



2021 ANNUAL REPORT



**National Ataxia
Foundation**

LETTER FROM EXECUTIVE DIRECTOR

Thinking back to writing this letter one year ago, I didn't think that anything could top 2020 in the challenges that the Ataxia community faced. Welcome, 2021. Another year of figuring out how to stay connected and find joy while doing everything we could to stay healthy. In times of economic or operational uncertainty, I believe staying focused on strategic goals is particularly important. NAF continues to prioritize the following key elements of our strategic plan:

1. Connect all people affected by Ataxia, both personally and professionally, with NAF.
2. Mobilize the Ataxia community to advance and participate in research and clinical trials.
3. Enhance local and national support for those living with Ataxia.

In the pages that follow, you will read a number of examples of our progress toward these goals, including our work with support groups, Ataxia advocacy, and our continued commitment to funding research studies.

You will also learn about our generous donors. During a year when it would have been easy to give a bit less or not at all, this remarkable group stepped up and provided the critical funding to allow us to continue to grow. THANK YOU! It is an exciting time for all people affected by Ataxia as many pharmaceutical companies are working on treatments and progressing toward clinical trials. We hope you'll continue to stay involved with NAF and take an active role in achieving our joint goals in 2022 and beyond.



A handwritten signature in blue ink that reads "Andrew Rosen".

Andrew Rosen,
Executive Director

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.



NAF MEMBERSHIP + 2021 AT A GLANCE

TOTAL MEMBERS
7,772



52% increase in
members during 2021



ABOUT OUR MEMBERS

4,563 → Person with Ataxia

430 → At-Risk for Ataxia

2,242 → Family Member of Person with Ataxia

289 → Friend of Person with Ataxia

248 → Ataxia Professional



2021 AT-A-GLANCE

2,203 → New members of NAF

15 → Research initiatives funded

\$1,032,212 → Total spent on research

674 → Participants in the Natural History Study

265 → Support group meetings

97 → Meetings with members of Congress

14 → Educational webinars / Ask the Ataxia Expert sessions hosted

10 → Pharmaceutical companies joined NAF's Drug Development Collaborative

COMMUNITY PROGRAMS & SERVICES IMPACT

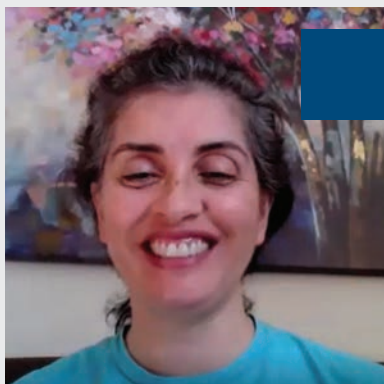
SUPPORT GROUPS

Connecting people affected by Ataxia to improve lives.

NAF coordinates Support Groups as a way for the Ataxia community to connect and learn from others. They ensure that nobody has to experience Ataxia alone. Our volunteer Support Group Leaders provide this invaluable service to the community.

65 → Support Groups

265 → Support Group Meetings



SG LEADER SPOTLIGHT

SHANNON DUNPHY LAZO

ST. LOUIS SUPPORT GROUP LEADER

Shannon went to school in Texas, studying biomedical engineering. She lived in Washington, DC for more than a decade working for the federal government before moving to St. Louis, where she currently lives. Shannon's journey with Ataxia started more than 20 years ago. As her symptoms progressed, she started to grapple with who she is,

saying, "I am still me, but I don't always feel it. Where is the girl who hiked the Grand Canyon and kayaked in Alaska?"

As Shannon learned to adapt to her new normal, she found that building a support system was an important way to take care of herself. She discovered that she could make lifelong friends and learn

from others who can relate to her own experiences. During her time in DC, she joined NAF's Chesapeake Chapter Support Group and worked closely with the Johns Hopkins Ataxia Center Support Group. When Shannon moved to St. Louis five years ago, she immediately wanted to join the local Ataxia support group. Unfortunately, she found that there wasn't a group in St. Louis. She welcomed this as an opportunity to step up to lead a group of her own using the things she'd learned from other groups. She describes her support group as "small but mighty."

