Donor Impact Report 2024

FARA
Friedreich's Ataxia Research Alliance

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Transformative change lies at the intersection of people and science.

OUR HISTORY

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

OUR APPROACH

We work in collaboration and with a sense of urgency to build strong relationships, expand knowledge, and remove uncertainty.

OUR PROMISE

We've made a promise to treat and cure FA through research.

Dear Friends,

Reflecting on the progress we've made this past year, we are filled with gratitude for the dedication and support of our Friedreich's ataxia community — donors, fundraisers, researchers, industry partners, and FA families.

This year, your generosity enabled FARA to fund 46 groundbreaking research grants across 13 countries and five continents. This global collaboration attracts diverse expertise and ideas, ensuring we fund impactful research that leads to breakthroughs in knowledge and accelerates our pursuit of treatments and, ultimately, a cure.

Remarkably, one-fourth of all FA scientific publications this year were based on FARA-funded research. This significant contribution underscores how FARA is driving progress by broadening our understanding of FA.

Your support has also expanded our research infrastructure. In the last two years, we have doubled the number of sites now part of the FA Global Clinical Consortium (FA GCC). Because FA is a global disease, we need FA research centers where there are individuals with FA. These more than 30 sites create opportunities for people to participate in clinical research, which leads to more robust data and faster progress in finding treatments that benefit the whole FA community.

An important project that we've sponsored is TRACK-FA, the world's largest FA neuroimaging study. This research is helping us understand the complex ways FA affects the brain and spinal cord, paving the way for new ways to measure therapeutic impact in clinical trials. To the hundreds of volunteers who participated in this study, thank you!

Looking ahead, we remain committed to ensuring that children and adults worldwide have access to clinical trials and the latest advancements in FA treatments. We are focused on developing the necessary resources to support pediatric inclusion in clinical trials, and we continue to advocate for broader global access.

None of these achievements would be possible without you. Your contributions drive these accomplishments, and your continued support will keep the momentum going. Every grassroots fundraiser, every rideATAXIA event, every dollar raised at the Energy Ball, and every person who shares their story brings us closer to treating and curing FA.

Looking ahead, we are filled with optimism, knowing that we have the strength of this amazing community behind us.

With sincere appreciation,

Jennifer Farmer, Chief Executive Officer

Ronald J. Bartek, President

2024 MILESTONES

FUNDED $10M+ IN RESEARCH
to support our mission to slow, stop, and reverse FA

ENRICHED THE FA TREATMENT PIPELINE
with novel and diverse approaches

HELPED EXPAND ACCESS TO THE FIRST APPROVED TREATMENT FOR FA

BUILT THE FA GLOBAL CLINICAL CONSORTIUM
to support next generation clinical trials

ADVOCATED FOR PEDIATRIC INCLUSION IN CLINICAL TRIALS

CO-HOSTED THE LARGEST INTERNATIONAL SCIENTIFIC MEETING FOR ATAXIA RESEARCHERS

GREW CENTERS OF EXCELLENCE
to new areas of investigation at world class universities

Children's Hospital of Philadelphia Friedreich's Ataxia Program
Penn
BROAD INSTITUTE
Oxford-Harrington RARE DISEASE CENTRE

Investing in the Next Breakthrough

Growing interest in FA research led to an increased number of grant application submissions to FARA and record research funding.

The FARA grant program drives discovery by funding research that expands our understanding of FA. The program prioritizes high-impact projects that address gaps in disease knowledge, supports early-stage therapeutic interventions, creates better research tools, and advances clinical research.

In 2024, FARA received more than 60 highly competitive grant applications from investigators across 13 countries. Nearly half of those applicants were new to FARA or FA research, reflecting the program's growing global reach and ability to attract experts with diverse ideas. This year also brought expanded international collaboration, with FARA co-funding grants alongside six nonprofit organizations worldwide.

As part of our commitment to continued innovation and the next generation of FA researchers, FARA awarded grants to 11 junior investigators last year. This is the highest number awarded in a single year.

Thanks to donor support, FARA is investing in the people and projects that are accelerating the path to treatments.

