2022 DONOR IMPACT REPORT

FARA Friedreich's Ataxia Research Alliance

BOARD OF DIRECTORS

Dear Friends,

Over the course of 2022, our community achieved several "firsts" that demonstrate progress in our mission to advance treatments for Friedreich's ataxia (FA). Achieving these important milestones would not have been possible without you. Your generous support and engagement in the FA community drives us toward new discoveries and progress in FARA's core programs.

In 2022, Reata Pharmaceuticals submitted the first-ever New Drug Application (NDA) for the treatment of Friedreich's ataxia to the Food and Drug Administration (FDA) and a Marketing Authorization Application (MAA) to the European Medicines Agency (EMA).

Rare Disease Day 2023 marked a pivotal milestone with the FDA's approval of this drug. Reata Pharmaceuticals' Skyclarys™ (omaveloxolone) is the first approved treatment in the United States for patients 16 and older with Friedreich's ataxia. This could not have been accomplished without dedicated support from the FA community. You made this happen, and we couldn't be more grateful.

In addition to the first NDA submission in 2022, there were four other clinical trial firsts. PTC Therapeutics conducted a large late-stage efficacy study of vatiquinone with more than 140 children and adults with FA as well as the first ever supplemental study enrolling very young children <7 years of age. There were three studies representing first-in-human trials of novel therapeutic approaches aimed at the root cause of FA: Larimar Therapeutics' CTI-1601 is targeting frataxin protein replacement, Design Therapeutics' DT-216 is aimed at increasing frataxin, and Weill Cornell and Lexeo Therapeutics launched the first-ever gene replacement clinical trials for cardiac disease in FA. These therapies and others in the pipeline are significant in our quest to develop treatments that can slow, stop, and reverse the progression of FA.

Over 400 individuals participated in FA clinical trials in 2022, which is remarkable and essential to moving research forward. To help our patient community navigate this rapidly developing environment with many clinical trials and studies, FARA developed educational materials with the support of a Pfizer Foundation grant.

For the first time ever, FARA funded more than $9 million in research covering 50 projects. Thanks to your generosity, we've been able to deploy more resources to early-stage research to add new treatment approaches into our pipeline, institutional funding to create centers where

new research breakthroughs can be rapidly translated, and directed projects to support drug development, such as TRACK-FA—a global neuroimaging study.

We also celebrated several firsts due to our advocacy efforts. In October 2022, FARA held a first-of-its-kind meeting with the Office of Tissue and Advanced Therapies division of the FDA. Through collaboration with key researchers, industry partners, and the FDA, we have begun an important conversation on gene therapy for FA including topics such as clinical trial design, measuring efficacy, and patient preference.

Another first was the inclusion of Friedreich's ataxia in the Department of Defense's Congressionally Directed Medical Research Programs (CDMRP) and the funding recommendation for six grants totaling $14M, which was a direct result of our community's legislative advocacy. This designation creates significant additional federal funding opportunities for global FA research.

We are also looking forward to the advancements that will come from the launch of the FA Global Clinical Consortium (FA GCC). The FA GCC brings together international clinical research investigators to make patient contributions to natural history even more powerful in understanding FA and evaluating the impact of treatment options for FA.

These firsts are just the beginning for FARA—in 2023 and beyond, we will be working with a renewed sense of urgency to #SlowStopReverse and #CureFA. With a strong community behind us and a movement that continues to grow, there is no milestone we cannot reach. Thank you.

With our gratitude,

Jennifer Farmer, *Chief Executive Officer*

Ronald J. Bartek, *President*

2022 MILESTONES

FIRST NEW DRUG APPLICATION
for FA submitted to the FDA
(Approved in early 2023!)

FUNDED $9M+ IN RESEARCH
to fuel drug discovery and accelerate therapeutic development

