



2023
Donor Impact Report

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Dear friends,

As we reflect on the significant strides we've made in 2023, it is with great excitement and gratitude that we share our donor impact report with you. Together, we celebrate not only our achievements but also the promise of what lies ahead in our relentless pursuit of treatments and cures for Friedreich's ataxia (FA).

Undoubtedly, the approval of SKYCLARYS® by the US Food and Drug Administration (FDA) on Rare Disease Day 2023 marked a historic milestone in our journey. This groundbreaking achievement, followed by the European Commission's approval in 2024, demonstrates progress for the entire FA community. We're not stopping here — our sights are set on global access and trials with pediatric participants. To bolster these efforts, we authored a white paper for our industry partners advocating for pediatric inclusion in clinical trials and co-sponsored a workshop focused on readiness for pediatric clinical trials.

SKYCLARYS is just the beginning. FARA continues to fund research at every stage of development, allocating \$9+ million and awarding 37 grants, including 22 new projects this year. Our commitment extends globally, with FARA-funded research projects spanning five continents and 10 countries. In addition to this research, the launch of the FA Global Clinical Consortium further harmonizes UNIFAI natural history data, and this collaboration enables us to advance research further and faster.

TRACK-FA, the largest global neuroimaging study, is further emblematic of FARA's worldwide research efforts. To the hundreds who are participating and helped fully enroll the study this year, your contributions are invaluable. Thank you!

Our advocates shared our mission with Congress during United Against Ataxia Hill Day, and we are pleased to see those efforts reflected in the \$10.4 million recommended for funding in Congressionally Directed Medical Research Programs (CDMRP) grants for Hereditary Ataxia researchers.

None of these achievements would have been possible without your steadfast support. From the 22 grassroots fundraisers to the tremendous success of events like rideATAXIA, which boasted over 1,600 participants this year and the exciting launch of rideATAXIA Hometown, to the electric atmosphere that raised \$2 million at the Energy Ball, every one of you plays an indispensable role in our mission. We extend our heartfelt gratitude to each person who participates, organizes, and contributes to these efforts, for it is your passion and generosity that propel us closer to our shared goal.

As we embark on this new chapter in an era with an approved treatment for FA, thank you for your unwavering commitment. We're just getting started, and together, we will slow, stop, reverse, and cure FA!

With sincere appreciation,



Jennifer Farmer, Chief Executive Officer

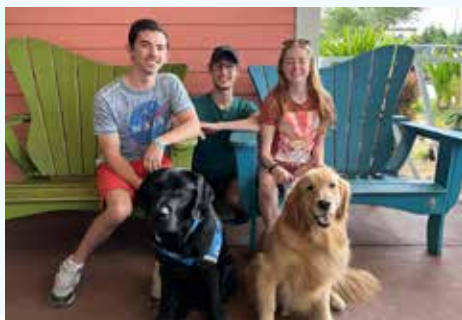


Ronald J. Bartek, President



YOUR IMPACT ON FRIEDREICH'S ATAXIA RESEARCH IN 2023

COLLABORATE



ADVOCATE



17 engagement events to elevate the patient voice with pharmaceutical companies, researchers, and medical professionals

7

Congressionally Directed Medical Research Programs (CDMRP) grants for Hereditary Ataxia



164 advocates from **33** states educated lawmakers on ataxia during **86** congressional meetings on United Against Ataxia Hill Day

INNOVATE



\$9M+ in FARA funded research



New potential therapeutic mechanisms of action discovered and developed at the FA Center of Excellence and the FA Accelerator

37

FARA-funded grants (22 newly awarded)

PARTICIPATE



FA Global Clinical Consortium expands worldwide to active participation from **54** investigators from **33** sites in **18** countries

279

participants enrolled in TRACK-FA neuroimaging study



Unified Global Natural History Study (UNIFAI) launched - **1,400** data points collected/visit

CELEBRATE

1ST APPROVED TREATMENT!

RESEARCH GRANT PROGRAM

2023 was an exciting year for the FARA Grant Program. The number of applications increased by almost 50% compared to previous years. These included several innovative proposals from established FA researchers as well as junior investigators and investigators new to FA.