$10M+ in research funding awarded in 2024

5 continents with ongoing FARA-funded research

6 nonprofits cofunded research with FARA

26 new grants awarded

46 total grants funded

FEATURED GENERAL GRANT: PAIRED PRIME EDITORS TO TREAT FRIEDREICH'S ATAXIA

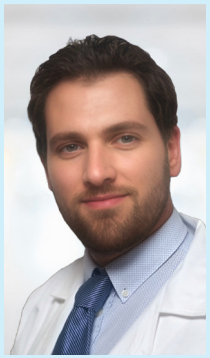
Jonathan Watts, PhD, Erik Sontheimer, PhD, Scot Wolfe, PhD and Wen Xue, PhD
University of Massachusetts Chan Medical School

This multi-disciplinary team of investigators is testing a set of novel prime editing tools to remove the GAA expansion in the FXN gene. Prime editing is an emerging form of gene editing that may offer greater safety than other editing approaches. One advantage of gene editing over gene addition therapy for FA is that, upon removal of the GAA repeats, the edited FXN gene remains under the control of its natural regulator, thus reducing concerns about the overexpression of frataxin and associated toxicity.
Co-sponsor: Muscular Dystrophy Association (MDA)

FEATURED AWARD FOR INNOVATIVE MINDSET: DELIVERABLE IN VITRO TRANSCRIBED mRNAS OF FRATAXIN AS A THERAPEUTIC APPROACH FOR FRIEDREICH'S ATAXIA

Lefkothea Papadopoulou, PhD, Aristotle University of Thessaloniki

Dr. Papadopoulou received an Award for Innovative Mindset (AIM) grant to explore an mRNA delivery platform as a potential treatment for FA. This approach builds on advances made during the COVID-19 pandemic and explores leveraging mRNA technologies to convert human cells into protein factories. With this technology, the mRNA expressing frataxin would be delivered to cells, resulting in the translation and production of this missing protein.
Co-sponsor: fara New Zealand



FEATURED POSTDOCTORAL FELLOWSHIP AWARD: UNDERSTANDING THE PATHOGENESIS OF FRIEDREICH'S ATAXIA BY SINGLE-CELL INTEGRATION OF GENE EXPRESSION, EPIGENETICS, AND CONNECTIVITY IN THE CEREBELLAR NUCLEI

Julian Cheron, MD, PhD, Johns Hopkins University

Dr. Cheron was awarded a Postdoctoral Fellowship to identify which specific cell types within the cerebellum are affected in FA and understand their role in disease progression. This project will use cutting-edge technologies to study the brain at a single-cell level in an FA mouse model. The goal is to gain new insights into disease mechanisms, including early changes in brain connectivity that may occur before cellular loss begins.
Co-sponsor: Association Francaise de l'Ataxia de Friedreich (AFAF)

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

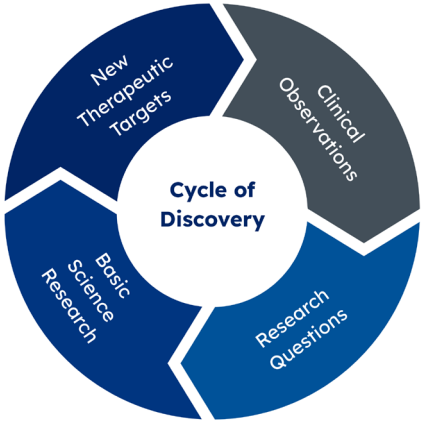
FRIEDREICH'S ATAXIA CENTER OF EXCELLENCE (COE)

at Children's Hospital of Philadelphia (CHOP) and University of Pennsylvania

Children's Hospital of Philadelphia® Friedreich's Ataxia Program

Penn University of Pennsylvania

Since 2014, funding provided by FARA, in partnership with the CureFA Foundation and the Hamilton and Finneran families, has supported the FA COE's distinctive model. This innovative approach to research consists of basic science researchers and clinicians working in close collaboration.



- COE clinicians observe FA in real-time, noticing subtle trends and unexpected features in people living with FA.
- These observations challenge our understanding of FA and raise new research questions, which are taken back to the COE.
- The COE labs investigate these questions, generating insights that feed directly back into clinical priorities.
- This collaboration extends beyond the COE to other FARA-funded researchers who share new tools and emerging data.

Projects and investigators with continued funding include:

Ian Blair, PhD: Biomarker Discovery

Kim Lin, MD: Cardiac Research

David Lynch, MD, PhD: Translational Clinical Neuroscience Research

Shana McCormack, MD, MTR: Metabolism and Endocrinology

Clementina Mesaros, PhD: Biomarker Discovery

Rob Wilson, MD, PhD: Drug Discovery

Discovery in Action: Learning from Non-GAA Repeat Mutations

95% of individuals with FA have the same gene mutation, a GAA repeat expansion, however 5% of individuals have non-GAA repeat mutations. COE clinicians observed that individuals with certain non-GAA mutations have different clinical symptoms and disease progression (both more and less severe). This led the clinicians to wonder why — would understanding how these point mutations impact the frataxin protein lead us to new insights into the role and function of the frataxin protein?