400+ PEOPLE WITH FA
participated in clinical trials

LAUNCHED THE FA GLOBAL CLINICAL CONSORTIUM

CO-HOSTED LARGEST CONFERENCE
for international ataxia research

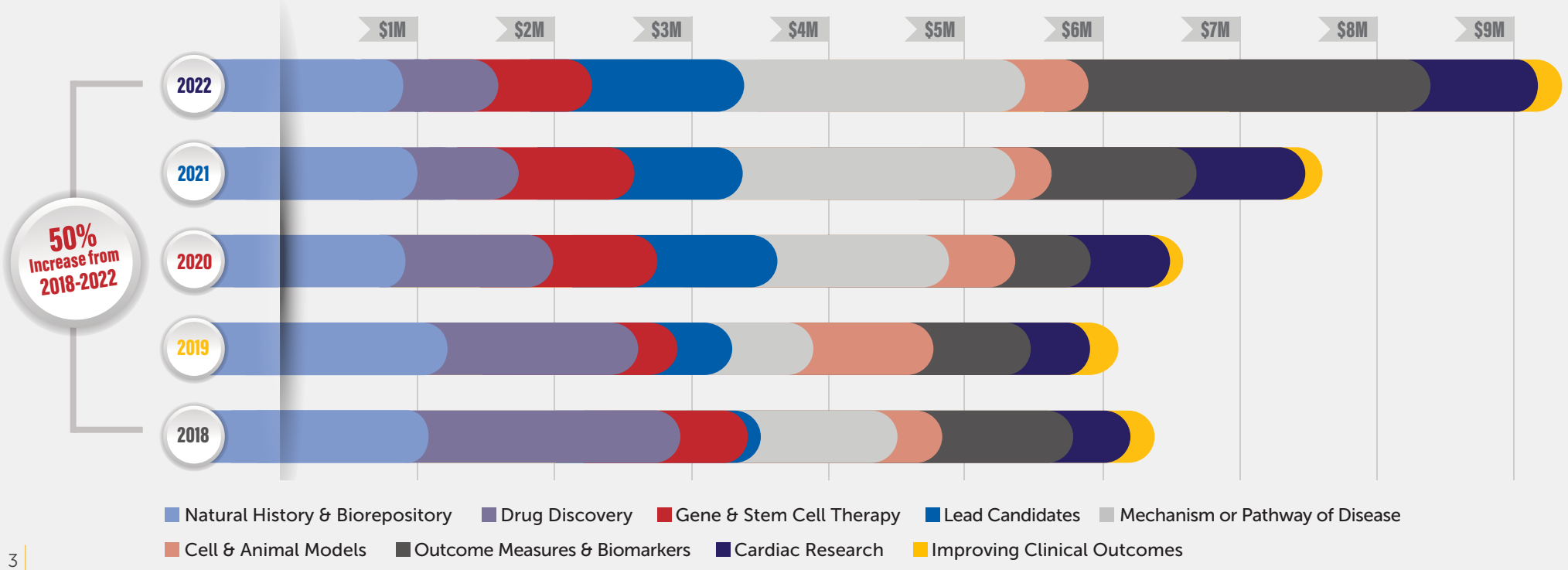
Friedreich's ataxia added to the
CONGRESSIONALLY DIRECTED MEDICAL RESEARCH PROGRAMS (CDMRP)

FIRST GENE THERAPY
clinical trial for cardiac disease in FA initiated

FARA's research funding has grown by 50% over the last five years thanks to your generous support.

One of the ways FARA advances research is by funding a competitive grant program that meets the research priorities set by FARA's Scientific Advisory Board, as outlined in the bar graph below. FARA funds high quality science performed by academic and for-profit investigators alike, and the program aims to provide tools that help advance therapeutic development, insights, and evidence for new treatment approaches.

FUNDED RESEARCH BY STRATEGIC INITIATIVE 2018-2022



FEATURED GENERAL RESEARCH GRANT: How can we accurately measure ataxia in children?

Measuring ataxia in children with the current mFARS rating scale can present challenges because the system that controls movement in children is still maturing. Dr. Louise Corben from Murdoch Children's Research Institute in Australia has developed two devices, the *Cup* and the *Pendant*, that use movement analysis technology to measure arm movement and balance. The hope is that these devices will provide accurate measurements of ataxia in children and will be useful in clinical trials to monitor their response to treatments.

FEATURED AWARD FOR INNOVATIVE MINDSET: How can we measure small (but potentially meaningful) changes in frataxin levels?

Dr. Ankur Jain (above), from the Whitehead Institute for Biomedical Research, and Dr. Ricardo Mouro Pinto, from Harvard Medical School and Massachusetts General Hospital, are adapting an innovative technology that Dr. Jain recently developed for the measurement of frataxin in serum, blood, or tissue extracts. This method uses antibodies to isolate frataxin from the specimen and a special microscope to visualize and count single molecules of frataxin. This assay will allow the detection of a very small amount of frataxin and measurement of even very subtle changes in its level that would be undetectable by conventional methods.

FEATURED YOUNG INVESTIGATORS AWARD: Can we identify AAV vectors that evade immune responses?

Among the young investigators awarded a FARA grant this year, Dr. Changfan Lin at Caltech is developing new Adeno-Associated Virus (AAV) vectors, the leading tools to deliver genetic material to the body for gene therapy. Some of the hurdles of using AAVs to deliver genes like frataxin include the potential for immune reactions to the virus that can lead to poor delivery of the "cargo" and, in some cases, to profoundly serious side effects. Dr. Lin is using a new technology to isolate AAV variants that do not induce immune reactions and engineering them to enter the human brain.

Learn more about all the research grants awarded by FARA at curefa.org/grant-awards. To access scientific publications on FA, many of which report results of research funded by FARA, visit curefa.org/scientific-news.

