NAF
National Ataxia Foundation

ANNUAL REPORT 2024

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ATAXIA.ORG

About NAF

Since 1957, NAF has been at the forefront of efforts to find treatments and a cure, providing hope and vital resources to the Ataxia community.

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.

CARING

COLLABORATIVE

IMPACTFUL

MOTIVATED

ACCOUNTABLE

CORE VALUES

Letter from the CEO

Andrew Rosen

Chief Executive Officer

Dear Friends,

Each year, I find myself inspired by the strength, passion, and determination of the Ataxia community—and 2024 was no exception. From record-breaking research investments to expanding access to expert care, this was a year of meaningful momentum.

Our community stepped up in powerful ways: we funded more research than ever before, connected families to life-changing support, and ensured Ataxia remained top of mind in key conversations on Capitol Hill. Thanks to your generosity, more people are receiving accurate diagnoses, gaining access to clinical trials, and finding hope through NAF's growing network of services and resources.

We also made significant strides in bringing new voices into our mission. Bill Nye the Science Guy's ongoing partnership helped amplify awareness, and our advocacy efforts led to critical wins—like increased federal research funding for Ataxia.

Of course, none of this would be possible without you. Whether you donated, volunteered, advocated, or simply shared your story, your commitment makes our work stronger. As we look ahead, we remain focused on one goal: accelerating the development of treatments and a cure while working to improve the lives of those living with Ataxia.

Thank you for being part of this journey. Together, we're building a future filled with possibility.

With gratitude,
Andrew

2024 at a Glance

$3.5 Million invested in research

18 Research studies funded

34 NAF Ataxia Centers of Excellence

56 Clinicians trained at ACT

$1.6 Million invested in community services

581 Support Group meetings

95 Educational sessions

94 Congressional meetings

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Our Members

From those newly diagnosed to long-standing advocates and healthcare professionals, our members form the core of our efforts, driving awareness and fueling our pursuit of a cure. Together, we are stronger.

+ **17,360**
Members

+ **561**
Researchers

+ **679**
Clinicians

In Their Own Words...

Each year, members of our community share their personal experiences living with Ataxia. These powerful quotes come from self-written stories—a favorite feature of our community. Visit www.ataxia.org/members to read full stories.

"Life is once, and I have to make full use of it."
-Kamal Ansari

"I've adapted to my new way of life and now this is my second chance."
-Charlie Ruehl

"I have finally accepted my disease and embraced it."
-LaTashia Allen

Community Services

Strengthening bonds within the Ataxia community, our programs support, educate, and unite patients and families, fostering a network of hope and resilience.

$1.6M

Spent on Community Services

Support

581

Support Group Meetings

Advocacy

94

Congressional Meetings

National Ataxia Foundation

Support Impact

The Ruehl Family

NAF Members

When Mary and Charlie Ruehl were both diagnosed with a rare subtype of Ataxia, their mom Susan—overwhelmed and uncertain—called NAF the very same day. That call connected her not only to trusted information and expert referrals, but also to another parent facing the same diagnosis. That single connection made all the difference. Over the years, Susan has found lifelong friends through NAF's support groups and annual conference. "I couldn't imagine my life without the Ataxia support group community and the friends I've made thanks to NAF," she shared. Today, her adult children lead full, independent lives, and Susan credits NAF's supportive network with helping her family move from crisis to confidence.

Thank you to our volunteer Support Group leaders!

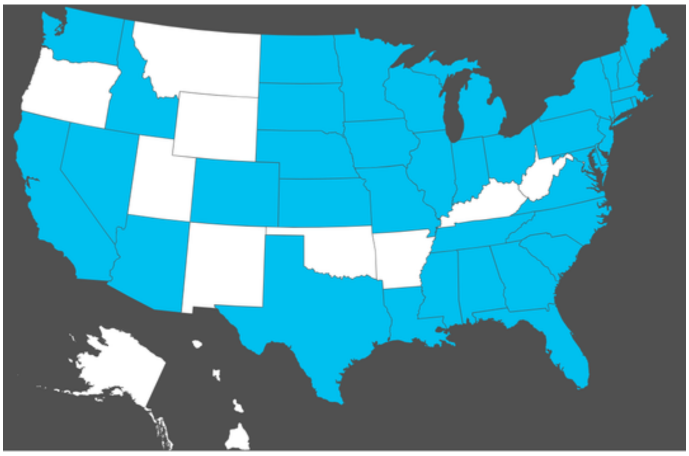
NAF's network of Support Groups provides vital connection, education, and encouragement for individuals and families affected by Ataxia. This would not be possible without the dedication of our volunteer Support Group Leaders, who generously give their time to foster community—both in person and online.