FARA proudly funded over \$9 million in FA research again in 2023. The FARA Grant Program is a competitive funding mechanism that supports research to further the understanding of FA and promote therapeutic discovery and development. FARA prioritizes projects that fill gaps in knowledge of disease mechanisms, support early development of therapeutic interventions, establish and advance the development of tools for drug developers and academic researchers, and focus on clinical research and trials.

To further inspire and build the next generation of FA scientists, FARA established two new programs in 2023: The FARA Graduate Research Fellowship to support young researchers engaged in graduate study leading to a PhD degree and the FARA Fellow Program to provide mentorship, training, and networking opportunities for talented young scientists.

FARA FELLOWS



FARA created the FARA Fellow Program with the aim of attracting and retaining talented young scientists to the FA research field. The Program recognizes young investigators who will commit their early career to FA research and want to grow their profile within the research community.

The 2023 FARA Fellows were: Sujoyoti Chandra, *Stanford University* Changfan Lin, *Caltech*
Xiaonan Guan, *Columbia University* Pouré Yameogo, *UT Southwestern*

The FARA Fellows participated in rideATAXIA Philly and presented their research at the FA Symposium in King of Prussia, PA.

2023
GRANT
PROGRAM

\$9M+
Research Funding
Awarded

37
Total # of
Grants Awarded

22
New Grants
Awarded

5
Continents where
FARA Funded Research

30+
FARA-Funded Research
Publications



FEATURED GENERAL RESEARCH GRANT: CELL MODELS

Modeling Friedreich's Ataxia in Human iPSC-derived Cerebellar Organoids

Dr. Esther Becker at the University of Oxford received a grant from FARA to create three-dimensional models of the human cerebellum, called organoids, using stem cells from patients with FA. Coaxing stem cells obtained from patients into brain cells allows for the study of living human nerve cells in the lab. This innovative method will allow us to better understand why nerve cells in the cerebellum are particularly vulnerable to low levels of frataxin and use this insight to test potential treatments.



FEATURED GENERAL RESEARCH GRANT: CARDIAC

Role of the Thromboxane-Prostanoid Receptor in Friedreich's Ataxia Cardiomyopathy

With this FARA funding, Dr. Mark Payne at Indiana University is working to determine if a drug called Ifetroban can stop or decrease fibrosis in the heart of a mouse model of FA, thus extending its life. It is known that the FA heart develops significant thickening and has extensive fibrosis that develops over time. This markedly decreases the function of the heart and leads to early death. Ifetroban targets a specific receptor that stimulates the production of fibrosis in the heart, thus potentially improving the heart function in people with FA.



FEATURED GRADUATE RESEARCH FELLOWSHIP

Population and Cellular Heterogeneity in Friedreich's Ataxia

Ms. Morgan Tackett at the University of Oklahoma Health Sciences Center received a Graduate Research Fellowship to focus her PhD studies on FA and investigate the distribution of FA worldwide. The known distribution of FA is that it affects people from Europe, North Africa, the Middle East, and South Asia, and is not commonly seen in people from Sub-Saharan Africa and East Asia. This broad description of FA distribution likely misses small and isolated populations that may have FA but are not presently recognized. The final goal of this project is to determine the true distribution of FA by searching for DNA markers of FA susceptibility in publicly available genomic sequence databases.



Learn more about research grants awarded by FARA and access scientific publications, many of which report results funded by FARA — visit curefa.org

YOUR IMPACT ON THE FIRST TREATMENT APPROVAL FOR FRIEDREICH'S ATAXIA

The FA community made many significant contributions to research on the path to Skyclarys® (omaveloxolone) — the first approved treatment for FA. Your fundraising efforts helped fund the FARA Grant Program where a basic science grant helped identify the therapeutic approach. Your participation contributed to natural history data that informed trial design and supported regulatory approval. Your story helped educate on meaningful treatment impact in FA. This approval is thanks to you and all we have accomplished together.

2009

Nrf2 target first reported by research group in France as a possible therapeutic approach in FA.



2015

First clinical trial launches. Trial is conducted at FA Global Clinical Consortium sites.



2017

Patient-focused drug development meeting brings the patient voice to the process.



2017

Second clinical trial launches and quickly enrolls individuals living with FA.



2013

California research group links Nrf2 to pathophysiology in FA mice. FARA seeks out Reata Pharmaceuticals, a company with a drug targeting the Nrf2 pathway.