ADVOCACY

Amplifying the voice of the Ataxia community.



NAF's advocacy activities expand our partnerships with other organizations and policy makers to help make a difference for people affected by Ataxia. Involvement in advocacy gives us a way to get our community's stories to policy makers and pharmaceutical companies to grow awareness, accelerate drug development, and ensure access to care and treatment services.

2021 Advocacy Impact

- Senate Resolution 339 to declare September 25th as National Ataxia Awareness Day was passed
- Efforts began to add "Hereditary Ataxia" into the Congressionally Directed Medical Research Program
- Worked to gain support for The ACT for ALS (S. 1813/H.R. 3537) and The BENEFIT Act (S. 373/H.R. 4472)
- Recognized Senators Cindy Hyde-Smith and Christopher Murphy with Ataxia Research Champion Awards for their work with Ataxia legislation

“

“There is power in partnership with community members, with organizations, and with lawmakers. It is in this partnership that our vision of a world without Ataxia will become a reality.”

— Andrew Rosen

ATAXIA HILL DAY



NAF and FARA coordinated the 3rd United Against Ataxia Hill Day on September 29, 2021 to meet with legislators about issues important to the Ataxia community. The turnout was incredible!

250 → Ataxia advocates

44 → States represented

97 → Meetings with lawmakers

We are extremely grateful for the commitment of the volunteer advocates who stepped forward to speak on behalf of the Ataxia community.

ANNUAL ATAXIA CONFERENCE



The Annual Ataxia Conference is a gathering where attendees learn from world-leading Ataxia researchers and clinicians, network, and make new friends. NAF held its first virtual conference in 2021, broadening the event's reach and making it accessible to our global community. There was record-breaking attendance, number of first-time attendees, and number of countries represented.

873 → Attendees

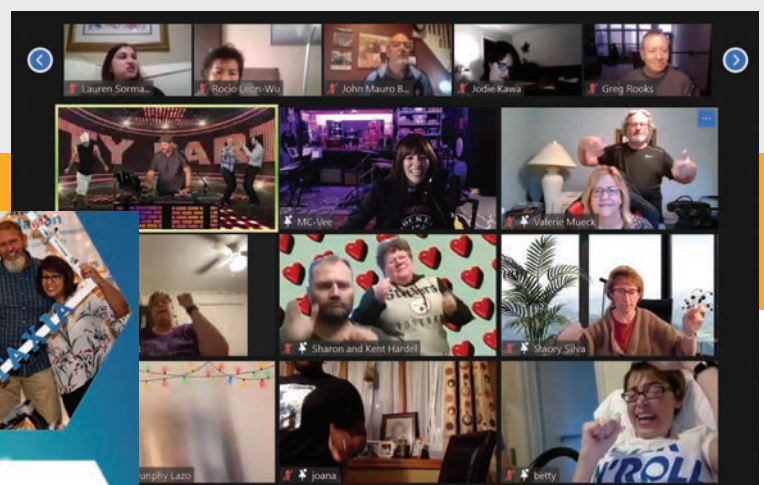
508 → First timers

23 → Countries represented

31 → Speakers

18 → Exhibitors

7 → Sponsors



COME AS YOU ARE:
ATAXIA **UNMASKED**

MARCH 10-13

Welcome to the largest Ataxia community gathering, now a virtual event for 2021.



RESEARCH IMPACT

“

“When I think about something like Ataxia...I think about how important it is to have a united front and how important it is to involve people, both in academia, internationally and domestically, as well as across foundations and pharmaceutical industries. And I really love the mission of the NAF...I saw an opportunity to further the NAF's mission and work on bringing therapies to these patients.”