Support

Support Groups serve as a vital lifeline within the Ataxia community, providing a supportive environment where individuals can share experiences, receive emotional support, and access valuable information. These groups empower participants by fostering connections and offering hope, ensuring that no one faces Ataxia alone.

> **“I couldn’t imagine my life without the Ataxia support group community and the friends I’ve made thanks to NAF.”**
>
> **-Susan Ruehl**

65 Support Groups in 41 States



+ 10 International or Demographic Groups

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Advocacy

NAF's advocacy efforts are dedicated to amplifying the voices of those affected by Ataxia and driving policy changes that enhance research funding and improve patient care. We strive to influence public policy to ensure that the needs of the Ataxia community are met and prioritized at all levels of government.

2024 Advocacy Achievements

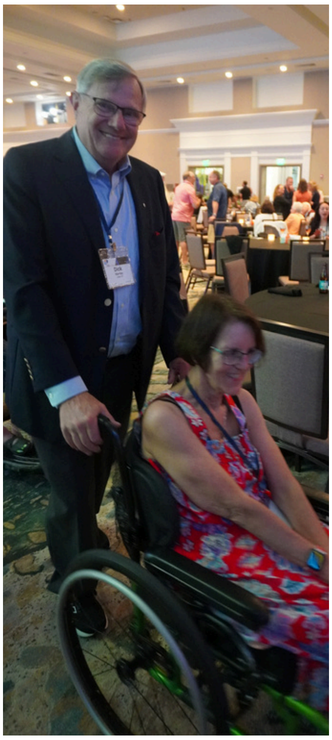
- Bill Nye joined NAF’s advocacy efforts!
- Inclusion of Hereditary Ataxias in the CDMRP
- 4 Hereditary Ataxia Grants from CDMRP totaling more than $12.5M
- September 25th designated as National Ataxia Awareness Day
- 94 congressional meetings to advocate for the Ataxia community

Hill Day

In its 6th year, United Against Ataxia Hill Day on September 25, 2024 brought together advocates from across the country to raise their voices for Ataxia on Capitol Hill. We met with members of Congress and their staff to share personal stories and advocate for legislative priorities that support research funding and access to treatments.

Annual Ataxia Conference

In 2024, NAF's Annual Ataxia Conference brought together over 700 attendees from across the globe for three impactful days of education, connection, and community. Held in Orlando, the event featured more than 50 expert-led sessions, research updates, and networking opportunities for people living with Ataxia, caregivers, clinicians, and researchers. With nearly half of attendees joining for the first time, the conference continues to grow as a cornerstone of support and information for the Ataxia community.



Highlights

- 705 Attendees
- 405 First Timers
- 20 Countries
- 62 Travel Grants → $55K
- 61 Virtual Scholarships → $3K

> **"We are so happy to have found you. My husband and daughter have been on this journey alone and they are not alone anymore. We are so grateful for the connections and information. Thank you for all the hard work that went into planning."**
>
> **-2024 AAC Attendee**

Research

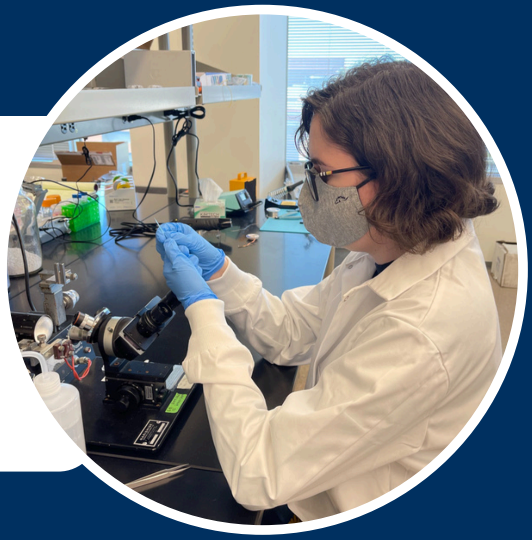
Pushing the boundaries of scientific understanding, our research initiatives focus on uncovering new knowledge and driving innovations that aim to solve the challenges of Ataxia.

$3.5M

Spent on Research

18

Research Studies Funded



398

Natural History Study Research Visits

Research Impact

Parna Mukherjee

NAF Member

For Parna, the path to diagnosis spanned decades and continents. With a deep family history of Ataxia, she knew the odds—but remained hopeful. After enrolling in a clinical trial at Columbia University, she finally received a diagnosis of SCA2 at age 50. A scientist at heart, she didn't hesitate to join the study: "I firmly believe in science… this shows a greater awareness for a little-known movement disorder called Ataxia." Today, she credits her daily commitment to movement with helping her manage symptoms. Stories like Parna's are a powerful reminder that research brings not only answers, but action. Thanks to NAF's support of clinical trial access and Ataxia Centers of Excellence, people like Parna are empowered to participate in research and take control of their journey.