These clinical observations sparked lab-based studies into how specific missense mutations may affect frataxin's function beyond its well-known role in iron-sulfur cluster synthesis. This work explores whether frataxin may have additional cellular activities, offering both a new lens through which to understand disease variability and the exploration of new therapeutic targets.

Lynch DR, Shen M, Wilson RB. Friedreich ataxia: what can we learn from non-GAA repeat mutations? Neurodegener Dis Manag. 2025 Feb;15(1):17-26. doi: 10.1080/17582024.2025.2452147. Epub 2025 Jan 15. PMID: 39810561; PMCID: PMC11938963

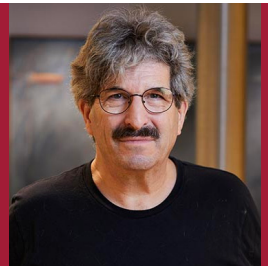
Shen MM, Rummey C, Lynch DR. Phenotypic variation of FXN compound heterozygotes in a Friedreich ataxia cohort. Ann Clin Transl Neurol. 2024 May;11(5):1110-1121. doi: 10.1002/acn3.52027. Epub 2024 Feb 23. PMID: 38396238; PMCID: PMC11093247

THE FRIEDREICH'S ATAXIA ACCELERATOR (FAA)
at the Broad Institute of MIT and Harvard




The Friedreich's Ataxia Accelerator at the Broad Institute of MIT and Harvard is committed to FA research. Led by Dr. Vamsi Mootha, the FAA's overarching goal is to nucleate a research community that leverages the latest advances in biomedical research to develop new therapeutic strategies. Dr. David Liu has been investigating therapeutic approaches that would edit the frataxin gene, with the goal of removing the GAA repeats (prime editing) or interrupting the GAA repeats (base editing) and thus reactivating the protein expression. Drs. Jonathan and Christine Seidman are discovering changes in the hearts of people with FA, including an increase in inflammation. This work is funded by FARA, in collaboration with the CureFA Foundation and EndFA. It deepens our knowledge of FA, and these learnings were shared by four members of the FAA who presented their work at the International Congress for Ataxia Research (ICAR) in November in London.

2024 Nobel Laureate



In December, FAA investigator Dr. Gary Ruvkun was awarded the Nobel Prize in Physiology or Medicine for the discovery of microRNA and its role in post-transcriptional gene regulation. His current work includes FA research where he is working to discover proteins that interact with frataxin.

Project Feature: At-Home Wearables

Investigators need robust, easy-to-use metrics to assess therapeutic candidates in clinical trials. The FAA has conducted a two-year project that has collected at-home quantitative data from wrist and ankle sensors. While longitudinal analysis of this data is still underway, this project is demonstrating the potential of building on this approach for future clinical trials.

Project Feature: Understanding the Heart

The Seidman lab is using cutting edge technology to understand the changes in the FA heart, including single nuclei RNA sequencing (snRNA-seq). They are learning how the cells present in the FA heart are different from those found in hearts with normal frataxin levels.

Building a Global Clinical Network

THE FA GCC GLOBAL CLINICAL CONSORTIUM

One of FARA's significant contributions to advancing FA research is to foster a global clinical research network and build a comprehensive natural history data set. FARA's investment in the Friedreich Ataxia Global Clinical Consortium (FA GCC) and the UNIFAI Natural History Study reflects our deep commitment to enabling clinical trials, responding to an expanding treatment pipeline, and ensuring that research continues to be informed by the patient experience. Over the past two years, FARA has doubled the number of the FA GCC sites to 34 institutions with clinical research teams devoted to FA.

This consortium growth helps:

- **Create a robust dataset** with diverse representation that enhances the statistical power and reliability of our findings and informs clinical trial design.
- **Facilitate patient recruitment** and increased participation in clinical trials.
- **Accelerate development** and access to therapies.
- **Improve the transfer of knowledge** through shared expertise of leading global experts.
- **Partner with global patient advocacy groups** to empower a patient-centered approach to shape therapies that truly address the challenges the FA community faces.

The Impact of FARA's Global Collaboration

The value of FARA's investment has been demonstrated in several ways. For example, the natural history data generated from individuals living with FA participating in research at FA GCC sites was used to support the regulatory decision of the first approved treatment for FA. Now, the global effort to advance FA research and treatment under the FA GCC provides the infrastructure to support a growing number of clinical trials and to learn how new treatments impact the natural history of the disease. Furthermore, the collaboration between researchers in the FA GCC has allowed experts to build off of each other's work, enhancing the overall impact and efficiency of their research efforts.