— Sharan Srinivasan, PhD

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

\$1,175,717 → Spent on Research Initiatives

NAF Research Grants

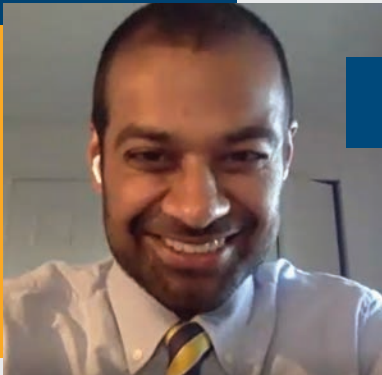
Accelerating Ataxia treatment development.

NAF grants are often the start-up funding needed for researchers who then add to our knowledge of Ataxia. Many discoveries can be traced back to NAF and support from our donors. Often these researchers secure larger grants from NIH for their continued Ataxia research.

\$655,000 → 15 Research Studies Supported

- 4 Seed money grants
- 1 Pioneer SCA3 Translational Award
- 5 Young Investigator Awards
- 3 Post-Doctoral Fellowship
- 2 Diverse Scientists in Ataxia Pre-Doctoral Research Fellowship

102 → Participants enrolled in the Brain Donation Program



RESEARCHER SPOTLIGHT

SHARAN SRINIVASAN, PHD

CLINICAL MOVEMENT DISORDERS FELLOW,

MASS GENERAL BRINGHAM, BOSTON, MA, USA

Dr. Srinivasan received NAF's Young Investigator Award to support his Ataxia research. He proclaims himself as a basic scientist at heart who fell in love with treating neurology patients clinically. Dr. Srinivasan took an interest in movement disorders during his medical rotation because he saw an opportunity to help patients. He took an even deeper interest in Ataxia because he was struck by how little there was to offer and how much need there was to help people and come up with ways to treat these diseases. Dr. Srinivasan says that the grant from NAF improved his ability to develop model systems for Ataxia and study the impact of a possible genetic therapy. Without NAF, he says he wouldn't have been able to complete the study. He plans to spend his career working as a physician scientist and academic neurologist studying degenerative Ataxias.

Ataxia Investigators Meeting

NAF's Ataxia Investigators Meeting (AIM) brings together world-leading Ataxia clinicians and scientists who are working to accelerate the pace of Ataxia research, better understand the disease, and develop therapies. A virtual AIM took place May 24-27, 2021. To increase NAF's impact on the international research stage, NAF will be partnering with FARA and Ataxia UK to host the first International Congress for Ataxia Research meeting in place of AIM in 2022.