Research Grants

NAF made unprecedented investments in advancing Ataxia research. Following rigorous scientific review, we awarded grants across six categories—from seed-money and early-career awards to graduate, post-doctoral, translational, and diversity-promoting fellowships—empowering a pipeline of innovative studies aimed at accelerating therapies for the Ataxia community.

Highlights

- $845K Funded
- 173 Letters of Intent
- 59 Grant Applications
- 18 Funded Studies
- 72% Increase in Submissions

Natural History Study

The Clinical Research Consortium for the Study of Cerebellar Ataxia (CRC-SCA) unites leading Ataxia clinicians and researchers from top medical institutions across the U.S. and Canada in a coordinated effort to advance care and treatment development. A cornerstone of this collaboration is the natural history study, which tracks how Ataxia progresses over time. This long-term data is critical to the success of clinical trials, providing a necessary comparison to evaluate the true effectiveness of new treatments. We are deeply thankful to the individuals and families who participate—your commitment is helping to pave the way for the therapies of tomorrow.

Highlights

- 1,105 enrolled participants
- 157 baseline visits
- 241 follow-up visits
- New Ataxia types added: RFC1-Ataxia and SCA27B
- 80% of participants donated blood to the biorepository

A heartfelt thank you to the dedicated leadership and clinical sites of the CRC-SCA. Your commitment to collaboration and excellence is driving real progress toward treatments and hope for families affected by Ataxia.

Drug Development Collaborative

The NAF Drug Development Collaborative brings together leading pharmaceutical companies to accelerate therapy development for Ataxia. Their support helps fund critical programs—including the CRC-SCA Natural History Study, clinic visits, and free genetic counseling—while benefiting from NAF's expertise, patient registry, and biospecimen resources.

Thank you to our DDC members who work tirelessly to develop therapies for Ataxia!

arrowhead pharmaceuticals

Biogen

biohaven

PTC THERAPEUTICS measured by moments

SERVIER moved by you

Solaxa

VICO Therapeutics

Free Genetic Counseling and Testing Initiative

Through our Genetic Counseling and Testing Initiative, NAF offers free virtual genetic counseling and testing for individuals at risk for SCA1, SCA2, or SCA3. The program, supported by DDC membership fees, is available to U.S. residents age 18 and older who have a family member with a confirmed diagnosis of one of these SCAs.

Highlights

- 191 Genetic Tests
- 199 Pre-Test Counseling Sessions
- 129 Post-Test Counseling Sessions

Clinical Services

Our clinical initiatives focus on enhancing treatment for Ataxia and increasing access to specialized care.

56

Healthcare Providers Trained in Ataxia Care

34

NAF Ataxia Centers of Excellence

679

Clinician Members

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Ataxia Clinical Training

NAF's Ataxia Clinical Training (ACT) program offers a unique, immersive learning opportunity for medical professionals—including neurology residents, fellows, and clinicians—to gain hands-on expertise in diagnosing and treating Ataxias through an intensive in-person agenda.

ACT plays a critical role in expanding access to knowledgeable, high-quality care. As more healthcare providers gain specialized experience, individuals with Ataxia will have greater access to earlier diagnoses, improved management options, and providers who understand their unique needs.

Highlights

- 56 Attendees
- Increased competency in Ataxia diagnosis & care
- 98% of attendees would recommend ACT to colleagues

Tom Lawson

NAF Member

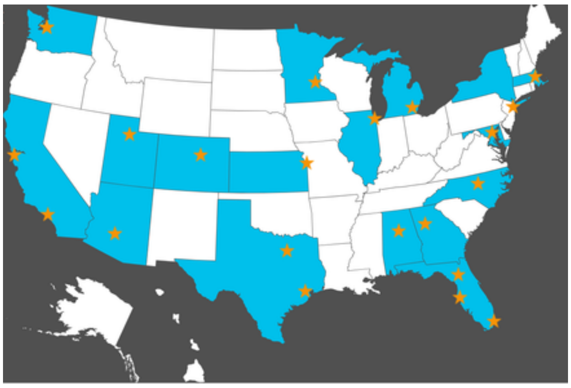
After years of unexplained symptoms, Tom Lawson finally found answers when he was diagnosed with Ataxia at the Johns Hopkins Ataxia Center. While the diagnosis brought clarity, it also came with emotional and physical challenges—navigating daily life with a visible disability, adjusting to a progressive disease, and facing uncertainty about the future.