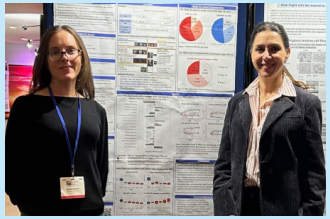
Nijmegen, Netherlands
Radboud University
Medical Center

Prague, Czech Republic
Motol University Hospital

Aachen, Germany
RWTH University
Hospital Aachen

New Delhi, India
All India Institute of
Medical Sciences (AIIMS)

TRACK-FA



TRACK-FA is a neuro-imaging study to track disease progression and meet the urgent need for clinical-trial-ready biomarkers. Initiated in 2020, this FARA-sponsored longitudinal study is a collaboration among a consortium of clinical sites and researchers from Australia, Brazil, Canada, Germany, and USA as well as industry partners.

2024 Progress: We are proud to report that of the 279 participants enrolled in the study, 100% have completed their baseline and 12-month visits, and more than half have completed their final visits. This remarkable progress keeps us on track to finalize data collection in 2025. Helena Bujalka, PhD and Professor Nellie Georgiou-Karistianis (pictured above) represented the TRACK-FA consortium and presented baseline data and initial results at the 2024 International Congress for Ataxia Research.

Early Findings: TRACK-FA is the first multi-modal neuroimaging study to encompass both children and adults, with a special cohort of very young participants with FA who are 5-10 years old. This allows us to identify differences early in the disease. Early results indicate:

- For some measurements – such as the size of the spinal cord – differences can be detected even in very young children, and those differences increase with age.
- For other measurements in the brain, differences can be detected only later, in older children or adults.

Advocating to Create Change

Whether it was meetings with elected officials, speaking at Medicaid hearings to secure access to treatment, or participating in awareness events, FARA and the FA community have continued to create change through advocacy in 2024!

In February 2024, FARA joined over 800 advocates in 330 Congressional meetings for Rare Disease Week on Capitol Hill. For the first time, the House Energy & Commerce Health Subcommittee held a hearing to highlight eighteen bills covering rare disease while the Biden White House Office of Science and Technology Policy's (OSTP) Health Outcomes Team held its first ever rare disease forum.

On September 25, 2024, FARA and the National Ataxia Foundation (NAF) celebrated the 6th Annual United Against Ataxia Hill Day. FARA and NAF were joined by 113 advocates from 32 states for 94 Congressional meetings. Advocates urged action on a number of policy priorities, including the continued inclusion of "Hereditary Ataxia" in the Congressionally Directed Medical Research Program (CDMRP), timely passage of the FY25 budget, robust funding for the Food and Drug Administration (FDA) and National Institutes of Health (NIH), and the extension of critical incentives for rare disease drug development. The Senate passed a resolution recognizing the day as "National Ataxia Awareness Day," led by Senator Hyde-Smith (MS) and co-sponsored by Senators Stabenow (MI), Moore Capito (WV), and Murphy (CT). Senators Amy Klobuchar (MN) and Bob Casey (PA) were honored as the 2024 Ataxia Research Champions (ARC).

The work done this past year has led to amazing results including four CDMRP grants being recommended for funding totaling over $12.25 million for hereditary ataxia research, the creation of the FDA Rare Disease Innovation Hub, and passage of important legislation like the reauthorization of the Federal Aviation Administration which included significant reforms aimed at improving air travel for passengers with disabilities.

>> You too can advocate for FA research in 2025! Get started by signing up for the Advocacy Newsletter at curefa.org/newsletters

PEDIATRIC-FOCUSED RESEARCH AND ADVOCACY

FARA remains committed to ensuring that children are included early in clinical research for FA. Giving children earlier access to treatments creates more opportunities to slow or alter the course of disease.

In July 2024, FARA partnered with Leavitt Partners to host the Pediatric Inclusion Roundtable: Effective Inclusion of Children Early in Clinical Trials. The event brought together key stakeholders, including representatives from the Food and Drug Administration (FDA), National Institutes of Health (NIH), pharmaceutical and biotech industries, and patient advocacy groups, to explore strategies for accelerating pediatric drug development in rare diseases like FA.

This roundtable led to the formation of the Pediatric Inclusion Alliance, a dedicated working group that will continue advancing efforts to promote early pediatric inclusion in clinical trials. FARA's co-founder, Ron Bartek, now co-chairs this initiative.

FARA also continues to advocate for federal programs like the Pediatric Priority Review Voucher, which encourage pediatric-focused innovation in rare disease drug development.

