



# National Ataxia Foundation

# ANNUAL REPORT



2023



# National Ataxia Foundation

## VISION

A world without Ataxia.

## MISSION

To accelerate the development of treatments and a cure while working to improve the lives of those living with Ataxia.

## CORE VALUES

### CARING

We respect one another and those living with Ataxia.

### MOTIVATED

We use our passion to inspire our community to act NOW!

### COLLABORATIVE

We evolve together and support each other to achieve our mission.

### IMPACTFUL

We listen to our members to build creative, meaningful programs.

### ACCOUNTABLE

We are transparent in our words, actions, and results.

## MEMBERSHIP

We're growing—and together, we're making a difference.



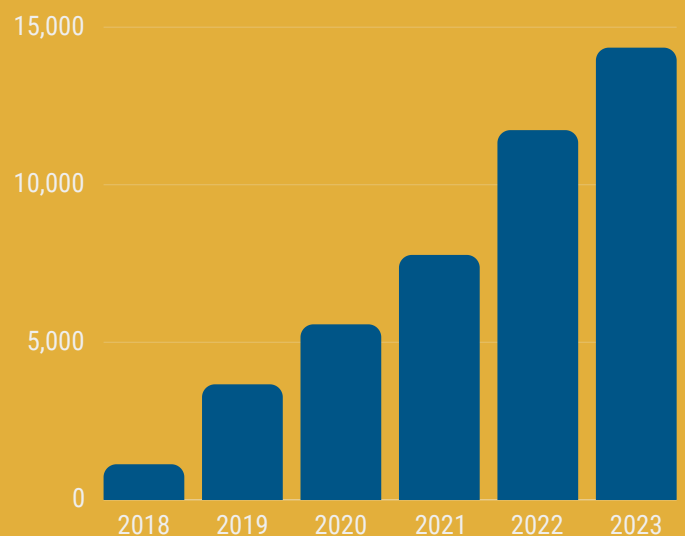
**14,351**

total members



**22%**

growth from 2022



# LETTER FROM ANDREW ROSEN, CHIEF EXECUTIVE OFFICER



I have always thought of my career in 5-year time periods. I try to pause and reflect on what I've accomplished and where my focus needs to be in the next 5-year cycle.

I joined NAF in 2019, and thus 2023 completes my first 5 years. Our organization has grown in so many ways during this time, and it is only because YOU have made it possible. Your generous support year after year allows us to add vital programming and expand our research grantmaking.

Allow me to share some highlights of what your loyal donations have accomplished:

- A staff that has grown from 9 people in 2019 to more than 20 today, including our first two scientific hires
- NAF membership growth from 1,100 to more than 14,300 at the end of 2023
- Pharmaceutical interest in developing treatments for Ataxia continues to grow. Our Drug Development Collaborative remains strong and added two new members this past year. And, of course, the very first treatment for any type of Ataxia was approved in 2023
- Our robust natural history study, the CRC-SCA, has added two new types of Ataxia and MR imaging as a potential biomarker
- We announced our first group of Ataxia Centers of Excellence in 2023—leading integrated Ataxia clinics located around the world
- We expanded our library of Ataxia webinars, both in live and on-demand formats, and our “Ask the Ataxia Expert” series remains very popular
- Our no-cost Genetic Counseling and Testing program continues to grow and has helped close to 400 people to date
- We hosted our first-ever Support Group Leader Summit in 2023 to say thank you and share tips and tricks with this remarkable group of volunteers

I can't wait to see what the next 5 years bring to our community! Please know that NAF is well-positioned to build on opportunities and to continue to make Ataxia attractive for drug developers going forward.

On behalf of our dedicated staff, Board of Directors, and those who benefit from your generosity, thank you for your continued support of our critical work.

With gratitude,

## 2023 AT A GLANCE



**\$2,763,781**

invested in research  
and drug development



**\$1,146,980**

invested in  
community services



**16**

research grants  
awarded



**25**

NAF Ataxia Centers of  
Excellence designated



**136**

support group  
meetings



**86**

meetings with  
members of Congress



**45**

webinars hosted

# COMMUNITY SERVICES

NAF supports those impacted by Ataxia and their families in a number of ways, including education, advocacy, and community events that foster a spirit of connection and learning to live better with Ataxia.

## Support Groups

Across the nation, NAF support groups connect people who have been affected by Ataxia. These groups ensure that nobody has to experience Ataxia alone.



*The Greater Atlanta Area Support Group gathered for their Annual Summer Picnic in June.*



*The April meeting was a special one for the Twin Cities Support Group: it was the first time back in person!*

## 2023 Support Groups by the numbers



63 support groups



136 support group meetings



37 leaders at the first-ever  
Support Group Leader Summit



## Support Groups Added in 2023

- 30-55 Years Old with Ataxia Support Group
- 55+ Years Old with Ataxia Support Group
- Ataxia Resources and Discussion Group
- Colorado Support Group
- Idaho Support Group
- Greater JAX Area Support Group
- Pensacola Support Group

## Support Group Leader Summit

The inaugural event, held in Orlando, FL, was a weekend filled with learning, connecting and collaborating.