2022 GRANT PROGRAM

30%	32	20	9	7	$9M+
Increase in Applications	Total # of Grants Awarded	New Grants Awarded	New Investigators	Countries Receiving Funding	Research Funding Awarded

FRIEDREICH'S ATAXIA CENTER OF EXCELLENCE (COE)

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

The Friedreich's Ataxia Center of Excellence (COE) was established in 2014, with a commitment to Children's Hospital of Philadelphia/Penn Medicine, presented by FARA in partnership with the Hamilton and Finneran families/CureFA Foundation. The COE engages in both basic science and clinical research that supports development of effective treatments for FA.

Children's Hospital of Philadelphia
Friedreich's Ataxia Program

Penn
University of Pennsylvania

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
Jennifer Phillips-Cremins, PhD: Genetic Modeling
Rob Wilson, MD, PhD: Drug Discovery

The investigators at the COE at CHOP actively contribute to FA treatment research by publishing their work, training new investigators dedicated to FA research, parlaying FARA funding into larger NIH grants, and serving as the primary site for the FA natural history study.

The collaborative synergy among these researchers enables them to exchange knowledge between basic science and clinical research, and it fosters advancements within and across institutions. Dr. Lynch's work exemplifies how clinical research informs basic science. Based on his observation of metabolic alterations in patients, Dr. Lynch began investigating whether this might be due to dysfunctions of specific enzymes when frataxin levels are low. This research holds promise in uncovering novel therapeutic targets.

Another instance is the Exercise in FA (ExRxFA) clinical trial, supported by the National Institutes of Health (NIH). This trial inspired preclinical studies on muscle and heart by COE collaborators Erin Seifert, PhD at Thomas Jefferson University, and Joseph Baur, PhD at the University of Pennsylvania. With FARA's support, the ExRxFA trial expanded to include the collection of biomarker data, which may be useful in future therapeutic trials.

FARA facilitated a meeting between the COE and the Friedreich Ataxia Accelerator (FAA) at the Broad Institute of MIT and Harvard. This resulted in a collaborative project between Dr. Kimberly Lin from the COE and Dr. Anthony Philippakis from the FAA. Dr. Philippakis will use AI tools to analyze FA cardiac data provided by Dr. Lin, with the goal of identifying early signs of heart stress in FA patients.

MILESTONES

101
Publications

5
New clinical trials in past 3 years

500
Clinical and research visits per year in neurology

30
Clinicians, scientists, lab techs and trainees collaborating

10
Trainees placed in new positions outside CHOP & University of Pennsylvania

FRIEDREICH'S ATAXIA ACCELERATOR (FAA)

at the Broad Institute of MIT and Harvard

The Friedreich's Ataxia Accelerator (FAA) was established in 2020. Funded by FARA, in collaboration with the CureFA Foundation and EndFA, the FAA is a multi-disciplinary effort aimed at galvanizing research into FA and seeding a growing community across the Broad Institute, MIT, Harvard, and affiliated institutions committed to tackling FA.

BROAD INSTITUTE

Led by:
Vamsi Mootha, MD

FAA investigators include:
Anoopum Gupta, MD, PhD
David Liu, PhD
Anthony Philippakis, MD, PhD
Gary Ruvkun, PhD
Christine Seidman, MD
Jonathan Seidman, PhD

In its first three years, the FAA has focused on research initiatives to understand the deep biochemical basis of FA as well as to evaluate the therapeutic potential of new early-stage innovative approaches in animal models. Projects included evaluating hypoxia as a therapy, direct editing of DNA to repair the FA repeat lesion, identifying genetic/chemical modifiers that can bypass the need for frataxin, and understanding the cause of FA cardiomyopathy. This year, the FAA has generated meaningful progress.

Launching Two New Research Projects

One of the projects aims to accelerate advancement of effective treatments by developing at-home assessments of movement and speech. The other project leverages existing large biobanks of genetic sequence data to further understand the prevalence of FA, as well as to potentially uncover novel genetic modifiers of the condition.

Exploring Prime Editing in FA

At the FAA, investments in understanding FA basic and translational biology have already yielded new discoveries, including work described in four new research papers, and have suggested three new therapeutic avenues (with three new patents submitted). In addition, the work from Dr. Liu's laboratory has supported the therapeutic approach of prime editing and brought a new company, Prime Medicine, into the research pipeline. Prime editing is a more exact way to edit or remove the GAA repeat which silences the Frataxin gene.

Expanding the FA Research Community

The FAA has helped grow the field by enabling over 20 researchers across five laboratories to apply their existing expertise toward FA research. Two FAA post-doctoral fellows have moved on to their own independent laboratories where they will continue FA-related research: Tslil Ast, PhD joined the Weizmann Institute of Science in Israel and Mandana Arbab, PhD joined the Boston Children's Hospital Translational Neuroscience Center and Harvard Medical School.