Through it all, Tom found connection and support in the Ataxia community. After reaching out to NAF, he spoke with our staff and shared his story—a moment he describes as both validating and therapeutic. **"My story is not over,"** he wrote. **"With all the continued hard work of NAF, others in my shoes can also find help and support to not go through this alone."** Tom's words reflect the heart of our mission: no one facing Ataxia should feel like they have to navigate it alone.

NAF Ataxia Centers of Excellence

NAF's Ataxia Centers of Excellence (ACE) program identifies and supports premier clinics that provide comprehensive, multidisciplinary care for people with Ataxia. These centers bring together expert neurologists, genetic counselors, rehabilitation specialists, and social workers to deliver coordinated, high-quality care.

Each center serves at least 30 Ataxia patients annually and is actively involved in research, clinical trials, and community education. With a growing network of 25 sites across the U.S. and 9 internationally, the ACE program is expanding access to expert care and helping accelerate progress toward effective treatments and, ultimately, a cure.



Highlights

- 25 U.S. designations
- 9 international designations
- Increased access to specialized Ataxia care
- Improved patient data for Ataxias

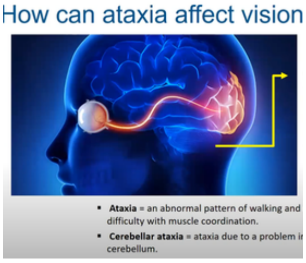
Education

Through targeted educational programs and resources, we empower patients, families, and healthcare providers with knowledge needed to manage Ataxia effectively.

15K+
People Reached

95
Webinars/ AAC Sessions

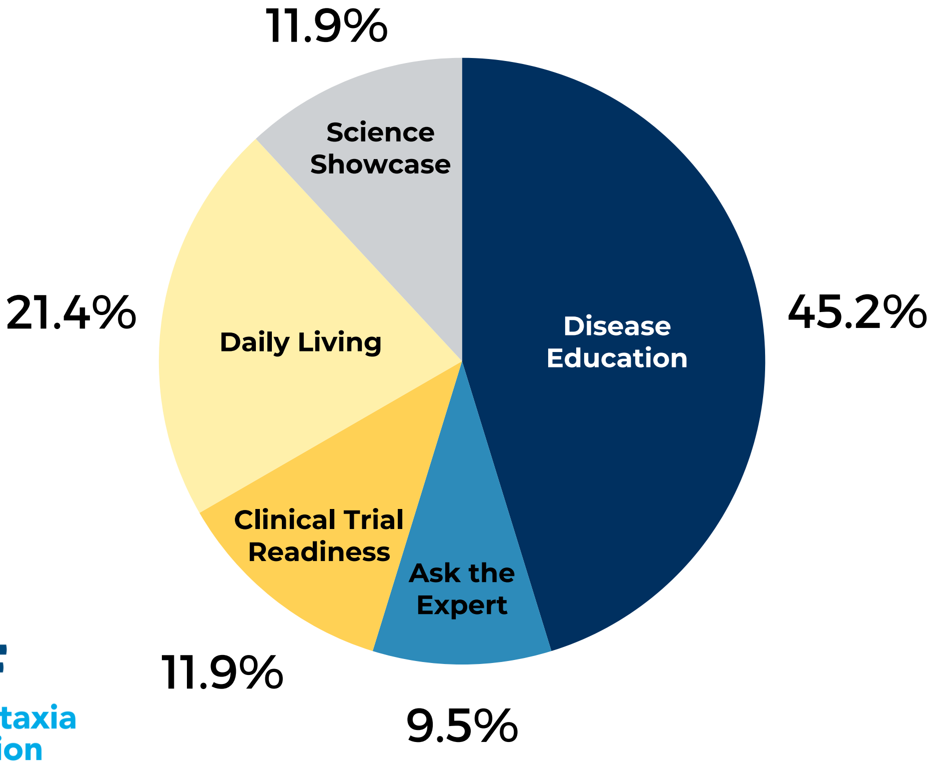
43
Articles



How can ataxia affect vision

- **Ataxia** = an abnormal pattern of walking and difficulty with muscle coordination.
- **Cerebellar ataxia** = ataxia due to a problem i cerebellum.

Webinar Topics Covered



Community Fundraising

Engaging supporters through creative and impactful fundraising initiatives, we harness the power of community contributions to fuel our mission and expand our reach.

17

Walk N' Rolls

16

Passion Fundraisers

$394K

Raised

Walk N’ Roll to Cure Ataxia

Walk N’ Roll events, our flagship grassroots fundraiser, bring communities together with a meaningful mission: walking, rolling, and rallying for Ataxia awareness and progress. These events—carefully planned and executed by volunteers—have grown nationwide, raising awareness, fostering camaraderie, and generating substantial support for research and services.