Shannon Dunphy-Lazo (St. Louis SG), Karen Russell (Richmond SG), Susan Masse (Connecticut SG), Susan Stiles (Ataxia Resources and Discussion Group) participated in the inaugural Support Group Leader Summit.

“

"My favorite part of the Support Group Leader Summit was finally meeting all my fellow support group leaders and NAF staff in person."

- **Susan Masse**,  
Connecticut Support  
Group Leader

# Meet Shelbi, a Support Group Leader



**One of Shelbi Davenport’s first experiences with the National Ataxia Foundation was impactful, to say the least.**

“I was at my first-ever Ataxia conference, in the ‘Under 30’ Birds of a Feather session, and I saw how the leaders were running the group - they were so great,” Shelbi recalls. “I thought, I have a background in leadership. I’m under 30. I like hosting events on Facebook and meeting new people. So why not lead a support group?”

Shelbi and her co-leader, Evan Gress, created a vision for their group: they wanted to create a safe place for people under 30 to be able to interact with each other, while not solely focusing on Ataxia. “We live with Ataxia every day. And yes, we do talk about nutrition, exercises, and things that help with Ataxia, but I wanted to bring light and fun to the group. I want to get people’s minds off the pain,” Shelbi says.

**“I want to get to know everybody and what they like to do. And if they say, ‘Ataxia is stopping me from doing this,’ then I’m going to say, ‘Hold up. Your Ataxia can’t stop you from doing anything. Let’s find another way to do that.’”**

With Shelbi and Evan leading the group, membership has grown from 50 to more than 250, and more people are joining their bi-weekly virtual meetings, too.

The positive response has been energizing to Shelbi. “I love being able to talk with people, and I also love seeing the interactions between others. They’d never have known each other without this support group,” she says. “That feels rewarding.”

“I want to bring light and fun to the group.”

**- Shelbi Davenport**



*Shelbi, pictured far right, enjoyed meeting new friends at the Annual Ataxia Conference.*

# Annual Ataxia Conference

Each year, we are honored to host the world’s largest gathering of the Ataxia community. In 2023, with sessions held both in person and virtually, we brought together hundreds of people—patients, caregivers, medical professionals, and more—to discuss the latest research, new therapies, caregiving, and many other aspects of living with Ataxia.



Guest speaker and Ataxia advocate Bill Nye—more commonly known as Bill Nye the Science Guy—presented “Breakthroughs in Ataxia Research” which was voted one of the most helpful and exciting sessions.

## Attendee Feedback



rated the experience **very good** or **excellent**



said the content was **very** or **extremely helpful**

## Partnering for Progress 2023 Annual Ataxia Conference



773 attendees



405 first-timers



30 speakers



13 general sessions



5 virtual sessions

*"I enjoyed meeting so many people. It's a wonderful way for people with Ataxia to interact and bond with others who have Ataxia."*



*"The conference was enlightening and helpful."*

*"It was an amazing conference. I'm so glad I attended in person. It had the perfect balance of light-hearted fun, information-packed seminars, networking, and rest time."*



*"It was marvelous to meet so many positive people with the same condition – with its challenges, and yes, opportunities."*



*"My son and I felt extremely welcomed. We are looking forward to next year's conference."*

## Generosity makes it possible

In 2023, we were able to award more conference grants and scholarships than ever before.



46 travel grants,  
totaling \$37,950



36 virtual scholarships,  
totaling \$2,700





Birds of a Feather breakout sessions, where clinicians facilitate small group discussions among people with the same Ataxia type, remain a conference highlight for many.

## An Immediate Connection

Before attending the NAF Conference, Kristy Taylor and Pamela Kahn had met virtually through Ataxia-related social media groups. But it was a special moment when the two women met in person at the conference.

“When you have a rare disease, you spend so much time and energy explaining everything to people. With a rare disease like Ataxia, it’s rare to meet someone who totally just gets you and knows what you’re going through,” Kristy said.

“Social media helps with that,” she continued. **“But meeting those people in person? Your heart explodes.”**

“It’s always nice to put a face to a name you only know via social media and Zoom,” Pamela echoed. “When I met Kristy in person, **I felt like we already had a great understanding of each other living in our rare world of Ataxia.**”

“We had loads of fun together on the dance floor,” Pamela said. “I just loved that because I knew then that she lives in the moment as much as possible, much like myself!”