INTERNATIONAL CONGRESS FOR ATAXIA RESEARCH

In November 2024, the International Congress for Ataxia Research (ICAR) took place in London and brought together over 600 researchers from around the world. It was the largest ICAR to date and a powerful example of how we accelerate progress when experts across different types of ataxia come together to share ideas and collaborate.

This year's program included a mix of plenary sessions, breakout workshops, and the always-popular scientific debate. The debate sparked thoughtful discussion about the strengths of in vivo vs. in vitro research models and highlighted how both approaches help to move the science forward.

Insights and Learnings from ICAR 2024

Potential New Therapeutic Target

Discovering that frataxin activity can be boosted by targeting other components of the iron-sulfur cluster assembly reveals a potential new treatment pathway.

Hidden Genetic Variant

Some GAA repeat interruptions are more common than previously known, impacting carrier detection and opening new therapeutic opportunities.

Inflammation as a Driver

Inflammation might contribute to nerve damage in FA.

Breakthrough in Gene Delivery

Capsid for an IV gene addition therapy reached key brain and heart areas in animal models.

Clinical Trials Show Momentum

Multiple therapies across different mechanisms of action are showing early promise.

FA research had a strong presence at the meeting. With multiple clinical trials underway and the first treatment now approved, there was a clear sense of momentum. Collaboration has always been core to FARA's mission, and ICAR reflected that — from global data sharing to joint projects with multiple institutions.

Importantly, the FA community was represented not just in the science but in the scientists themselves — three researchers living with FA presented their work. ICAR also invested in the future of the field by providing meaningful mentorship and networking opportunities for early-career researchers. These experiences are vital for building the next generation of leaders in ataxia research.

COMMUNITY ENGAGEMENT & EDUCATION

An engaged, educated, and connected community is a strong one, and the FA community excelled in all of these areas over the last year. Participation reached record levels and made a meaningful impact on fellow FA families as well as partner entities.

EDUCATION

FARA hosted five research receptions and symposiums to share information about the FA drug development pipeline, ongoing clinical trials, clinical management, and FARA resources.

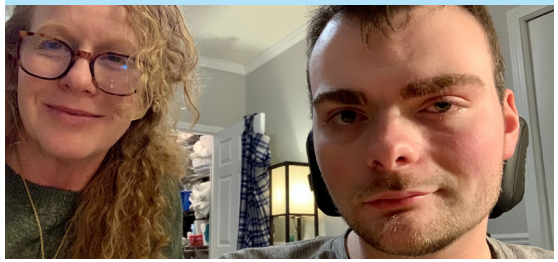
Virtual education sessions included Flash Talks with FARA-funded researchers, Community Conversation webinars with FARA leadership, and information sessions with pharmaceutical partners.

ENGAGING WITH STAKEHOLDERS

As experts in living with FA, individuals and families shared their stories in many forums and to many audiences.

In 2024, over 50 individuals from the FA community worked with FARA to engage with pharmaceutical partners, researchers, future healthcare professionals, Medicaid committees, and the Food and Drug Administration at 33 different events.

Their voices provide essential insights that advance meaningful and accessible treatments.



CULTIVATING COMMUNITY

Throughout 2024, FARA worked to strengthen the FA community by facilitating opportunities for connection and collaboration through virtual and in-person events. Individuals new to the FA community had the opportunity to meet other FA families for the first time.

The FARA Ambassador Program, a group of adults with FA who volunteer to support FARA's mission, grew to 100 members from countries around the world. Ambassadors now represent 14 countries globally plus 32 states throughout the US.

GRASSROOTS
$1.6M+ RAISED

Whether it's a musical soirée, a 5K walk/run, or a golf tournament, FARA grassroots fundraisers take on many different forms. These events are hosted by members of the FA community, and they reflect their creativity and passions while generating critical funds to advance FARA's research mission.

In 2024, both seasoned and new volunteer fundraisers hosted more than two dozen grassroots events.

The Race for Matt and Grace (RFMG) didn't let the rain get in the way of celebrating the incredible milestone of 15 years of fundraising. The DiIorio, Hopkins, and Fielding families united to host their signature RFMG 5K walk/run as well as other events throughout the year such as a golf tournament, pig roast, and Oktoberfest.

The Cure FA Soirée, led by the Gehr Family, rocked their way to the top of our fundraising charts with their 7th annual event, which featured live music, dinner, and an auction.

We were also excited to welcome Epic Game Day as one of the new events on the scene this year, where attendees enjoyed an array of board games and camaraderie. The event was organized by the family of Jack Mohamed, who lives with FA, and the concept was inspired by his love of chess and board games.