2020

Multiple meetings with FDA.



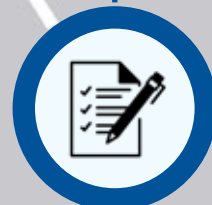
2021

FARA coordinates a petition to Reata and the FDA to submit and review a New Drug Application (NDA) for omaveloxolone — 74,000+ signatures are collected!



2022

FARA-funded FA natural history study provides confirmatory evidence through a propensity-matched study.



2022

Reata initiates rolling submission of NDA for omaveloxolone.



2023

FDA approves first-ever treatment for Friedreich's ataxia: SKYCLARYS®

2024

European Commission approves SKYCLARYS®



THE FA GLOBAL CLINICAL CONSORTIUM (FA GCC)



FARA and the FA community's dedication to collecting natural history study data over the past two decades proved instrumental in the approval of the first-ever treatment for FA. Through the FA Global Clinical Consortium (FA GCC), FARA has redoubled its investment in natural history data by enabling the transition to an industry-leading data collection platform and a *unified* global natural history protocol (UNIFAI) resulting from the harmonization of two well-established natural history studies, the FA Clinical Outcome Measures Study (FA-COMS) and the European Friedreich's Ataxia Consortium for Translational Studies (EFACTS).

The FA GCC and the UNIFAI study have been expanded to make patient contributions to natural history even more powerful in understanding FA. At each UNIFAI study visit, there are more than 1,400 data elements recorded.

In 2023, the FA GCC had active participation from 54 investigators at 33 sites in 18 countries, along with representatives from patient advocacy and research organizations.



FA GCC Research Activities

The FA GCC leadership identified initial scientific priorities and created workgroups to address these priorities. The following workgroups, each made up of 5-10 consortium members, met regularly to address gaps in current FA research:

- Cardiac Natural History
- Late-stage Symptoms
- Pediatric/Presymptomatic
- Bio-samples
- Mood and Cognition
- Patient Advocacy/Advisory Team

Quarterly consortium meetings serve as a platform for investigators to establish common research interests, form collaborations, and share their global clinical experiences.

Impact and Future Direction

The FA GCC has a long-term objective of fostering multilateral research and collaboration across continents, unifying global opinions to regulators and industry partners, accelerating the development of new therapies, and improving outcomes for those living with FA.



TRACK-FA: LARGEST GLOBAL FA NEUROIMAGING STUDY

Thanks to global participation from the FA community, the TRACK-FA study finished enrolling participants in 2023 and is anticipated to complete data collection before the end of 2025.



TRACK-FA is the largest global collaborative neuroimaging effort to track FA disease progression and meet the urgent need for clinical-

trial-ready biomarkers. Initiated in 2020, this FARA-sponsored network includes clinical sites and researchers from Australia, Brazil, Canada, Germany, and the United States, in collaboration with global industry partners.

As of the close of 2023, across all study sites, 279 participants have completed study visits, including 182 participants with Friedreich's ataxia and 97 matched healthy controls. With this, TRACK-FA has finished recruitment and started analyzing baseline data.

This FARA Directed Project is important to FA research for several reasons:

- It follows both children and adults across disease stages and onsets over three years.
- Its dataset uniquely includes very young participants with FA, with 10% aged 10 years or younger.
- It successfully recruited the largest-ever cohort of participants with FA — and matched controls — in a multi-modal neuroimaging study on a global scale.
- It will allow discovery of sensitive neuroimaging biomarkers of disease progression of FA.

TRACK-FA Progress to Study Completion



FARA Ambassador Mekayla and her niece Brooklin participate respectively in the FA and control cohorts of TRACK-FA.

PEDIATRIC-FOCUSED RESEARCH AND ADVOCACY

Since the organization’s founding in 1998, FARA has been committed to pediatric research and drug development. The very first clinical trial in FA was conducted with both children and adults simultaneously. In the years since, many other clinical trials in FA have included children.



Promoting pediatric-focused research and advocacy initiatives remains a key priority for FARA. In August 2023, the **Pediatric Friedreich's Ataxia Outcome Measures Collaborative Workshop** — powered by St. Jude's Pediatric Translational Neuroscience Initiative (PTNI) and FARA — explored approaches to clinical trials in children with FA, evaluated learnings from the patient experience, reviewed natural history study data, and discussed further development and research on pediatric outcome measures and biomarkers. The event brought together researchers, clinicians, and physical therapists in the field of FA and parents of children living with FA.