*Pamela Kahn, pictured left, and Kristy Taylor, right, met in person for the first time at the conference.*

# ADVOCACY

**At NAF, we are passionate about advocating for those with Ataxia. We provide community members with opportunities to get involved, expand partnerships with other organizations, and help policy makers and pharmaceutical companies understand Ataxia. In this way, we grow awareness, accelerate drug development, and ensure access to care and treatment services.**

## Ataxia Hill Day

On September 20, 164 Ataxia advocates from 33 states met with Congressional leaders to urge action in funding research programs and expediting treatments. Ataxia Hill Day was a strategic joint effort of NAF and Friedreich's Ataxia Research Alliance (FARA) to influence public policy by directly engaging with policymakers in the nation's capital.

Prior to meeting with their legislator, these advocates were offered training opportunities that including meeting with other advocates to practice sharing their stories about their own Ataxia experiences and how they would ask for support of specific legislation.

Together, they helped raise awareness about the journey of being diagnosed, living with Ataxia, and the search for treatment. Thanks to their courage, our representatives will think of them and their stories when considering future legislation that could impact the entire Ataxia community.



Over the course of 86 Zoom meetings, many NAF members spoke about their Ataxia experiences with many representatives, including Senator Tammy Baldwin from Wisconsin, shown in the lower left.

# Meet Mary & Mark, Hill Day 2023 Advocates

“It was exciting to speak directly with our legislators and their staffers. The responses were positive and encouraging.

The legislators were very interested to hear our personal stories of living with Ataxia, and seemed willing to support our requests.

It is rewarding to see that these efforts have had positive results– and I’m hopeful they will continue to!”



– **Mary Choi Smith**,  
NAF member

“As a PR person in Washington, DC, I’ve been to these advocacy events before. I have a good idea of how they typically go and what to expect. But, those previous events were for my job.

This time, I was talking directly to my elected official about something I cared about personally.

Joined by fellow advocates who shared a common goal, we formed a strong and united front. Together, we amplified the urgency of finding effective treatments and ultimately a cure for Ataxia.”



– **Mark Hazlin**,  
NAF board member

# Advocacy Opens Doors to Ataxia Research Grants

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Since 1992, the Congressionally Directed Medical Research Programs (CDMRP) has funded medical research programs that address the health care needs of military service members, veterans, and the general public. Each year, hundreds of millions of dollars are awarded to researchers who are leading scientific advancements in their respective areas of study.

However, because Ataxia was not included in the list of qualifying medical conditions, Ataxia research was not eligible for funding.

**Thanks to the hard work and passion of many, that began to change just a few years ago.**

Courageous advocates worked with NAF and the Friedreich's Ataxia Research Alliance and successfully campaigned for Hereditary Ataxia to be added to the list of eligible conditions. We're so proud of the incredible progress we've made together since!

# A Path of Progress



*That's nearly  
\$25 million for  
Ataxia research grants  
in less than 2 years!*



## Congratulations to the FY23 CDMRP Awarded Grantees

### **4 Pioneer Awards totaling \$1,232,678**

- Yuho Kim, University of Massachusetts, Lowell
- Joan O'Keefe, Rush University Medical Center
- Yina Dong, The Children's Hospital of Philadelphia, Pennsylvania
- Shiang Lim, St. Vincent's Institute of Medical Research, Australia

### **3 Investigator-Initiated Research Awards totaling \$9,241,805**

- The Children's Hospital of Philadelphia, David Lynch\*
- The Children's Hospital of Philadelphia, Donald Joseph
- The Children's Hospital of Philadelphia, Liming Pei
- The Children's Hospital of Philadelphia, Robert Wilson\*
- University of Florida, Eric Wang
- University of Florida, Laura Ranum\*
- University of Florida, Monica Banez-Coronel

*\* serves as NAF Medical and Research Advisory Board Member*

# RESEARCH

NAF supports Ataxia research in a variety of ways, including direct funding, drug development collaboration, education for neurologists, and providing professional networking opportunities for researchers and clinicians.

## Research Grants

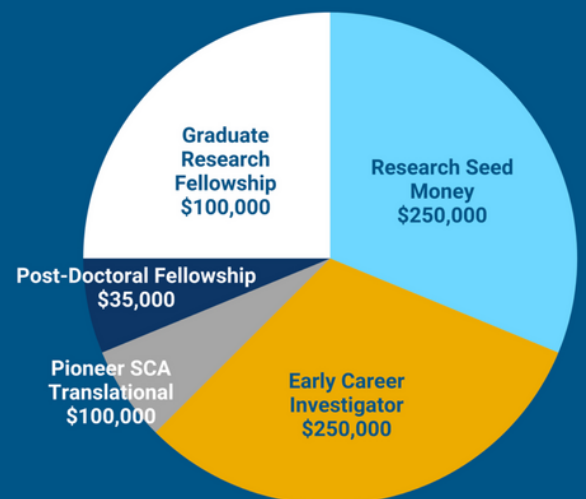
Thanks to the generosity of our donors, we were able to fund 16 research grants totaling \$735,000.