To everyone who planned, attended, or supported a grassroots event in 2024, thank you. Together, you raised over $1.6 million for FA research. Your efforts are making a difference.

2024 Grassroots Campaigns ($5,000+)

$450,000+

Cure FA Soirée
Edmond, OK

$100,000+

Burrows Hill Foundation: Night to Fight FA
Annapolis, MD

Juip Family | FBMJ Drive-In Movie Fundraiser
Livonia, MI

Pull for a Cure
Tampa, FL

Race for Matt & Grace
Providence, RI (15th Year)

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

$50,000-$99,999

N.J. Seaside Stride
Seaside Heights, NJ

$20,000-$49,999

Epic Game Day
Henderson, NV

Fuzzy Buzzy Golf Tournament
Windham, NH (20th Year)

Living A Courageous Life:
An Evening to Cure FA
Branford, CT

Morrow Lacrosse Challenge
Baltimore, MD

Sadie's Dance
Opelika, AL

The Smith Family
Auburn, AL

$10,000-$19,999

#CureFA Baseball Game
Terre Haute, IN (5th Year)

Fine Arts for Friedreich's Ataxia
Sioux Falls, SD

Cousins for a Cure | GolfATAXIA
Commerce Charter Township, MI

The Leonard Family
Virginia

The Stoneham Open
Portsmouth, NH

Team FARA: David Welch
Boston, MA

$5,000-$9,999

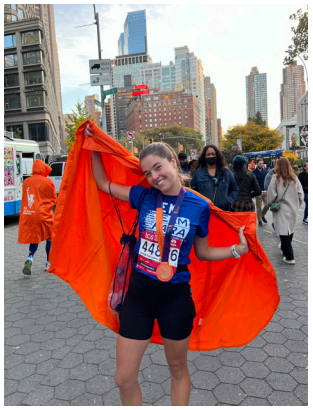
F3 The Capital
Washington, DC

FA Indy
Indianapolis, IN

The Snead Family
Washington

The Stacks Family
Georgia

Tee It Up Flower Fundraiser
Marysville, OH



rideATAXIA

rideATAXIA is a national cycling program for people of all abilities that gathers FA families and their communities to be active, build connection, and fundraise for research. Over 100 FA families participated in the 2024 rideATAXIA program, which consisted of four national events and nine hometown events and raised over $1.3 million.

rideATAXIA Hometown
Since its launch in 2023, rideATAXIA Hometown has continued to see incredible growth in both fundraising and participation. Local communities gathered for small neighborhood group rides or large trail rides and offered different ways for FA families to bring rideATAXIA to their hometown. In its second year, rideATAXIA Hometown grew to more than 500 participants and raised $185,000 — an incredible 60% increase in participation and a 120% boost in fundraising!

rideATAXIA National Events
The rideATAXIA national events feature a variety of options to be active — different cycling routes, a walking path, and cheer stations — followed by lunch and a celebration of fundraising efforts. In addition to these core activities, the program has incorporated new elements to foster community engagement and fun.

rideATAXIA Gainesville was all about bringing people together. With the addition of a pre-ride meetup and a post-event gathering, participants had more opportunities to connect, share stories, and strengthen their sense of community.

rideATAXIA Chicago celebrated Team Spirit! Participants arrived with their best costumes, team t-shirts, and tent decorations, taking the event energy to the next level.

rideATAXIA Philly amped up the excitement with the rock ‘n’ roll energy of a live band, and cyclists also had the opportunity to refuel at a rest stop with signature Philly pretzels.

rideATAXIA Dallas took on a fresh look with a new beautiful venue at Railroad Park and scenic trail rides along the DCTA Rail Trail.

Thanks to all of the FA families, donors, committee members, and volunteers who make rideATAXIA a success!

THE FARA ENERGY BALL

The FARA Energy Ball raised over $1.6 million, continuing the journey toward a cure.

The 16th FARA Energy Ball was a remarkable celebration of resilience, community, and progress. In a year marked by the challenges of Hurricanes Helene and Milton, the Tampa community showed unwavering support for families affected by FA. Despite the storms' impact on the region, the Tampa community rallied together, embodying the strength that has defined the FA community.

To kick-start the day, the University of South Florida (USF) and FARA co-hosted a research reception brunch. The event included impact updates from both organizations as well as panel discussions featuring representatives from pharmaceutical companies with clinical stage programs in FA and community members living with FA. Attendees gained an understanding of research advancement from the perspectives of both the drug developers and community members.