Tslil Ast, PhD

Mandana Arbab, PhD

TRACK-FA is a world-first intensive collaborative effort to track disease progression and address the urgent need for clinical-trial-ready biomarkers. Initiated in 2020, this FARA-sponsored global neuroimaging consortium includes researchers from Australia, USA, Germany, Brazil, and Canada in collaboration with global industry partners.

At the close of 2022, 122 participants with Friedreich's ataxia and 43 matched controls were taking part in this natural history study. With this, TRACK-FA has reached over half of its overall recruitment target. Follow-up study visits are underway, and the earliest participants are starting their third and final study visit for TRACK-FA in early 2023.

By following individuals over three years, TRACK-FA can discover sensitive neuroimaging biomarkers of FA disease progression. The consortium published its first scientific article that presents the background on the TRACK-FA study and the scientific procedures. The publication is open access at: **www.curefa.org/TRACK-FApublication**

CLINICAL MANAGEMENT GUIDELINES

One of FARA's initiatives is to provide access to continuous educational materials for physicians and individuals living with FA. In 2014, FARA facilitated the first comprehensive Clinical Management Guidelines for FA. In 2022, an update was published that considers new evidence and uses a comprehensive new grading system to provide a greater scope of information for patients and physicians, better assisting in the management of FA.

The Clinical Management Guidelines are available online at: **frdaguidelines.org**. The website is organized into topic chapters with lay summaries, best practice statements, links to the evidence, and recommendations for each topic. It also includes three new topic chapters on emergency medicine, digital and assistive technologies, and mental health.

This project, led by Dr. Louise Corben, is the result of the efforts of a 12-person steering committee, 70 expert authors, and an 11-person patient and caregiver panel.

THE FA GLOBAL CLINICAL CONSORTIUM (FA GCC)

THE FA GCC GLOBAL CLINICAL CONSORTIUM

The FA Clinical Outcome Measures Study (FA-COMS) and the European Friedreich's Ataxia Consortium for Translational Studies (EFACTS) are are two well-established natural history studies that have significantly contributed to our understanding of how FA affects individuals. The FA Global Clinical Consortium (FA GCC) will make patients' contributions to natural history even more powerful because FARA has brought together investigators of both FA-COMS and EFACTS to combine efforts into a single global consortium with a unified natural history and clinical research infrastructure.

The FA GCC will enable collaborative global clinical research, accelerate development of new therapies, and improve outcomes for those living with FA. FA-COMS, supported by FARA, has been conducted in the US, Canada, Australia, New Zealand and India. EFACTS has been a natural history study conducted throughout Europe. These studies have been carried out in parallel for over a decade, with many similarities.

A single global study protocol was developed by the FA GCC, called the UNIFAI Study. The UNIFAI Study will continue to improve the panel of outcome measures that can be used in FA clinical trials, with the goal to better organize and harmonize the natural history ecosystem and to allow for a complete view of disease progression of FA.

The FA GCC has combined the existing networks, leveraging current resources and staff. This new structure encourages balanced global interaction and collaboration. The consortium is comprised of a funding board, committees, working groups, a patient advocacy/advisory team and the investigator members of each clinical site; participation includes investigators from 33 sites representing 18 countries.

PARTICIPATING COUNTRIES

Australia
Austria
Brazil
Belgium
Canada
Czech Republic
France
Germany
Greece
India
Ireland
Italy
Netherlands
New Zealand
Spain
Switzerland
United Kingdom
United States

GENE THERAPY MEETING WITH FDA

In October 2022, FARA coordinated a first-of-its-kind meeting with over a dozen pharmaceutical companies and the FDA Office of Tissues and Advanced Therapies (OTAT), the office that directly oversees the safety and efficacy of gene and cell therapy products.

One of the biggest challenges in advancing new therapies for any disease is meeting regulatory requirements, especially when working with new technologies or treatment approaches like genetic therapies. With that in mind, FARA set out to facilitate a meeting to promote knowledge sharing between stakeholders and bring them into better alignment.

The meeting objectives included growing the understanding of FA with the FDA as well as gaining a better insight into the FDA's perspective on issues related to developing genetic therapies for FA. The meeting was attended by 23 FDA regulatory staffers, 30 industry partners, FA patient representatives, and FARA scientific advisors and staff.

The FDA's feedback was valuable on topics such as:

- methods to confirm frataxin levels in target tissues and cells
- ways to demonstrate the efficacy of a treatment in preclinical (animal and cellular) models
- the appropriate length of safety assessments to move a program into the clinic
- an approach to including children with FA in gene therapy clinical trials
- the utility of natural history data in the design of clinical trials

The result was the successful alignment of the FDA, industry partners, and FARA on important and complex aspects of innovative gene therapy development.