We received more than 112 letters of intent and 65 completed applications for research grants this year. There were many proposed studies with high scientific merit and it was thrilling to see so much energy dedicated to accelerating the treatment of Ataxia!

Ultimately, 16 projects were chosen for funding. Their research will span more than 10 genetic forms of Ataxia—from the most common to some of the rarest—as well as address shared disease pathways that could provide insights into all of the Ataxias.



### 2023 Grant Breakdown



# Natural History Study

Composed of the country's top Ataxia experts, the Clinical Research Consortium for the Study of Cerebellar Ataxia (CRC-SCA) is closely working together to better understand the disease process and identify standards of care for those with Ataxia. As part of their work, they conduct an ongoing natural history study to better understand how the disease progresses over time. These kinds of studies are essential for scientists designing clinical trials because it allows them to prove the impact of the treatment vs. a natural, no-treatment alternative.

We are grateful for those who participate in this study and give of themselves so researchers have robust natural history and biomarker development data as they develop new therapies.

*These samples are critical to understanding the disease process, identifying novel biomarkers, and designing clinical trials. Thank you for your participation!*

## Natural History 2023 Numbers



963 participants



89 new participants



327 clinical assessments



*Each year, members of the CRC-SCA meet in person at the Katie Campbell Clinical Trial Readiness Conference to discuss the latest Ataxia research and discoveries with each other.*

# A Heartfelt Thank You to Dr. Tee



**When Dr. Tetsuo Ashizawa—more commonly known as Dr. Tee—moved to the United States for his residency, his first career path was ill-fated, which ended up being a gift to the Ataxia community.**

After years of research on myasthenia gravis and Huntington’s, Dr. Tee saw opportunities to participate in the expanding field of Ataxia research in the 1990’s. Soon after, he became one of the founding members of the CRC-SCA. In addition, he served on multiple grant review panels, including NIH study sections, and on multiple scientific advisory boards. Over his career, he published more than 200 peer-reviewed original papers on basic and clinical research and led international Ataxia clinical research projects, such as NIH-funded READISCA.

Yet, when reflecting on his internationally acclaimed career, Dr. Tee muses he was never motivated by seeing his name on a paper or in a journal. “The impact on the research field is important—publishing in journals like *Nature* and *Science* is important and indicates the quality of the work you’ve done—but that shouldn’t be your goal,” he explains.

“Your goal should be to find a solution to the problems your patients and their families have. Academic triumphs will come as a result of such efforts.”

**NAF is grateful for the incredible work and legacy that Dr. Tee left behind when he officially retired at the end of 2023. His work has touched countless lives and we are indebted to his commitment to the understanding of Ataxia.**

“Your goal should be to find a solution to the problems your patients and their families have.”

- Dr. Tee





# Leaving a Legacy to Advance Ataxia Research: Brain Donation

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**We are deeply grateful to the 70 individuals who pledged this year to become future brain donors in the fight against Ataxia.**

Today, more than 200 people have signed up to donate their brains to furthering Ataxia research upon their passing. Many of our brain donors and their families now feel empowered, knowing they will, one day, provide researchers with an opportunity to better understand, treat, and ultimately cure Ataxia.



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*“As my husband’s health declined, my stepson requested that when the time came, I donate my husband’s brain for Ataxia research. Having worked for many years at a medical school, I understood that such a donation would be invaluable to researching such a terrible disease. I was glad to make such a donation to further the understanding of Ataxia.”*

*– Betty, NAF member*

# Ataxia Centers of Excellence

In 2023, we were thrilled to launch a new way to help connect patients with experts who provide quality care for those with Ataxia.

**NAF's Ataxia Centers of Excellence, also known as ACE, now offer an easy way to recognize exceptional medical centers that provide comprehensive care and services to individuals affected by Ataxia and their families.**

In addition to providing quality care for a variety of Ataxias and Ataxia-related disorders, these centers are also engaged in clinical research and/or clinical trials, provide education to patients and their families, and work with NAF in our efforts to continually improve the lives of those affected by Ataxia.



*Team members at Columbia University Medical Center stand in front of a plaque that shows their designation as an Ataxia Center of Excellence.*



## 2023 Designations

We were pleased to welcome our first-ever Ataxia Centers of Excellence. We thank them for their exemplary commitment to caring for those with Ataxia.