Walk N’ Roll events require dedicated local committees—making them powerful ambassadors and essential pillars of our mission.

Highlights

- 17 Walk N’ Rolls
- 1,776 Donations
- $242.6K Raised

2024 Walk Locations

Atlanta
Central Ohio
Chicago
Denver
Jacksonville
Las Vegas
Lower Michigan
Milwaukee
Minnesota
North Carolina
Pittsburgh
Sioux Empire
St. Louis
Tampa Bay
Treasure Coast
Virginia Tech
DIY Virtual Walk

Passion Fundraisers

From comedy shows and poker nights to tea parties and community barbecues, volunteer fundraisers across the country are turning their passions into powerful support for the Ataxia community. These dedicated individuals and families generously give their time and creativity to host events that raise both awareness and critical funds for our mission. Each passion fundraiser helps build community, inspire hope, and bring us one step closer to a world without Ataxia. We are deeply grateful for their commitment and heart.

Highlights

16 Events

787 Donations

$151.5K Raised

2024 Events

Artisans for Ataxia
Bowl for a Cure
Chuck & Duck
Fairies and Shadows
Florida 500
Lenusa Concert
Serving Up a Cure
Los Angeles Event
San Diego Potluck

Stand Up To Ataxia Events:

Atlanta
Dallas
Massachusetts
Philadelphia
Northern California
Minnesota
Tri-State

Fundraising Impact

Dan Queirolo

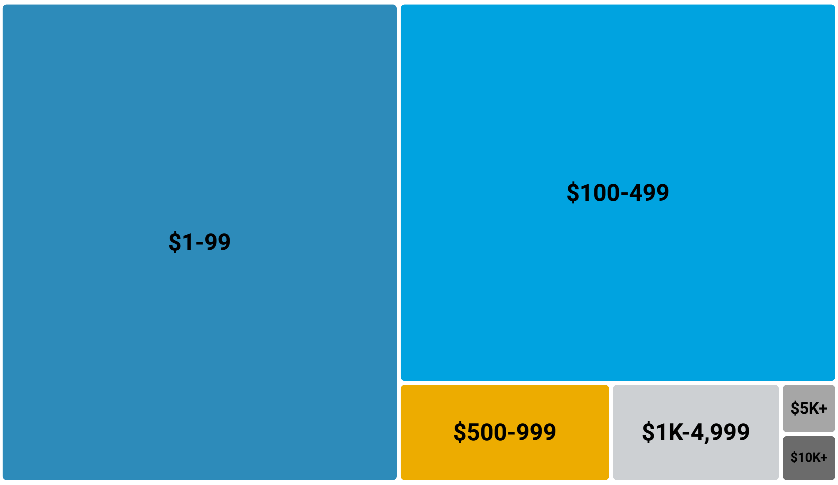
NAF Member

After his diagnosis in 2024, Dan set out to learn everything he could about Ataxia and how to live well with it. A husband, father, artist, and athlete, Dan embraced a new way of life centered on movement, purpose, and connection. He launched an Instagram platform to raise awareness and planned his first fundraising initiative to support Ataxia research. Though he lives in Brazil, Dan discovered NAF's resources and immediately put them to use in his own journey. His commitment to helping others find hope and knowledge reflects the power of global community—and the growing impact of donors who turn their personal stories into action.

"I decided that I don't want to regret not having lived everything I could, while I could."

Donations by Gift Size

Our mission is driven by the generosity of everyday donors. Small gifts - often under $500 - add up to make a big impact in the fight against Ataxia.



Revenue & Philanthropy

The generosity of our donors fuels every aspect of our mission—from accelerating research to expanding support services for families affected by Ataxia.

4,379

Donors

$925

Average Gift

$6.1M

Total Revenue

CORPORATE PARTNERS

We thank our corporate partners for their generous support.

$25K+

Arrowhead Pharmaceuticals
Biogen
Biohaven Pharmaceuticals
Columbia University
Google Inc.
PTC Therapeutics
Servier Pharmaceuticals
Solaxa Pharmaceuticals
Vico Therapeutics B.V.