FARA also authored a **white paper on Clinical Trials in Children with FA** to communicate best practices for pediatric trials in FA and establish a path forward for parallel pediatric and adult drug development. In the clinic, FARA has invested research dollars into biomarker studies such as TRACK-FA and natural history studies like UNIFAI and FA-CHILD to support the discovery and development of outcome measures and other tools that will help design better clinical trials for children.

The FA community advocated for fair access to medication and increased research funding in 2023.

In February, FARA joined over 600 advocates in Washington, D.C. for the first in-person Rare Disease Week since 2020. The highlight of the week came during the National Institutes of Health (NIH) Rare Disease Day when FARA President and Co-Founder Ron Bartek proudly shared the news of the FDA approval of the first treatment for FA. This incredible milestone would not have been possible without the FDA applying flexibility in the review process, a feature that many dedicated advocates and supportive Congressional Members have long sought.

After the first treatment approval, FA advocates were needed at the state level. Every state Medicaid office makes its own determination on coverage, and the patient voice needed to be part of that conversation. Community members joined FARA at state Medicaid hearings to address restrictive prior authorization criteria and request fair access to SKYCLARYS® according to the FDA's label. Hearings will continue in 2024.

In September, FARA and the National Ataxia Foundation (NAF) celebrated the 5th United Against Ataxia Hill Day with an impressive 164 advocates from 33 states holding 86 Congressional meetings. As a result of the Congressional relationships fostered over the years, "Hereditary Ataxia" was again included in the Congressionally Directed Medical Research Programs (CDMRP). This incredible funding source has doubled the funds for ataxia research and recruited new researchers into the field.

Be a voice for the FA community – sign up for the advocacy newsletter on curefa.org



The Bode-Carusio Family with Congresswoman Rosa DeLauro.



FARA President Ron Bartek, National Institute of Neurological Disorders and Stroke Director Dr. Walter Koroshetz, and FARA Director of Advocacy Brigid Brennan.



FARA Ambassador Mary advocates for rare disease during Rare Across America.

FRIEDREICH'S ATAXIA CENTER OF EXCELLENCE (COE)

at Children's Hospital of Philadelphia (CHOP) and Penn Medicine



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

Funding multiple investigators with an expertise and commitment to FA research creates opportunities to leverage advanced technologies, inspire innovation, and further grow the FA research community.



Since 2014, FARA — in partnership with the Hamilton and Finneran families and the CureFA Foundation — has provided institutional-based research support for the FA Center of Excellence at Penn Medicine / Children's Hospital of Philadelphia (COE). The COE funds basic scientists and clinical researchers who work together to advance the development of effective treatments for FA.

Over the past year, the synergy between 30 clinicians, scientists, lab techs, and trainees across disciplines has resulted in meaningful strides forward in FA research. For example, the basic research programs have provided insights into changes in the cerebellum that suggest a novel therapeutic target, a specific type of glutamate receptor. Work in model systems has also suggested that the immune system may play a role in FA, providing an additional avenue for therapeutic intervention. The labs at Penn have developed sensitive and specific assays for forms of frataxin, as well as assays for metabolites that are altered in FA. These biomarker assays are critical to therapeutic development. Finally, the clinicians at CHOP have made major contributions to the clinical care guidelines for the treatment and management of FA and have participated in the testing of therapeutics in clinical trials.

At the end of 2023, four COE investigators were recommended for funding for approximately \$7M in grants from the Department of Defense's Congressionally Directed Medical Research Programs (CDMRP). This is a great example of how the foundational work supported by FARA attracts significant additional funding to continue to advance these important FA programs.

FRIEDREICH'S ATAXIA ACCELERATOR (FAA)

at the Broad Institute of MIT and Harvard



Led by:
Vamsi Mootha, MD

FAA investigators include:
Anoopum Gupta, MD, PhD
David Liu, PhD
Gary Ruvkun, PhD

Christine Seidman, MD
Jonathan Seidman, PhD

Recognizing the innovative work being done at the Broad Institute, MIT, Harvard, and affiliated institutions, FARA — in collaboration with End FA and the CureFA Foundation — helped establish the Friedreich's Ataxia Accelerator (FAA). Since 2020, this multi-disciplinary effort has aimed at galvanizing research in FA and seeding a growing community to foster breakthrough research.