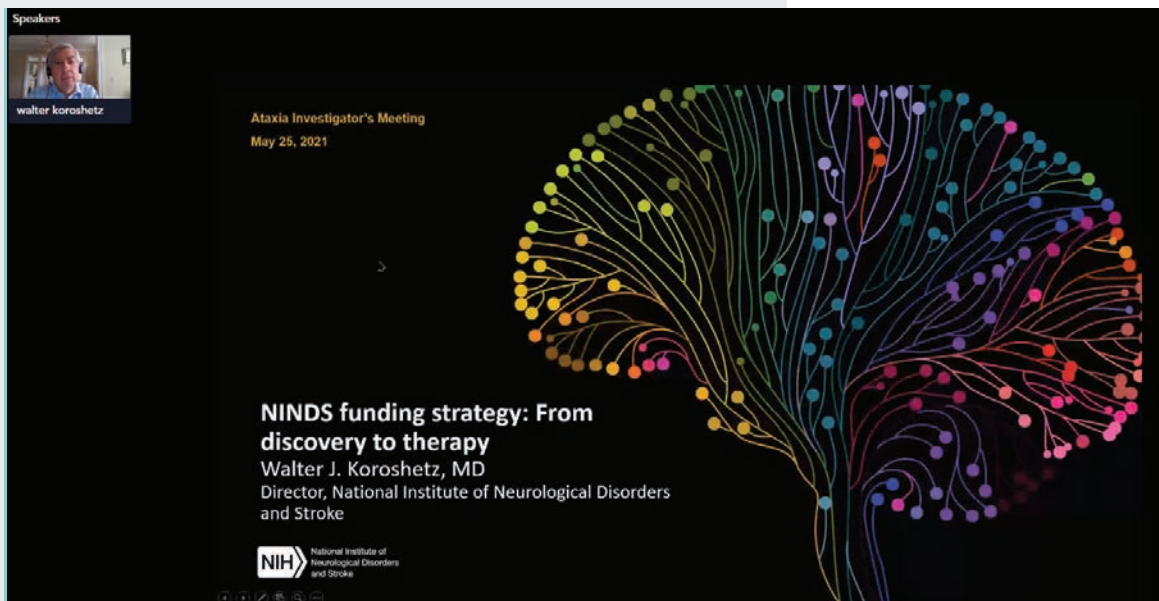
240 → Attendees

16 → Countries Represented

35 → Speakers

- Presentation from NINDS
- Presentation from Nobel Laureate Thomas Cech
- Featured 9 Early Career Investigator presenters

9 → Sponsors



NAF Drug Development Collaborative

The NAF Drug Development Collaborative is designed to address shared challenges and opportunities in Ataxia therapy development. The Collaborative provides a centralized source of Ataxia expertise, patient registry and natural history data plus a collection of curated/annotated biospecimens to support preclinical and clinical research and development.

Thank You DDC Members!



Clinical Research Consortium for the Study of Cerebellar Ataxia (CRC-SCA)

The CRC-SCA is a collaborative group of Ataxia researchers with a mission to better understand factors that determine Ataxia progression to improve understanding of the disease process and help with developing treatments. They coordinate a natural history study of Cerebellar Ataxias that has been important to advancements being made toward drug development.

674 → Participants enrolled

15 → Sites

STUDY COVERS → SCA 1, 2, 3, 6, 7, 8 and 10



“

“Continuing natural history data collection will truly make the CRC-SCA clinical trial ready. This is evidenced by numerous pharmaceutical companies expressing interest in both the natural history data, as well as enrolling research participants through CRC-SCA sites.”

— Vikram Shakkottai, MD, PhD
Chair of NAF's Medical and Research Advisory Board



DONOR SPOTLIGHT

THE MICHAEL AND PATRICIA

CLEMENTZ-PETERSON FAMILY FUND

The Michael and Patricia Clementz-Peterson Family Fund was established in 2005 to contribute financially to SCA3 research. Several family members on Patricia's side of the family are affected by SCA3, including their daughter who passed away in her early 50's after a courageous battle with Ataxia. Michael and Patricia wanted to ensure that their donations would continue after they were gone. Their hope is that research for neurological diseases will eventually bring relief and hope for this painful, heartbreaking condition.

In 2017, Michael and Patricia decided that they wanted to do more. To inspire others to get involved, they pledged to match every donation to NAF. The Summer Match Challenge was born! Each year, they continued to generously match donations during the month of June. In 2021, the annual campaign completed its 5th year – surpassing a total of \$1 million raised! We'd like to thank them for their unwavering support of NAF's mission.

“

“Together it has become our shared lifetime mission to help those who struggle physically and suffer so much. It hurts to see the difficulties and pain our own loved ones face day and night just to even do simple movements that healthy people can take for granted.

We are grateful for NAF and their dedicated staff and volunteers.

We also are very thankful for the scientists and researchers worldwide and participants who give so much in order to discover life-saving knowledge of this debilitating disease.”