$10K-$24,999

Epic Games
Microsoft
Morgan Stanley Gift Fund
National Financial Services, LLC
UBS Financial Services
Vanguard Corporation

$5K-$9,999

Ameriprise Financial
Jackson National Life Insurance
TIAA
Torres Electrical Supply Co, Inc.
Variantyx

$2,500-$9,999

Cigna
Farm Bureau Insurance
Los Alamos National Security LLC
Thrivent Choice

$1K-$2,499

Abbott Laboratories
Artisan Partners Limited Partnership
BMI Federal Credit Union

$1K-$2,499 (continued)

Booz Allen
Construction General Laborers & Mtrl Handlers
Cruisin Cajun Country, Inc.
Federal Home Loan Bank Of Pittsburgh
Gartner, Inc.
Hunt & Viveiros, LLC
Pershing Advisor Solutions LLC
Restore Physical Therapy And Wellness Corporation
RunSignUp
The Boeing Company
University Of Tampa
Wells Fargo Clearing Services, LLC
Old Homeplace Vineyard Stone
Thrivent Financial
Klingberg Trucking

COMMUNITY GIVING PLATFORMS

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

$25K+

Fidelity Charitable
Benevity Community Fund
Schwab Charitable/Dafgiving 360
Paypal Giving Fund
National Christian Foundation Heartland

$5K-$9,999

Edward Jones Charitable Gift Fund
Nationwide Life Insurance
Bank Of America Charitable Gift Fund

$2,500-$4,999

American Endowment Foundation
Community Health Charities
Yourcause
Burnt Hills - Ballston Lake School District
JPMorgan Chase Foundation

$1K-$2,499

Hirtle Callaghan Charitable
Dailykarma
Charities Aid Foundation Of America
Network For Good
Raymond James Charitable
E-Trade Morgan Stanley
Renaissance Charitable Foundation

FOUNDATIONS

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

$25K+

Cossack Family Foundation
The Clementz Foundation
The Warchol Family Giving Fund
Once Upon A Time Foundation

$10K-$24,999

Haider Quality Freedom Foundation
Susan Harris Family Trust
Community Foundation For The Land of Lincoln
Schmidt Family Fund
Don & Jodi Heeringa Family Fund of the Community Foundation of the Holland/Zeeland Area
The Ho Hing Dai Family Foundation Inc
Chip & Susan Carlisle Charitable Fund
Leader Family Foundation

$5K-$9,999

Chan Zuckerberg Initiative
Karen Brown & Michael Peffer Giving Fund
Greater KC Community Foundation
Mississippi Ataxia Support Group
Thurmes Reilly Charitable Fund
The Shannon Foundation
Bob & Cappa Woodward Charitable Fund
Fugate Family Fund
Everence Foundation Inc

$2,500-$4,999

Ataxia Connection
Dr. Bobby & Julie Baker Foundation
Ted & Debra Durdel Charitable Fund
The Thomas & Suzanne Harris LEP
Vitrano Family Giving Fund
Alabama Power Foundation
PSEG Foundation
Cybergrants 3M Foundation
Lincoln Financial Foundation Inc.
Steele Family Foundation
Community Foundation For A Greater Richmond
Braswell Giving Fund
Hankins Family Fund

$1K-$2,499

Tom & Deb Swenson Foundation
The Fairlady Fund Of The St Paul & Minnesota Foundation
Saint Paul & Minnesota Foundation
Direct Supply Foundation, Inc
The JMA Foundation
Drinane Family Fund
Evelyn S & Jim Horne Hankins Foundation
James H. Miller Fund
Liou Family Fund
Texas Instruments Foundation
Gates Foundation
Pledgeling Foundation
Exelon Foundation
Intel Foundation
Buzz & Carolyn Pierce Family Fund
United Mine Workers of America
Marshall-Schneider Charitable Fund
Bailey Family Giving Fund
Enterprise Holdings Foundation
Dennis & Peggy Boik Fund

INDIVIDUALS

We are deeply grateful for the generous donors who supported the National Ataxia Foundation in 2024. Their contributions make it possible for NAF to drive progress toward treatments and a cure—while continuing to improve the daily lives of those affected by Ataxia.

$25K+

Joseph & Amber Frei
Steven Thomas Jr. Estate
Nina Meister Estate
Susan Huffman
Marcia Neugebauer
Gregory Klassen
Randy Hayes Estate
Nancy & Rob Schultz
Kathryn Reed Perkins Estate Trust
Jim Keene

$10K-$24,999

Michael & Karen Leader
Jerry Lemire
Margaret Head
Nancy Haugen
Cathy & Richard Bethay
Cheri & Gil Bearman
Nancy Kochevar & Michael Lurie
Michael & Bonnie Westhusing
Melissa Clausen
Linda & Timothy Conely
Cecily Jaynes
Laurie & Tom Likai
Russ & Susan Roller
George Maguire
Marjorie Clay

$5K-$9,999

Jennifer Austin
Mary Bird
Nelia Aguiar
Maryann Sweeney & Jack Dyer
Coreen Gililland
Serena Hung
Mark Machado
Carolyn & Dan Allen
William Sweeney
Maria Gilbert
Allan Jane Defante
Jane Jaffe

$5K-$9,999 (continued)