The FAA consists of over 20 scientists — principal investigators, postdoctoral researchers, as well as graduate and undergraduate students who work on a portfolio of complementary projects that are creating a growing Boston-based community committed to FA research. This portfolio includes gene editing strategies, small molecule drug discovery, frataxin bypass therapeutic approaches, genetic modifier studies, and cardiac research.

The work at the FAA has yielded insights in key research areas for FA in 2023. The Mootha lab has advanced an understanding of the interaction of frataxin function and environmental stressors, while the Ruvkun lab has generated preliminary data on potential mechanisms to bypass frataxin loss. The Liu lab, experts in gene editing approaches, are optimizing this technique for reactivating frataxin expression. Dr. Gupta launched a new project with at-home quantitative motor-phenotyping in FA (wearable sensors). Finally, the Seidmans have brought deep experience and knowledge of cardiomyopathy and how FA is similar to other diseases affecting the heart, and this has the potential to provide the basis for the use of existing heart medications in FA.



COMMUNITY ENGAGEMENT & EDUCATION

The FA community's participation in advocacy, fundraising, and clinical research is key to advancing treatments for FA. In 2023, FARA supported community engagement in several ways.



Fostering Education

FARA hosted five research receptions and symposiums to share information about the FA research pipeline, current clinical trials, clinical management of FA, mental wellness, and more. Over 400 community members attended these events to learn and connect with each other. Virtual education sessions — including Flash Talks and webinars — were also shared throughout the year.



Cultivating Community

In 2023, FARA strove to support the FA community by providing avenues for connection and collaboration. The FARA Ambassador Program, a group of individuals with FA who volunteer to support FARA's mission, grew to 82 members from countries around the world. Ambassadors now represent 12 countries globally, plus 32 states throughout the US.



Engaging With Stakeholders

Through the sharing of lived experiences, members of the FA community raised awareness of FA and provided feedback to different stakeholders including researchers, pharmaceutical partners, and genetic counseling students, at 17 different events. Several pharmaceutical partners working on FA treatments communicated directly with the FA community at webinars and research receptions throughout the year.



Elevating the FA Voice

Individuals and families living with FA provide expert insights necessary to advance meaningful and accessible treatments. This past year, members of the FA community advocated for fair coverage of SKYCLARYS® at five state Medicaid meetings. Individuals with FA and caregivers also provided guidance for the design of a patient preference study, which will investigate the FA community's attitudes towards the risks and benefits of gene therapy.

GRASSROOTS

\$1.5M+ RAISED

Grassroots fundraising has played an integral role in the fulfillment of FARA's mission since the organization's inception and has continued to do so — raising over \$1.5 million for FA research in 2023. One highlight of the 2023 FARA calendar was the Cure FA Soirée, held in Edmond, OK and hosted by the Gehr Family and other area FA families. With over \$400,000 raised, including a generous matching gift, it is the highest grossing grassroots event in FARA's history. The event welcomed over 300 people, including nearly 30 FA families, with dinner by Outback Steakhouse, live performances, speeches, and a silent auction. With so many FA families gathered, it also provided an opportunity for FARA to host a research reception earlier in the day, furthering the organization's mission in ways beyond research dollars. Thank you to all of FARA's volunteer grassroots fundraisers across the country.



2023 Grassroots Campaigns (\$5,000+)

\$400,000+

Cure FA Soirée
Edmond, OK

\$100,000+

Burrows Hill Foundation: Night to Fight FA
Annapolis, MD

Juip Family's Movie Fundraiser for FARA
Livonia, MI

Pull for a Cure
Tampa, FL

Race for Matt & Grace
Providence, RI

Runway to the Cure
Fort Lauderdale, FL

Sweet Caroline's 18
Tuskegee, AL

\$50,000-\$99,999

BBQ Love Fest
Tampa, FL

N.J. Seaside Stride
Seaside Heights, NJ

\$20,000-\$49,999

Fuzzy Buzzy Golf Tournament
Windham, NH

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

University of Southern Indiana v. University of
Evansville Exhibition Baseball Game
Evansville, IN

