right collectively contributed more than $1.6 million to FARA's work.

These contributions span many areas of the organization. A significant portion helped support community-based initiatives, including grassroots fundraisers, rideATAXIA, the FARA Energy Ball, the FA Research Reception series, United Against Ataxia Hill Day, as well as research meetings like the Clinical Trials in Inherited Ataxias Conference (CTAX) and the Industry Advisory Summit (IAS).

Nearly half of this funding helped support FARA's research and patient-focused programs, including the FA Global Clinical Consortium, cardiac natural history research, community education, and the TRACK-FA neuroimaging study and consortium.

We are grateful to our industry sponsors whose shared commitment continues to drive progress and strengthen the programs serving the FA community.

FARA GRATEFULLY ACKNOWLEDGES THE SUPPORT OF OUR INDUSTRY PARTNERS

Alexion Pharmaceuticals
Amgen Rare Disease
Arrowhead Pharmaceuticals
Biogen*
Biohaven Pharmaceuticals
Biologics by McKesson
Design Therapeutics
Larimar Therapeutics*
Lexeo Therapeutics
Neurocrine Biosciences
PTC Therapeutics
Servier
Solid Biosciences
Stealth BioTherapeutics
Voyager Therapeutics

**Indicates Core Program Sponsors*

FARA Friedreich's Ataxia Research Alliance

533 W Uwchlan Ave
Downingtown, PA 19335
(484) 879-6160

PRESORTED
FIRST CLASS MAIL
U.S. POSTAGE
PAID
PERMIT #1935
SACRAMENTO, CA

facebook.com/CureFA

instagram.com/curefa_org

linkedin.com/company/fara

cureFA.org