Tammy Humes
Rob Burlington
Jennifer Leader
Ben Frei
Michael & Janet Sweeney
Laura Ranum
Roger Hayes Estate
Thomas Schlickbernd
Judy Marten
Sandra Johnson
Karen & Thomas Ganey
Richard & Lois Bierschbach
Marsha Asp
Wendy & Richard Clemens
Celia Baculi
Jean Booher
Charles Davis

$2,500-$4,999

Sergio Damasio
Linda Snider & Mark "Skippy" Sidwell
Bruce & Susan Ruehl
Cherie Nixon
Drew Pickering
Dorothy Bowdon
Samuel & Susan Kirton
Jason Pruet
Karin Westgate
Michael Willard
Mark & Marcia Stewart
Roberta Santa Croce
Judith Chronister
Jeanette Pinkney
Karen & Barton Suchomel
Ruth Coffey
Lisa Angelastro
Kenneth Kueny
Joe Yosick
Sandy And Howard Miller
Blair Eklund
Levi Bailey
Joe Ackerman
Charles Ludvik
Paul Wilner

$1K-$2,499

Karen Stickle
Jonathan & Jacqlyn Hogan
Laura Ospanik & Stephen Robbins
Deanna Povolny
Pam Graber
Brittany Botelho
Theresa Witters
Frances Moody
David & Becky Face
Paul & Karen Silva
Amala Dlamini
Louise Lawrence
William Maitland
Jon Larson
K. C. & Nancy Turnbull
Carol Dennison
Richard Biagini
Priscilla Wallack
Andrew Schwartz
Terri Villanueva
Doug Brunnert
John & Edith Collin
Edith Payne
Rhonda & Thomas Otway
Connie & Don Hilger
Sarah Stangle
Mark & Jill Steppe
Bill Laine
Mary Ann Tucci
Mike & Carol Ingram
Sue & Bill Moore
Jerry Hall
Greg Rooks
David Brunnert
Cheryll & Trent Peterson
Ann Riley
Chris Arnold
Calvin & Bonita Mallory
Paul Ketteridge
Meg McLane
Eric & Amy Swierczek
Dick & Robin Manley
Joseph Santy

INDIVIDUALS (CONTINUED)

$1K-$2,499 (continued)

Marcie Anthone
Bill Nye
Gary Johnson
Marlene Napalo
Ranjani Venkataraman
Michael Estabrook
Dawn Ngo
Harry Orr
Charles Place
Lawrence Adair
Laddy Ospanik
Kathryn Youngblood
Sean Buckle
Daniel & Sheila Irwin
Dan & Julie Brunnert
Robert Rivard
Rob & Ann Baker
David Spotts
David Schwandt
Bradly Labrum
Martha Hildreth
Patsy Gaffney
Charlotte Depew
Joel & Pam Sutherland
Barton Beck
Gina Bryzgalski
Chaitra Sridhar
Judith Van Dyke
Lori & Rich Hensler
Terry Carr
Thomas Yogan
Jeri & Robert Leach
Bryan Tabery
Lisa Buhr
Christine Esau
Ron & Linda Weaver
Lola Tanzer
Stephen Krasner
Linda Wilson
Richard Lavery
Anna Matykowski & Greg Poduska
Rick Stanley
Eugene & Margaret Klingberg
Ryan Beck
Francesca Tetreault
Sophie Decker
Linda Corsetti & Allen Jaffe
Tracey Gibbs
Amy Ducharme
Christopher Bishop
Peter Johnson
Jenny Parker
William Meier
Marcia Keiter
Laura Schlichtmann
Yasushi Kisanuki
John & Lisa Dix
Greg Kemp
Sam Orley
Tricia Tripp
Anthony & Robyn Zeller
Jerry Williams
Paul Nye
David Ferrainolo
Damien Gottschalk
Gina Backman
John Ferguson
Joseph & Joan Cronin
Ronald & Lyn Mason
Elaine & Raymond Hansen
Kerry Enright
Rayna Latimore
Howard Martin
Rebecca Lipner
Terry Tripp
Renee Dushane
Katharine Adams
Donna Rohs
Roy Francis O'Connor
Richard & Marie Brand
Chelsea Apke
Richard Berkins
Scott Unger
Thomas Malia
Eugene & Carol Mayhew
Darlene & Terry Glenn
Ted Clark
Myrna Prophet
Adrienne Doobin
Vicki Merrill
John Smithers
Gayle Acuff
Dave Henry
Blayne & Karen Cannon
Linda Hunnius
Valerie & Denis Rodgers
Dorothy Beix
Mary Harrold
Dawn Thibeault
Jim Martin
Fredrik Sachs
Amy Lau
Roger Kaufman

Working Towards a Cure

At NAF, every dollar we receive moves us closer to treatments and a cure. We are committed to transparency and thoughtful stewardship of our resources—ensuring your support makes the greatest possible impact for people living with Ataxia. The summary below reflects how your generosity fuels meaningful progress.