### USA

#### Alabama

- University of Alabama at Birmingham

#### Arizona

- Muhammad Ali Parkinson's Center at Barrow Neurological Institute

#### California

- UCLA Ataxia Center
- UCSF Ataxia Clinic

#### Florida

- University of Florida
- University of South Florida Ataxia Research Center

#### Georgia

- Emory University

#### Illinois

- Northwestern Memorial Hospital
- Rush University Medical Center
- University of Chicago Ataxia Center

#### Maryland

- Johns Hopkins Ataxia Clinic

#### Massachusetts

- Massachusetts General Hospital Ataxia Center

#### Michigan

- University of Michigan Multidisciplinary Ataxia Clinic

#### New York

- Neurological Institute at Columbia University Medical Center

#### Texas

- Houston Methodist Neurological Institute
- University of Texas Southwestern Medical Center

#### Washington

- Swedish Movement Disorders Clinic
- University of Washington Medical Center Neurogenetics Clinic

### INTERNATIONAL

#### Australia

- Royal Victorian Eye and Ear Hospital's Ataxia Clinic
- MJD Foundation

#### Canada

- Université de Montréal

#### Germany

- University Hospital Bonn/German Center for Neurodegenerative Diseases

#### Peru

- Neurogenetics Research Center at Instituto Nacional de Ciencias Neurológicas

#### United Kingdom

- The Ataxia Center London

# Bringing Ataxia to Center Stage

As part of the criteria to become an Ataxia Center of Excellence, organizations are required to share how they provide support to those with Ataxia.

For Columbia University Medical Center, that part of the application was straight-forward. In addition to participating in Walk N' Rolls and offering Ataxia-specific resources on physical therapy, clinical trials, and more, Dr. Sheng-Han Kuo and the Cerebellar Ataxia team at Columbia University had created a nonprofit called Broadway for Ataxia.

This unique program offers group and one-on-one workshops in acting, singing, and dancing based on neurocognitive neuro-rehabilitation principles.

**“This program is great because it utilizes the talents of the Broadway community to create magical experiences for people living with Ataxia,” Dr. Kuo shares. “People with Ataxia are entitled to fun, joy, and inspiration.”**

“People with Ataxia are entitled to fun, joy, and inspiration.”

- Dr. Kuo



*The Neurological Institute at Columbia University Medical Center was recognized as an Ataxia Center of Excellence in 2023.*

# Ataxia Education

## Webinars

In 2023, more than 6,000 attended our 45 webinars.



**1,322**

attended the **“Ask the Ataxia Expert”** sessions with Dr. Susan Perlman from UCLA



**351**

attended **“Visual Symptoms & Treatments for Ataxia”** led by Dr. Ali Hamedani from University of Pennsylvania



**145**

attended **“Low-cost to No-cost: Everyday Products for Accessible Living”** led by Kate Leader and Liam Dougherty from Day Undefined

## All About Ataxia

With more than 100 types of Ataxia, it's not surprising that each sub-type has specific characteristics and challenges.

To help address those unique concerns, we launched a webinar series that focuses on clinical care and research for specific types of Ataxia.

Each month, we offer two webinars, each focused on the same sub-type of Ataxia. In the first webinar, we discuss all things related to that type, and in the second session, we share research and treatment development options for that specific Ataxia.



### Series Highlights

- 10** types of Ataxia addressed in 2023
- 20** webinars hosted
- 2,682** total attendees

# PrepRARE: Getting “Clinical Trial Ready”



## Series Highlights

7 webinars hosted

747 attendees

4 articles published  
on our blog

Joining a clinical trial is a personal decision, yet there is an urgent need for members of the Ataxia community to be ready to join a clinical trial because many therapies are currently being developed and need to be tested before they enter the market.

That’s why we developed PrepRARE—an educational series to help people understand the clinical trial process so they can be ready to join if the trial is right for them.

## Drug Development Collaborative

For the last three years, a select group of pharmaceutical companies have collaborated with NAF to further therapy development.

The NAF Drug Development Collaborative provides a centralized source of Ataxia expertise, patient registry and natural history data, and a collection of biospecimens to support clinical research and development.

Members of the Drug Development Collaborative financially support NAF, and the revenue generated from their membership supports the work of the CRC-SCA Natural History Study, clinic visits, and our free genetic counseling program.

**NAF is grateful for our members who work tirelessly to develop therapies for Ataxia. Thank you!**



# Ataxia Clinical Training

After the resounding success of last year's workshop, we once again offered Ataxia Clinical Training, a unique two-day program for medical fellows to acquire practical knowledge about the diagnostic investigation and treatment of the Ataxia.

**This year, 35 participants received specialized training in assessing and treating Ataxia.**



*Ataxia Clinical Training allows for interactions between medical fellows and patients who are affected by a wide spectrum of Ataxic disorders. This creates a unique and memorable offering that truly brings the disease to life.*



“Engaging in the Ataxia Clinical Training program has not only deepened my understanding of Ataxia but has also allowed me to connect intimately with patients facing this condition.”

**— Ignacio Keller Sarmiento, MD,**  
Northwestern University  
Feinberg School of  
Medicine

# COMMUNITY FUNDRAISING

NAF has been the grateful recipient of community fundraisers for decades. These volunteer-led events have spread the word about Ataxia, raised money to support our work, and made sure that no one has to fight Ataxia alone.