> *Profuse gratitude for FARA's stewardship regarding the FDA / Industry interact meeting. From my standpoint, it was a resounding success.*
>
> *- Industry Attendee*



The meeting also created an opportunity for the FDA participants to better understand the patient perspective direct from people living with FA. FARA ambassadors **Jack DeWitt, Alex Fielding, and Shandra Trantham** shared their personal experiences living with FA and discussed patient preferences related to treatments, benefit-risk considerations, and clinical trial experience.

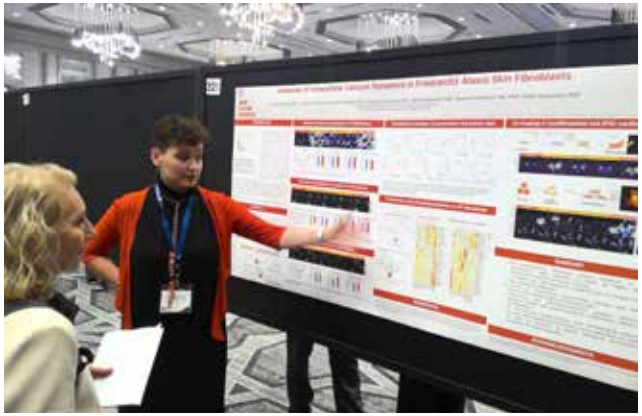
INTERNATIONAL CONGRESS FOR ATAXIA RESEARCH (ICAR)

In November 2022, FARA co-hosted the International Congress for Ataxia Research (ICAR) in partnership with the National Ataxia Foundation and Ataxia UK. Over 450 people from academia, industry, and patient advocacy groups attended. More than one-third of the participants were junior investigators, which supports FARA's goal of bringing new talent to the field and growing the next generation of ataxia researchers. In addition to the opportunity to view nearly 300 presentations, attendees reported making new contacts, which stimulates collaboration and partnerships.

Key takeaways from the meeting included new insights into the disease mechanisms in FA, potential new biomarkers, and the use of digital assessments for ataxia. A patient panel chaired by FARA CEO, Jen Farmer was cited by many attendees as the most impactful portion of the meeting, as it connects the scientific work to the needs of the patients.

300 SCIENTIFIC PRESENTATIONS

450+ PEOPLE ATTENDED



The FA Community's advocacy resulted in milestone accomplishments in 2022.

At the start of the year, FA advocates participated in Rare Disease Week on Capitol Hill. Bonus highlight from the week: Kelly Hennessy, FA community member, was one of ten people selected as a Rare Artist Award Recipient, and her piece *Hope Through Trees* was showcased in the Rare Hub.

Incredible news arrived in March when FARA learned that Friedreich's ataxia was added to the Congressionally Directed Medical Research Programs (CDMRP) making FA researchers eligible for Department of Defense (DoD) grants. The excitement continued when the DoD announced that six FA grants were recommended for funding, totaling over $14 million. This amazing opportunity was a direct result of many dedicated FA champions taking the time to connect with their Congressional Members, explain FA, and request support for FARA's initiatives.

In September, FA advocates were busy with the fourth United Against Ataxia Hill Day. Working in collaboration with the National Ataxia Foundation, 78 Congressional meetings were held with 31 states and DC. The advocates were prepared and passionate, and their voices were heard. They secured bipartisan support for both a Senate National Ataxia Awareness Day Resolution (S.Res 850) and broadened the term to "Hereditary Ataxia" on the CDMRP. Moreover, they joined the call, and later the celebration, to pass the Prescription Drug User Fee Act (PDUFA VII) and the FY23 budget, which included increased funding for federal research agencies. Representatives Rosa DeLauro and Chrissy Houlahan were honored by FARA and NAF as the 2022 Ataxia Research Champions.

Sign up for the advocacy newsletter at curefa.org/advocacy to be a voice for the FA community.

COMMUNITY EDUCATION & ENGAGEMENT

In 2022, FARA continued its commitment to community education and engagement by sharing information about several new and ongoing clinical trials, continuing to grow the FARA Ambassador Program, promoting awareness and disease state education for pharmaceutical and academic partners, and hosting research receptions and symposia for FA families.

Clinical Trials 101: A Guide for Participants

With support from a Pfizer Foundation grant, FARA created a clinical trials guide. This 12-page document contains information on the different phases of clinical trials, terms to know, clinical trial etiquette, safety monitoring, and a guide to informed consent. It is intended to help people understand the drug development process so that they can make informed decisions about participating in clinical trials. A copy of the guide can be downloaded at: curefa.org/trial

Ambassador Program

FARA's Ambassador Program continued to grow in 2022, with more than 80 individuals living with FA from nine different countries serving as advocates for the FA community. Ambassadors participated in clinical trials and educational events, raised awareness about FA to government representatives, and engaged with their local communities to raise funds for research. The ambassadors delivered another successful year of creating social media content, sending notes of appreciation to donors and researchers, public speaking, and hosting virtual hangout groups for adults and teens with FA.