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

Welsh Bash in the Backyard
Harrisburg, PA

\$10,000-\$19,999

100 Days 'Til Summer
Brighton, MI

Fine Arts for Friedreich's Ataxia
Sioux Falls, SD

GCMS High School Fundraiser
Gibson City, IL

GolfATAXIA
Commerce Charter Township, MI

The Stoneham Open
Portsmouth, NH

Team FARA: Marine Corps Marathon
Washington, DC

Team FARA: Team Alison Price
Wake Forest, NC

Team FARA: Team Full Ascent
Mount Aconcagua, Argentina

\$5,000-\$9,999

The Stacks Family
Cumming, GA

Team Donovan
Westchester, NY

Tee It Up Flower Fundraiser
Marysville, OH

rideATAXIA

rideATAXIA is a nationwide fundraising and community building program that empowers individuals who want to connect and make a difference. In 2023, the rideATAXIA program raised \$1 million through the effort of 1,600 participants, including 93 FA families.



Four signature events were held throughout the US in Gainesville, Chicago, Philadelphia, and Dallas. Each event was filled with uplifting energy and endless team spirit as participants took to the roads and trailways on bikes, trikes, handcycles, or on foot to raise funds for FA research.

What began as a cycling event to support FA research has expanded into a program that offers opportunities for people of all ages and ability levels. Whether you're challenging yourself on a longer route, participating in a walk, or simply enjoying the community-building festivities of the event, rideATAXIA is for everyone.

2023 marked the launch of rideATAXIA Hometown, a new addition to the ride program that offers teammates the opportunity to ride individually or host a rideATAXIA event on a trail in their own neighborhood. This past year, six communities rallied to host trail rides and raise funds in Michigan, Minnesota, Massachusetts, and California. In total, this new initiative welcomed 200 participants who raised \$83,000 in support of FA research. These local events included rideATAXIA staples such as post-ride gatherings with delicious food and opportunities to build new relationships.

Whether you attend one of our signature events or create a Hometown ride in your own neighborhood, we hope to see you at a rideATAXIA event in the near future.

For dates and locations visit rideataxia.org



THE FARA ENERGY BALL



The 15th FARA Energy Ball raised \$2 million, bringing the total raised to over \$20 million since 2009.

The FARA Energy Ball experience continued to live up to its name in a day filled with activities designed to educate, raise funds and awareness for FA research, and celebrate. 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, 500 guests gathered at the Tampa Marriott Water Street for the FARA Energy Ball gala to rock the night away at “A Night at the Grammys.” Wendy Ryan, ABC News Anchor, shined as the evening’s emcee, and the ICON band kept attendees dancing with everyone’s favorite high energy anthems. The live and silent auctions continued to be competitive among guests as they vied for exclusive trips, dining experiences, and memorabilia, and the Tampa Community demonstrated their incredible generosity by contributing \$500,000 to FA research during the Fund a Cure.

A heartfelt thank you to the event founders, The Avery Family, Honorary Energy Ball Chairs, Steve and Janell Griggs, the hardworking planning committee, generous sponsors, auction donors, and all who made the 2023 Energy Ball a success.