## Walk N' Roll to Cure Ataxia

1,499 donors in 17 cities raised \$239,297

The ultimate finish line at these walks is when we find a cure for Ataxia. Until that day, we're grateful for the thousands of people who turn out each year to walk or roll through their neighborhoods to raise awareness and funds in support of our mission.



Treasure Coast, Florida





## 2023 Walk N' Roll Event Hosts

- Atlanta
- Central Ohio
- Central Pennsylvania
- Chicago
- Hampton Roads
- Kansas City
- Las Vegas
- Massachusetts
- Lower Michigan
- Minnesota
- Orange County
- Pittsburgh
- San Diego
- Sioux Empire
- Treasure Coast
- Tri-State
- Washington



*Treasure Coast, Florida*



*Boston, Massachusetts*



*Sioux Empire, South Dakota*

# Passion Fundraising

19 passion fundraisers led efforts to raise \$195,699 through 947 donations

In 2023, our development team partnered with nearly 20 creative and compassionate benefactors who wanted to support the Ataxia community while hosting unique and fun-filled events.



The first "Chuck & Duck" dodgeball tournament was held at Burnt Hills-Ballston Lake Central School District in Ballston Lake, NY in 2010. Over the years, participants have raised more than \$47,000 for Ataxia research – including \$7,600 in 2023.



Each year, Cameron Cobb's family chooses a community-based event to raise money for Ataxia research in Cam's honor. In 2023, Cameron's Call for a Cure was a movie night at River Run Park in Naperville, IL that raised \$8,200.



## 2023 Passion Fundraisers

- Artisans for Ataxia
- Bowl for a Cure
- Cam's Call
- Chuck & Duck
- Climbing Kili for a Cure
- Destroyer Golf
- Georgia Stand Up to Ataxia
- Hike for Mike
- Houston Stand Up to Ataxia
- Las Vegas Epic Game Night
- Leroy Bader
- Massachusetts Stand Up to Ataxia
- Otem's Ride
- Raj Art Auction
- Ride for a Cure
- Saddle Up
- Minnesota Stand Up to Ataxia
- Tackle Ataxia
- Tea Time



## Meet Andrew, a 13 year-old fundraiser

**Andrew Flower, who organized a bowling fundraising event, was one of NAF's youngest passion fundraisers in 2023.**

In the Jewish faith, a Bar Mitzvah is a ceremony that marks the coming of age for a young man. As part of this celebration, the honoree is encouraged to take on a mitzvah project—an opportunity to promote kindness, community service, or charitable work.

When Andrew Flower was preparing for his Bar Mitzvah, the inspiration for his mitzvah project was close to his heart. “I wanted to do something to help my dad,” he explains simply. “My dad suffers from Ataxia and I wanted to do something that would help raise money for more research.”

“I thought it would be fun to do a bowl-a-thon to raise money.” Andrew set about planning the event and inviting his friends and his parents’ friends to the event. With his mom’s help, they created an event on Facebook so family and friends near and far could donate, even if they couldn’t attend the bowl-a-thon in person.

“This was a great way to raise awareness and funds for Ataxia. The bowling alley even helped by announcing it while we were there. It was a great event,” Andrew said.

**By the time the last pin fell, Andrew had received \$2,690 in donations in honor of his dad, Scott Flower, to support the National Ataxia Foundation.**



“My dad has Ataxia and I wanted to do something that would help raise money for more research.”  
- **Andrew Flower**

*Andrew Flower, second from left, is all smiles as he stands with friends at his bowl-a-thon in Winter Garden, FL.*

# Meet Mike, a Green Beret turned Ataxia Advocate



**Mike De Rosa, a 23-year Green Beret Special Forces veteran, was diagnosed with Spinocerebellar Ataxia in 2013.**

For years, Mike worked to raise awareness of Ataxia by competing in the Bataan Memorial Death March, a 26.2 mile hike through the New Mexico desert.

**Yet ten years after his diagnosis, Mike literally took his efforts to spread awareness about Ataxia to the next level by climbing one of the world’s tallest mountains.**

“Since being diagnosed with SCA, my focus has been to spread awareness about the disease and help raise funds for Ataxia research,” Mike explains. “My hope is that by raising awareness and collecting donations, I can help further the development of treatments and a cure while also working to improve the lives of those living with Ataxia today.”

After months of rigorous training and gathering donations, Mike hiked Mt. Kilimanjaro in Tanzania in November 2023.

**When he reached the summit, he was able to celebrate an inspiring lifetime accomplishment—and the feat of raising more than \$50,000 for Ataxia research in the process.**

“My focus has been to spread awareness about the disease and help raise funds for Ataxia research.”

**- Mike De Rosa**



*Mike and the rest of his hiking group posed with a NAF banner at the summit of Mt Kilimanjaro.*

# REVENUE & PHILANTHROPY

National Ataxia Foundation is a philanthropically funded organization, which means everything we do is because of the generous support from our donors. We're so grateful.