Amplifying the Patient Voice

FARA continued its collaboration with pharmaceutical companies and academic research partners, working to develop new treatments for FA as quickly as possible. Bringing the patient experience and patient voice into this process is essential. In 2022, FARA facilitated fifteen in-person and virtual meetings between people living with FA and pharmaceutical partners, academic labs, and regulatory agencies.

Education Events

FARA hosted four in-person education events throughout the year. Three were Research Receptions- one in Gainesville, FL in collaboration with University of Florida, one in Tampa, FL in partnership with University of South Florida, and one in Addison, TX. FARA also held its annual symposium in collaboration with the FA program at the Center of Excellence at Children's Hospital of Philadelphia (CHOP) in King of Prussia, PA. These events brought together leading researchers, clinicians, and patients to share the latest developments in FA research and clinical care. In addition to presentations on clinical trials and gene therapy, this year's events featured several community-led panels on topics such as advocacy, emotional wellness, and taking control of your care.

FA Woodstock: Thank You for Over a Decade of Family Fun & Contributions to Research!

FA Woodstock was held in July 2022 at Flying H Ranch in Indiana. For the past 11 years, the Hook family—Tom, Paula, and their three daughters, two of whom have FA—have hosted this annual summer retreat for fellow FA families. This past year's gathering featured a t-shirt tie dye station, seated yoga, pool time, and all-you-can-eat ice cream. In addition to this fun in the sun, a notable highlight was the research that took place at the event. The team at the Children's Hospital of Philadelphia (CHOP) gathered research samples from participants—individuals with FA, carriers, and controls—to send to pharmaceutical companies and academic researchers working on FA. Thank you to the Hook family and their friends for hosting this meaningful event, creating lasting memories, and aiding in research.

The 14th FARA Energy Ball raised an incredible $2 million!

Awareness, camaraderie, and fundraising in support of FA research—these are the some of the key aims of the Energy Ball. The day kicked off with with a Research Reception brunch co-hosted by FARA and the University of South Florida. A panel with pharmaceutical company representatives discussed their ongoing clinical trials in FA and how FARA and the community have played a role in advancing them. Then, a panel of patient community members helped the audience better understand the patient perspective, and attendees left with a greater appreciation of their role in propelling research forward.

In the evening, 650 guests gathered in Tampa for the Energy Ball celebration, themed "Saturday Night FARA Fever." Those in attendance were transported back to the 1970s with sparkling disco décor including vinyl records, disco balls, and balloons.

The evening featured several fun and moving moments. ABC News Anchor Wendy Ryan dazzled in her signature role as the event emcee. On behalf of their family and the FA Community, Alison and Laurel Avery recognized Honorary Chairs Steve and Janell Griggs for their years of service with a touching tribute. Guests engaged in friendly competition with the live and silent auction, and the night ended on a high-energy note with a packed dance floor grooving with the sound of Paradigm Party Band.

Thank you to event founders, The Avery Family, the hardworking planning committee, generous sponsors, auction donors, and all who made the 2022 Energy Ball a success.

rideATAXIA POWERED BY FARA Friedreich's Ataxia Research Alliance

RAISED $1.1M+ IN 2022

rideATAXIA is a nationwide cycling program that welcomes people of all abilities to ride and raise funds for FA research. In 2022, the rideATAXIA Program raised $1.1 million over six rides with 1,500 participants, including 94 FA families, 16 researchers, and 12 industry partners

This year was particularly special, as the community was able to reunite in person at every planned rideATAXIA event for the first time since 2019. Those in attendance were able to build new relationships, catch up with old friends, and feel the support of the entire FA community behind them—proving that we are truly stronger together.

With the help of the volunteer planning committees, FARA enhanced the rideATAXIA post-ride celebrations to focus on team building and engagement with features such as lawn games, painting walls, and dessert trucks. These additions amplified the experience for families, who are the core of these rideATAXIA events–both in fundraising and beyond.

FARA was also proud to welcome our pharmaceutical partners and academic researchers at this year's events. rideATAXIA Dallas hosted many international researchers following the International Congress of Ataxia Research (ICAR) which was held locally. It is a powerful experience when FA families and researchers come together to ride as one team to treat and cure FA.