FINANCIALS

STATEMENTS OF FINANCIAL POSITION

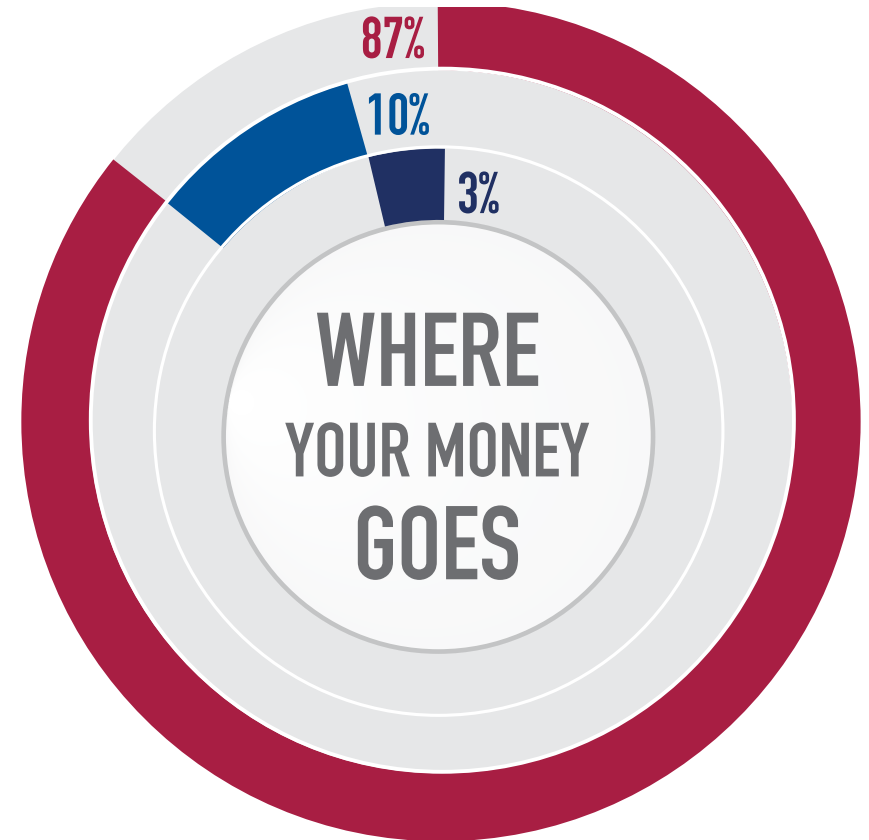
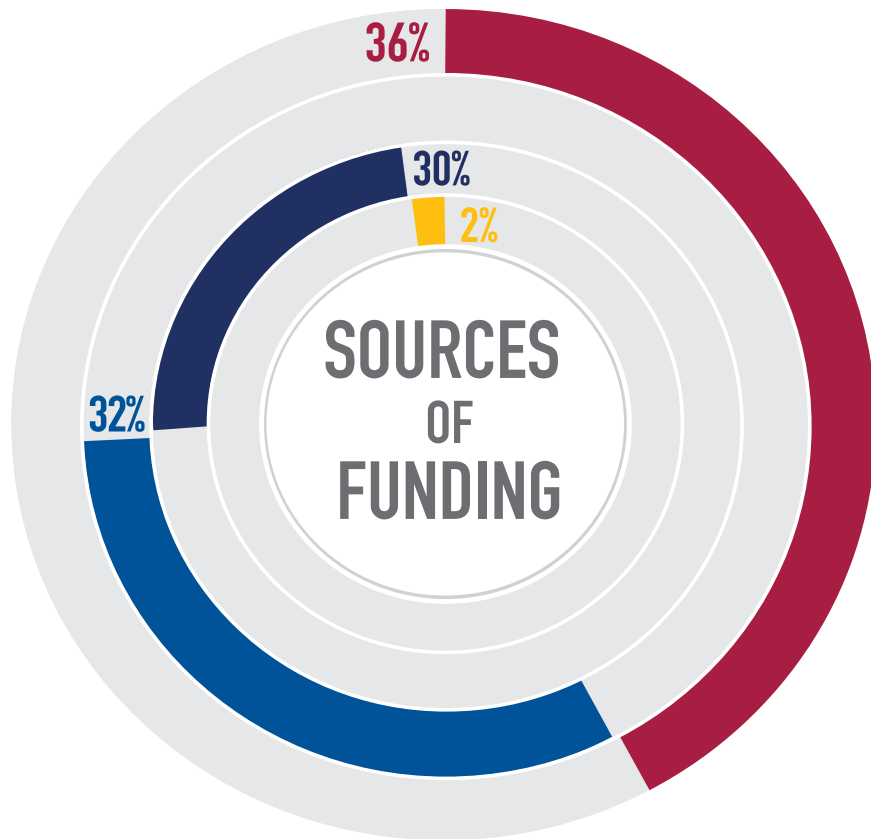
December 31, 2023 and 2022