## Thanks to Donors

We are deeply grateful for the generosity of our individual donors who fund everything from research and treatment development initiatives to supporting our Ataxia community.



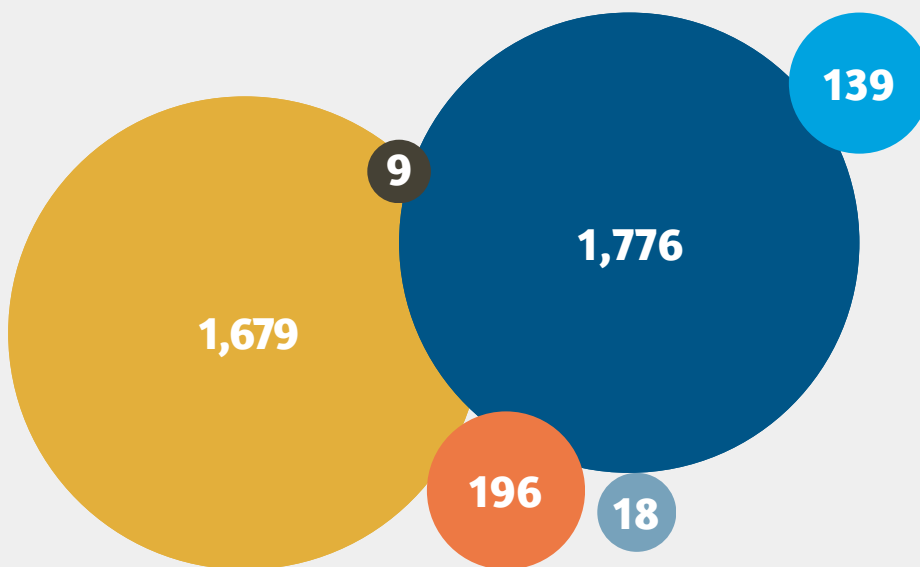
**3,817**  
people donated



**\$1,620,934**  
total amount donated

### Number of Donations by Gift Amount

- \$1 to \$99
- \$100 to \$499
- \$500 to \$999
- \$1,000 to \$4,999
- \$5,000 to \$9,999
- \$10,000+



# Corporate Partners

We thank our corporate partners for their generous support.

## \$25,000+

Arrowhead Pharmaceuticals  
Biohaven Pharmaceuticals  
Google Inc.  
PTC Therapeutics  
Reata Pharmaceuticals Inc.  
Servier Pharmaceuticals  
Solaxa Pharmaceuticals  
Vico Therapeutics B.V.

## \$10,000 to \$24,999

Epic Games  
Lacerta Therapeutics  
Microsoft

## \$5,000 to \$9,999

Insperty Services, LP  
Torres Electrical Supply Co, Inc.

## \$2,500 to \$4,999

Destroyer Park Golf  
Los Alamos National Security LLC  
Natural Twenty Games, LLC

## \$1,000 to \$2,499

Artisan Partners Limited Partnership

The Boeing Company  
Coastal Ridge  
Comedy for Cash Fundraising  
Construction General Laborers & Mtrl  
Handlers  
Cruisin Cajun Country, Inc.  
Garris Evans Lumber Co.  
Hunt & Viveiros, LLC  
Perry's Ice Cream Company, Inc  
Thrivent Choice  
Wells Fargo Clearing Services, LLC

# Foundations

We thank the following foundations for their support and commitment to our mission.

## \$100,000+

Cossack Family Foundation  
The Gordon and Marilyn Macklin  
Foundation

## \$25,000+

The Clementz Foundation  
Once Upon a Time Foundation  
Bob & Cappa Woodward Charitable Fund

## \$10,000 to \$24,999

Big Hug Charity  
Everence Foundation Inc  
Miner Anderson Family Foundation  
Don and Jodi Heeringa Family Fund of  
the Community Foundation of the  
Holland/Zeeland Area

## \$5,000 to \$9,999

Karen Brown & Michael Peffer Giving  
Fund  
Fugate Family Fund of the Greater KC  
Community Foundation

Global Genes  
David McCormick Family Charitable Fund  
Brett and Melody McKay Charitable Giving  
Fund  
National Christian Foundation Houston  
The Susan Scott Foundation

## \$2,500 to \$4,999

Burnt Hills - Ballston Lake School District  
Community Health Charities  
Cybergrants 3M Foundation  
Goldstein/Garfinkel Family Charitable  
Fund  
R Johnson Fund  
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Renaissance Charitable Foundation  
Mike and Toni Rosen Family Fund of the  
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## \$1,000 to \$2,499

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Chip & Susan Carlisle Charitable Fund  
Ted & Debra Durdel Charitable Fund  
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The Saint Paul Foundation  
Special Forces Association - Sandhill  
Chapter 62  
Special Forces Charitable Trust  
Tom & Deb Swenson Foundation  
United Mine Workers of America  
The U.S. Charitable Gift Trust

# Community Giving Platforms

While we do not receive individual donor information from third-party giving platforms, we want to acknowledge this generosity. We are appreciative of the donations from the following community giving platforms.