Later in the evening, over 400 guests gathered at the JW Marriott Tampa Water Street for the FARA Energy Ball gala, where the colorful "FARA Festival" came to life in a night of music, dancing, and celebration. Wendy Ryan, ABC News Anchor, shined as the evening's emcee, and the Blonde Ambition band kept attendees dancing with everyone's favorite high energy anthems.

This milestone "Sweet Sixteen" event was a celebration of the progress we've made, but also a reminder of the work that remains. The commitment from families, volunteers, and supporters has never wavered. The evening was filled with heartfelt moments of reflection on the strides made in FA research, but also a renewed commitment to pursuing treatments and a cure.

FINANCIALS

STATEMENTS OF FINANCIAL POSITION

December 31, 2024 and 2023

ASSETS	2024*	2023*
CURRENT ASSETS		
Cash & Cash Equivalents	$1,959,581	$3,993,332
Restricted Cash	2,350,400	963,779
Contributions Receivable, Net	682,067	747,478
Prepaid Expenses	67,503	49,155
Investments	2,137,780	1,870,166
TOTAL CURRENT ASSETS	**7,197,331**	**7,623,910**
OTHER ASSETS	51,862	109,254
TOTAL ASSETS	**$7,249,193**	**$7,733,164**

LIABILITIES & NET ASSETS	2024	2023
LIABILITIES		
Accounts Payable	$689,951	$1,164,034
Deferred Revenues	10,630	4,567
Lease Liabilities	49,940	112,047
TOTAL LIABILITIES	**750,521**	**1,280,648**
NET ASSETS		
Without Donor Restrictions	4,148,272	5,488,737
With Donor Restrictions	2,350,400	963,779
TOTAL NET ASSETS	**6,498,672**	**6,452,516**
TOTAL LIABILITIES & NET ASSETS	**$7,249,193**	**$7,733,164**

STATEMENTS OF ACTIVITIES

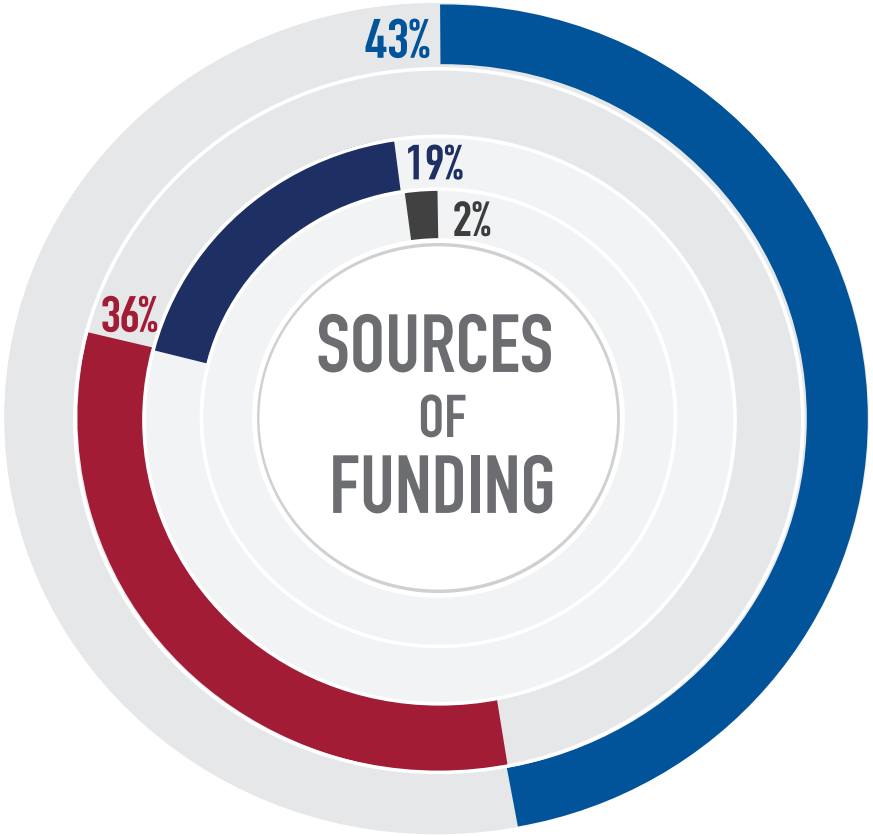
Years Ended December 31, 2024 and 2023

NET ASSETS WITHOUT DONOR RESTRICTIONS	2024*	2023*
REVENUE & SUPPORT		
Contributions, Conferences & Grants	$2,497,238	$4,037,159
Special Events & In-kind Contributions	4,690,438	4,804,770
Investment Return	346,163	266,862
Net Assets Released from Restrictions	5,652,908	4,294,300
TOTAL REVENUE & SUPPORT	**13,186,747**	**13,403,091**
EXPENSES		
Program Services	12,740,598	11,366,576
Fundraising	1,349,672	1,301,838
General & Administrative	436,942	392, 212
TOTAL EXPENSES	**14,527,212**	**13,060,626**
CHANGE IN NET ASSETS WITHOUT DONOR RESTRICTIONS	**(1,340,465)**	**342,465**