SUPPORT AND REVENUE

- Contributions: $5,988,769
- Drug Development Collaborative: $717,250
- Conference Income: $308,264
- Other Income: $108,072

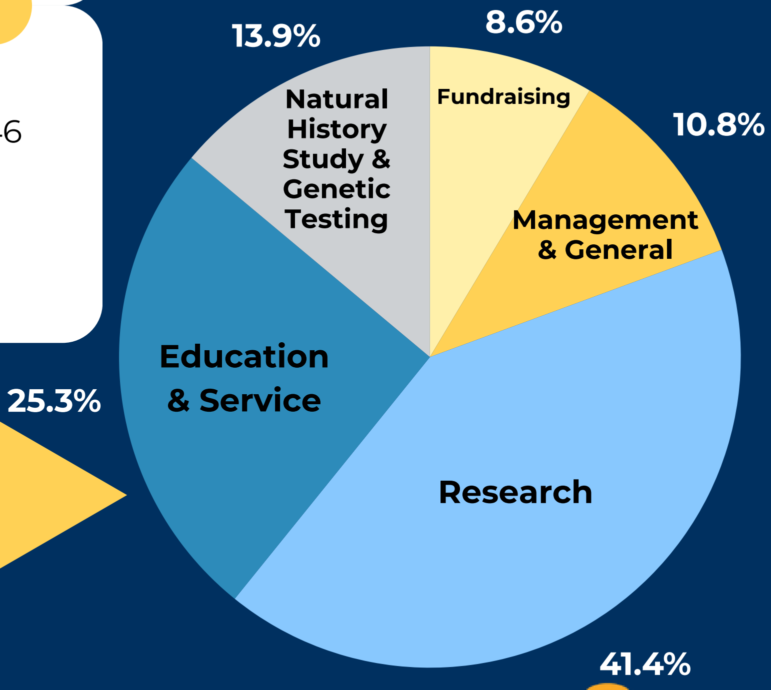
EXPENSES

- Research: $2,646,653
- Education and Service: $1,615,459
- CRC-SCA Natural History Study & Genetic Testing Programs: $889,489
- Management and General: $690,726
- Fundraising: $548,618

NET ASSETS

- Change in Net Assets: $692,206
- Net Assets, beginning: $3,614,946
- Net Assets, ending: $4,307,152
- Total Liabilities: $482,274
- Total Assets: $4,791,426

HOW WE DELIVER ON OUR MISSION



Organization Leadership

NAF STAFF

Senior Leadership

Chief Executive Officer

Andrew Rosen, MBA
andrew@ataxia.org

VP, Research & Chief Scientific Officer

Lauren Moore, PhD
lauren@ataxia.org

VP, Operations & Community Services

Kyle Billadeau
kyle@ataxia.org

VP, Development

Joel Sutherland
joel@ataxia.org

Community Services Director

Lori Shogren
lori@ataxia.org

Communications Director

Stephanie Lucas
stephanie@ataxia.org

Meet the Team

Clinical Services Director

Kelsey Trace

Patient Engagement Manager

Celeste Suart, PhD

Clinical Research Coordinator

Laura Crespo

Research Coordinator

Aimee Alcott

Research Services Associate

Mary Ann Peterson

Community Services Coordinator

Kari Brooks

Development Manager

Jon Wegman

Development Manager

Rich McCutchen

Development Coordinator

Meg Hanna

Controller

Patricia Morel

Senior Accountant

Sue Baker

Senior Communications Coordinator

Mollie Utting

Communications Coordinator

Tanoa Thomé

BOARD OF DIRECTORS

The Board of Directors is the governing body of the organization, responsible for determining NAF's overall mission and strategic goals. They ensure that NAF is managed with fiscal responsibility.

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THANK
YOU

As we reflect on the past year, we extend our deepest gratitude to each of you—our donors, volunteers, healthcare providers, fundraisers, and members. Your unwavering support and dedication have been the cornerstone of our efforts to improve the lives of those affected by Ataxia. Your contributions, whether time, expertise, or resources, have propelled us forward and enabled us to continue our mission with renewed vigor and hope. Thank you for your commitment to our cause and for being such an integral part of our community. Together, we are making a profound impact, and we look forward to achieving even more in the coming year.

We extend our heartfelt condolences to the family of Cameryn Cobb, pictured here with her father Devin—a former NAF Board Member. Cameryn passed away in early 2025. Her passion and advocacy continue to inspire the Ataxia community.

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