GRASSROOTS $1.5M+ RAISED

Since FARA's founding in 1998, the FA community has fundraised through a variety of grassroots activities and events. These campaigns continued to be integral in advancing FA research in 2022. This success is a credit to the FA community's ability to leverage the diversity of their interests and talents towards our common goal of treatments and cures for FA. This past year, grassroots supporters walked and rolled along the boardwalk at the N.J. Seaside Stride, sang their hearts out at the Cure FA Soirée, ran a marathon through New York City, took in a drive-in movie in Michigan, and much more. FARA is grateful to all of the volunteer grassroots fundraisers and their communities for their enduring dedication to our mission.

2022 Grassroots Campaigns ($5,000+)

$300,000

Pull for a Cure
Tampa, FL

$200,000+

Burrows Hill Foundation: Night to Fight FA
Annapolis, MD

Cure FA Soirée
Edmond, OK

Runway to the Cure
Fort Lauderdale, FL

$100,000+

Juip Family's Movie Fundraiser for FARA
Sterling Heights, MI

Race for Matt & Grace
Providence, RI

Sweet Caroline's Soirée for FA
Tuskegee, AL

$50,000-$99,999

N.J. Seaside Stride
Seaside Heights, NJ

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

$20,000-$49,999

Fuzzy Buzzy Golf Tournament
Windham, NH

Peace, Love, Acceptance and an evening to Cure FA *Branford, CT*

USI v. Kent State Exhibition Baseball Game
Evansville, IN

$10,000-$19,999

PAX River Charity Ryder Cup Golf Days
Patuxent River, MD

Fine Arts for Friedreich's Ataxia
Sioux Falls, SD

Stoneham Open Golf Tournament
Portsmouth, NH

Team FARA: Team Alison Price
Wake Forest, NC

The Lamascus Family
Rancho Cucamonga, CA

The Leonard Family
Virginia Beach, VA

Viv's #FallForFA
Virtual

$5,000-$9,999

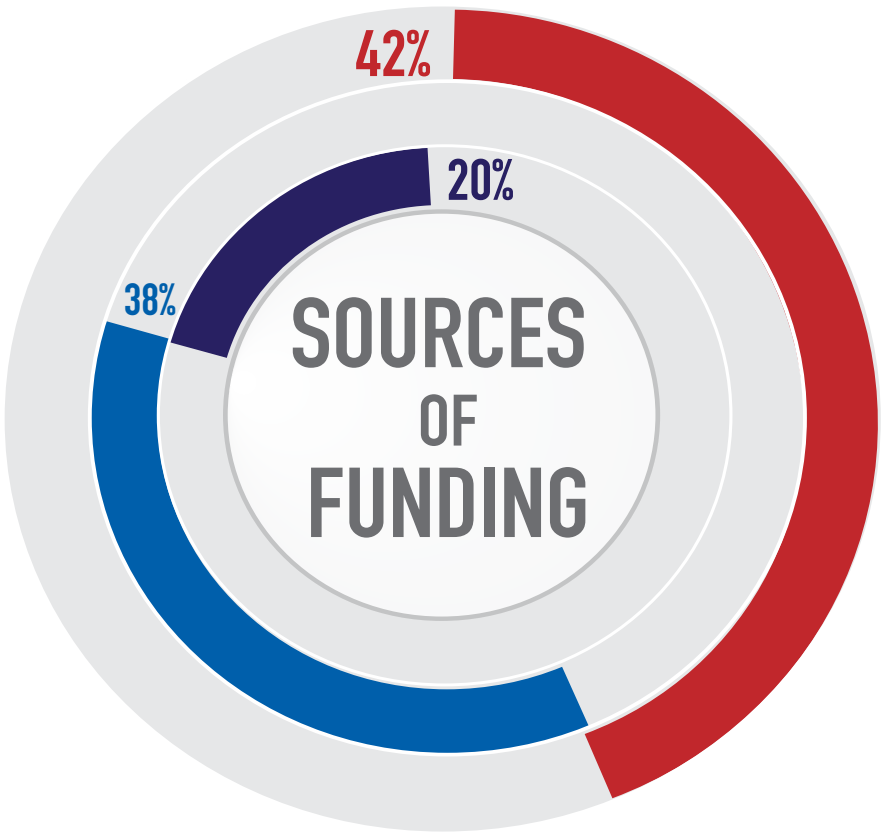
Leroy Garner Charity Shoot
Salinas, CA

Claxton Classic Golf Tournament
Crownsville, MD

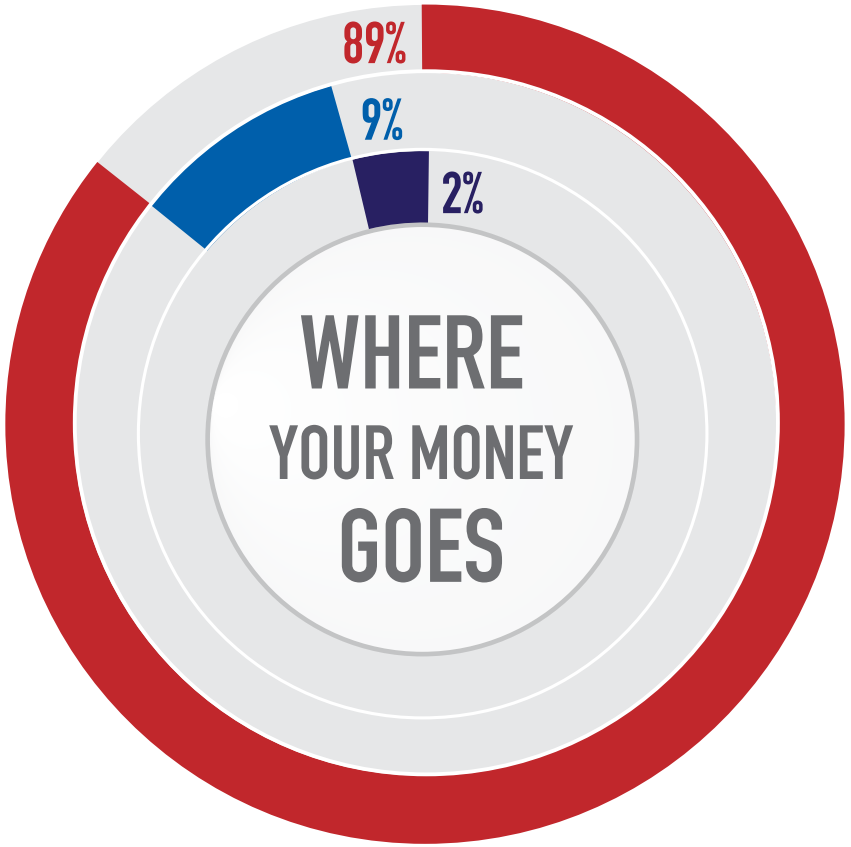
Lend Us Some Muscle
Virtual

Mother's Day 5K for Christina
Richboro, PA

The Stacks Family
Cumming, GA