NET ASSETS WITH DONOR RESTRICTIONS		
Contributions, Conferences, & Grants	7,039,529	3,573,926
Net Assets Released from Restrictions	(5,652,908)	(4,294,300)
CHANGE IN NET ASSETS WITH DONOR RESTRICTIONS	**1,386,621**	**(720,374)**

TOTAL NET ASSETS		
CHANGE IN NET ASSETS	46,156	(377,909)
NET ASSETS AT BEGINNING OF YEAR	6,452,516	6,830,425
NET ASSETS AT END OF YEAR	$6,498,672	$6,452,516

**FARA and FARA Europe consolidated*



- Donor-directed Contributions
- Special Events (Energy Ball, rideATAXIA & Grassroots)
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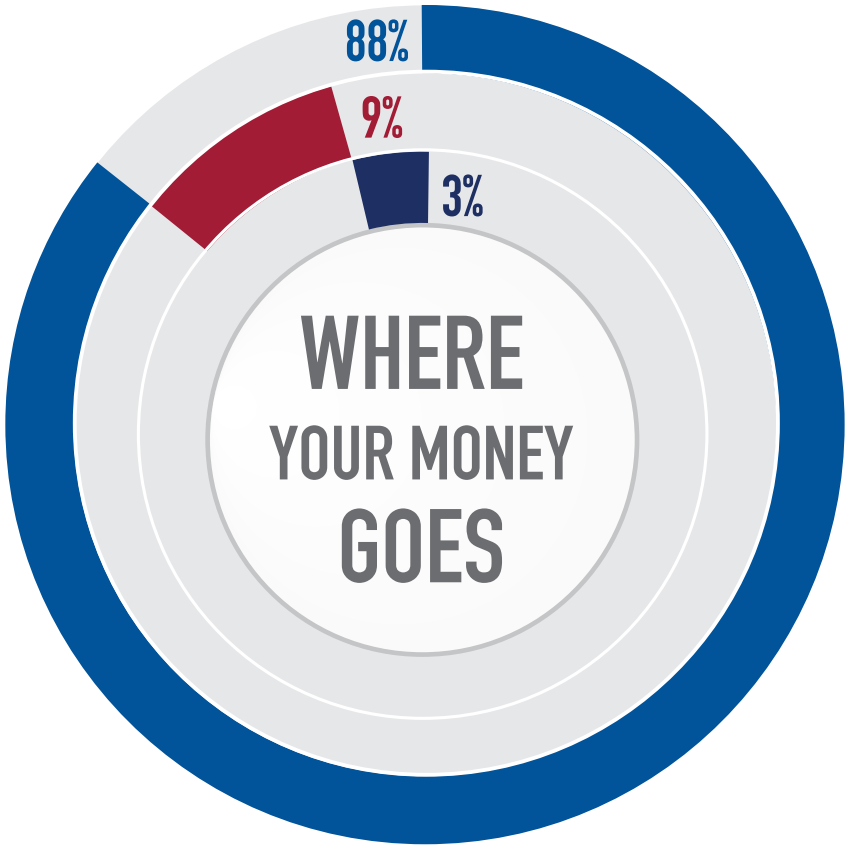
- Investment



- Research & Programs
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In the spirit of collaboration, we recognize the important role that biotechnology and pharmaceutical companies play in advancing FARA's mission to treat and cure FA. We're grateful for the support of our industry partners, who collectively have contributed more than $1,600,000 to FARA programs in 2024.

Many of these contributions came in the form of sponsorship for community-focused FARA events, including grassroots fundraisers, rideATAXIA, the FARA Energy Ball, the FA Research Reception series, and United Against Ataxia Hill Day, as well as for the Industry Advisory Summit (IAS).

More than half of these funds supported FARA's core programs and services, such as the FA Global Patient Registry, the FA Global Clinical Consortium, community education, and Clinical Management Guidelines as well as the TRACK-FA neuroimaging consortium and study.

These partnerships help move our mission forward, and we appreciate the commitment behind each contribution.

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