ASSETS	2023*	2022
CURRENT ASSETS		
Cash & Cash Equivalents	\$3,993,332	\$3,279,967
Restricted Cash	963,779	1,684,153
Contributions Receivable	747,478	369,612
Prepaid Expenses	49,155	52,398
Investments	1,870,166	1,728,750
TOTAL CURRENT ASSETS	7,623,910	7,114,880
OTHER ASSETS	109,254	145,894
TOTAL ASSETS	\$7,733,164	\$7,260,774
LIABILITIES & NET ASSETS	2023	2022
LIABILITIES		
Accounts Payable	\$1,164,034	\$276,962
Deferred Revenues	4,567	11,490
Lease Liabilities	112,047	141,897
TOTAL LIABILITIES	1,280,648	430,349
NET ASSETS		
Without Donor Restrictions	5,488,737	5,146,272
With Donor Restrictions	963,779	1,684,153
TOTAL NET ASSETS	6,452,516	6,830,425
TOTAL LIABILITIES & NET ASSETS	\$7,733,164	\$7,260,774

STATEMENTS OF ACTIVITIES

Years Ended December 31, 2023 and 2022

NET ASSETS WITHOUT DONOR RESTRICTIONS	2023*	2022
REVENUE & SUPPORT		
Contributions, Conferences & Grants	\$4,037,159	\$2,771,949
Special Events & In-kind Contributions	4,804,770	4,850,554
Investment Return	266,862	(270,929)
Net Assets Released from Restrictions	4,294,300	5,285,834
TOTAL REVENUE & SUPPORT	13,403,091	12,637,408
EXPENSES		
Program Services	11,366,576	10,740,547
Fundraising	1,301,838	1,064,618
General & Administrative	392,212	293,984
TOTAL EXPENSES	13,060,626	12,099,149
CHANGE IN NET ASSETS WITHOUT DONOR RESTRICTIONS	342,465	538,259
NET ASSETS WITH DONOR RESTRICTIONS		
Contributions, Conferences, & Grants	3,573,926	4,382,724
Net Assets Released from Restrictions	(4,294,300)	(5,285,834)
CHANGE IN NET ASSETS WITH DONOR RESTRICTIONS	(720,374)	(903,110)
TOTAL NET ASSETS		
CHANGE IN NET ASSETS	(377,909)	(364,851)
NET ASSETS AT BEGINNING OF YEAR	6,830,425	7,195,276
NET ASSETS AT END OF YEAR	\$6,452,516	\$6,830,425



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

- Research & Programs
- Fundraising
- General & Administrative

DONORS & CONTRIBUTORS

\$1 Million+

Anonymous*

CureFA Foundation*

\$250,000-\$499,000

Anonymous

\$100,000-\$249,999

Anonymous

The Avery Family Foundation

Brigid Brennan and Michael Henry

The Burrows Hill Foundation

The Crisp Family Fund

fara Australia (Friedreich Ataxia
Research Association)*

First Light Asset Management LLC

Oak Foundation

The Ritschel Family

The Villages- Richard and Tracy Dadeo

www.TheEventHelper.com

\$50,000-\$99,999

Amalie Oil Company

Dr. Stephen Klasko & Mrs. Colleen Wyse

Lilli and Robbi Friendship Fund, a tribute to Lilli Grenvicz
and Robbi Van Schoick

McDaniel Charitable Foundation

Peace Love & BBQ Inc.

The Brad and Nancy Rex Family

VoLo Foundation

\$25,000-\$49,999

David and Gretchen Anderson

Anonymous

Association Francaise de l'Ataxie de Friedreich (AFAF)*

Ball Horticultural Company – PanAmerican Seed

The Boardman Family Foundation

The Bradley Family

Chris T. Sullivan Foundation

The Doremus Family

Terry and Michele Edmonson

Colin and Jessica Meyer

Odyssey Group Foundation

Race for Matt and Grace

Roger Klauber Family Foundation

Doug and Kathy Rothschild

Jason and Nancy Wilson

You for Two

* Grant Co-Funder

\$15,000-\$24,999

The Bennett Family Foundation
Bir Family Foundation
Paul and Gloria Burke
Dan Kirkland Wells Foundation
DBL Delivery Systems, Inc.
The Gehr Family
Steve and Janell Griggs
Jeffrey Hills
Warren Huff
Kurt and Amy Hull
James and Julie Wooten

\$10,000-\$14,999

The Barnes Family Foundation -
Rob and Shelley Barnes
Ulrich Boser and Nora Gallagher
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