## \$25,000+

Benevity Community Fund  
Facebook Fundraisers  
Fidelity Charitable  
Raymond James Charitable  
Schwab Charitable

## \$10,000 to \$24,999

Paypal Giving Fund  
Morgan Stanley Gift Fund  
National Financial Services, LLC

TD Ameritrade Clearing  
Vanguard Corporation

## \$5,000 to \$9,999

Amazon Smile Shopping program  
Johnson & Johnson  
JPMorgan Chase  
Lincoln Financial Foundation Inc.  
Network for Good

## \$2,500 to \$4,999

American Endowment Foundation

Ameriprise Financial  
Edward Jones Charitable Gift Fund  
Farm Bureau Insurance  
PSEG Foundation  
YourCause

## \$1,000 to \$2,499

Bank of America Employee Giving Campaign  
Charities Aid Foundation of America  
Enterprise Holdings Foundation  
Federal Home Loan Bank of Pittsburgh

# Individuals

We are humbled by our generous donors who supported the National Ataxia Foundation in 2023. Their generosity ensures that NAF can continue to accelerate the development of treatments and a cure while working to improve the lives of those living with Ataxia.

## \$25,000+

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William and Martha Elliott Estate  
Jim Keene  
Gregory Klassen  
Marcia Neugebauer  
John Patterson Estate  
John & Kathleen Schnobrich

## \$10,000 to \$24,999

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Michael & Patricia Brennan  
Marjorie Clay  
Wendy & Richard Clemens  
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Nancy Haugen  
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Marcia Stewart  
Karen Suchomel

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## Why They Give

*"I support NAF because I've had an Ataxia of unknown type for 13 years and the NAF support groups have been important to my mental health."*  
— Don

*"My adult son has Ataxia. I support research because I want to give hope to all dealing with Ataxia."*  
— Jenean

## Impact Partners

**Impact Partners are a passionate and determined group of monthly givers who are on a mission to find a cure for Ataxia in our lifetime.**



**103**

monthly donors



**\$35,334**

donated in 2023



# Working Towards a Cure

## Support and Revenue

- Contributions: \$3,205,136
- Research Collaborative: \$570,833
- Conference Income: \$264,816
- Other Income: \$144,002

## Expenses

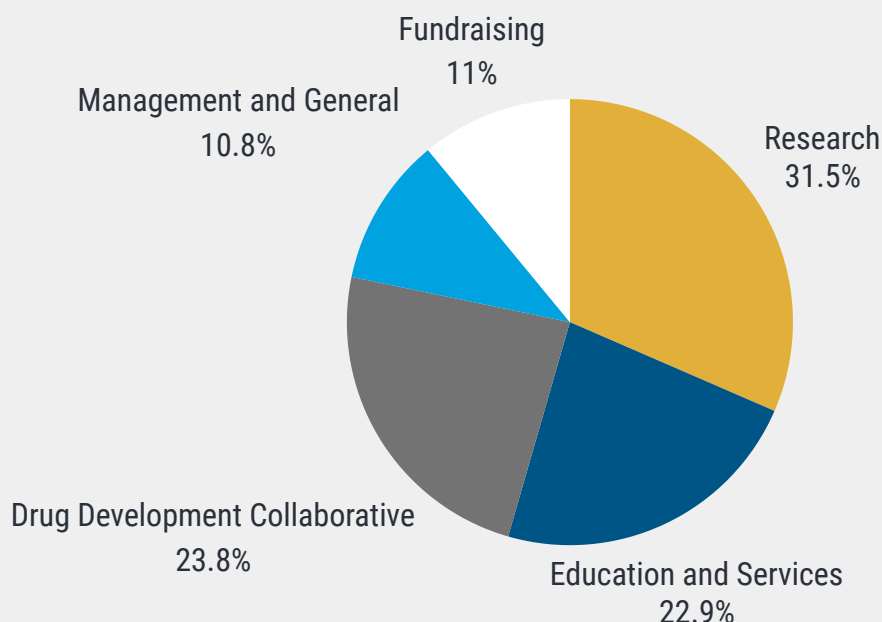
- Research: \$1,574,354
- Education and Service: \$1,146,980
- Drug Development Collaborative: \$1,188,427
- Management and General: \$538,079
- Fundraising: \$548,618

## Net Assets

- Change in Net Assets: -\$811,671
- Net Assets, beginning: \$4,426,617
- Net Assets, ending: \$3,614,946
- Total Liabilities: \$501,880
- Total Assets: \$4,116,826



## How We Deliver on Our Mission



# ORGANIZATION LEADERSHIP

We are grateful for those who share their time and talent in support of our mission to accelerate the development of treatments and a cure, while working to improve the lives of those living with Ataxia.

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