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



- Research & Programs
- Fundraising
- General & Administrative

STATEMENTS OF FINANCIAL POSITION

December 31, 2022 and 2021

ASSETS	2022	2021
CURRENT ASSETS		
Cash & Cash Equivalents	$3,279,967	$2,555,336
Restricted Cash	1,684,153	2,587,263
Contributions Receivable	369,612	259,819
Prepaid Expenses	52,398	94,042
Investments	1,728,750	1,976,866
TOTAL CURRENT ASSETS	**7,114,880**	**7,473,326**
OTHER ASSETS	145,894	5,458
TOTAL ASSETS	**$7,260,774**	**$7,478,784**

LIABILITIES & NET ASSETS	2022	2021
LIABILITIES		
Accounts Payable	$276,962	$261,148
Deferred Revenues	11,490	22,360
Lease Liabilities	141,897	-
TOTAL LIABILITIES	**430,349**	**283,508**
NET ASSETS		
Without Donor Restrictions	5,146,272	4,608,013
With Donor Restrictions	1,684,153	2,587,263
TOTAL NET ASSETS	**6,830,425**	**7,195,276**
TOTAL LIABILITIES & NET ASSETS	**$7,260,774**	**$7,478,784**

STATEMENTS OF ACTIVITIES

Years Ended December 31, 2022 and 2021

NET ASSETS WITHOUT DONOR RESTRICTIONS	2022	2021
REVENUE & SUPPORT		
Contributions, Conferences & Grants	$2,771,949	$1,715,245
Special Events & In-kind Contributions	4,850,554	4,212,916
Investment Return	(270,929)	189,134
Net Assets Released from Restrictions	5,285,834	4,270,568
TOTAL REVENUE & SUPPORT	**12,637,408**	**10,387,863**
EXPENSES		
Program Services	10,740,547	8,737,439
Fundraising	1,064,618	911,791
General & Administrative	293,984	255,521
TOTAL EXPENSES	**12,099,149**	**9,904,752**
CHANGE IN NET ASSETS WITHOUT DONOR RESTRICTIONS	**538,259**	**483,111**
NET ASSETS WITH DONOR RESTRICTIONS		
Contributions, Conferences, & Grants	4,382,724	2,277,362
Net Assets Released from Restrictions	(5,285,834)	(4,270,568)
CHANGE IN NET ASSETS WITH DONOR RESTRICTIONS	**(903,110)**	**(1,993,206)**
TOTAL NET ASSETS		
CHANGE IN NET ASSETS	(364,851)	(1,510,095)
NET ASSETS AT BEGINNING OF YEAR	7,195,276	8,705,371
NET ASSETS AT END OF YEAR	$6,830,425	$7,195,276

$1 Million+

Anonymous*

$500,000-$999,000

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