— Patricia Clementz-Peterson

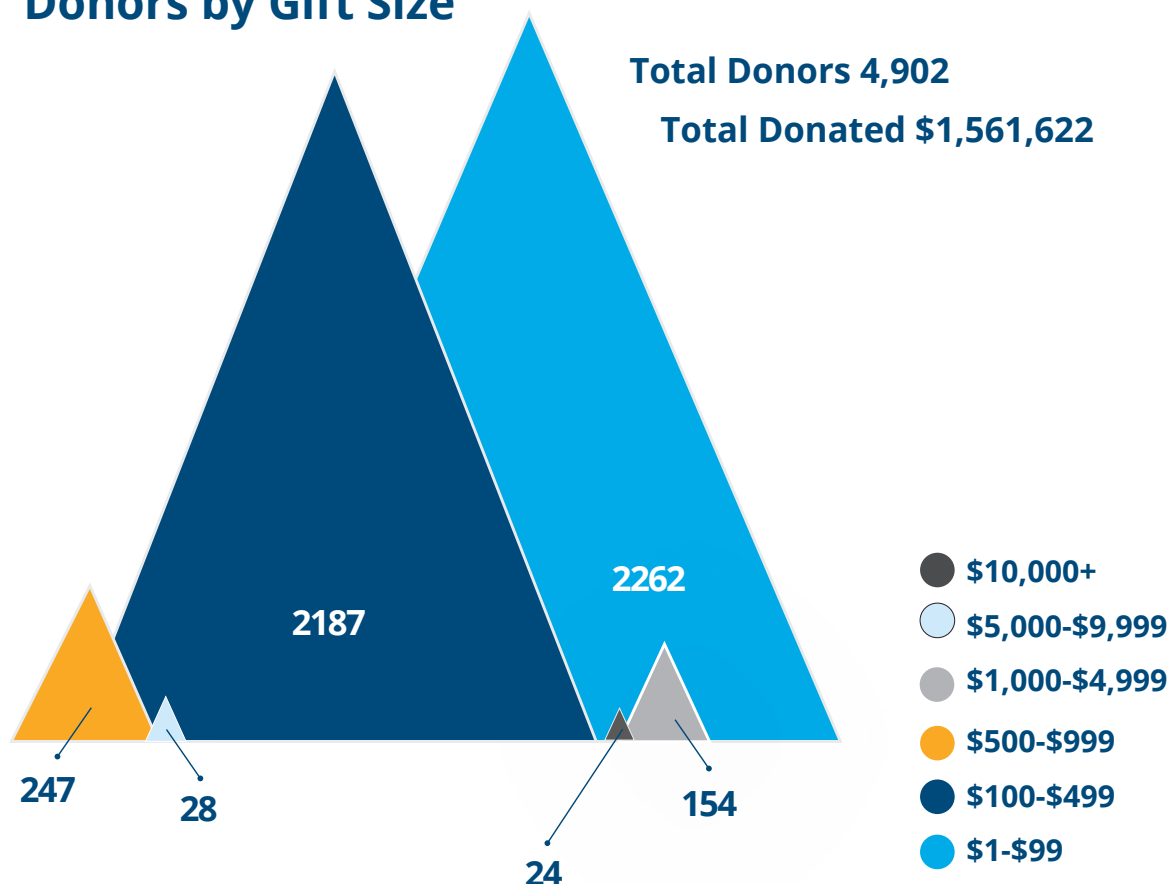
REVENUE AND FUNDRAISING

Thanks to Donors

The generosity of our donors directly impacts the lives of people affected by Ataxia. It allows us to offer programs to improve the lives of persons living with this disease, advocate for policies that impact the Ataxia community, and accelerate drug development efforts. Thank you!



Donors by Gift Size



CORPORATE PARTNERS

NAF partners with a variety of corporations. We would like to recognize our corporate partners who provided much needed support in 2021.

\$25,000+

AavantiBio
Biohaven Pharmaceuticals
Biogen
F. Hoffman-LaRoche Ltd.
Ionis Pharmaceuticals
PTC Therapeutics
Reata Pharmaceuticals Inc.
Seelos Therapeutics
Takeda Pharmaceuticals
UniQure
Vico Therapeutics B.V.

\$10,000 - \$24,999

Lacerta Therapeutics
Variantyx

\$5,000 - \$9,999

BioSensics LLC
Cure DRPLA
Destroyer Park Golf
Exicure
Google, Inc
Insperity Services, LP
Jackson National Life Insurance
Larimar Therapeutics
Microsoft

\$2,500 - \$4,999

Asper Biogene
Cigna
Gene DX, Inc
Paypal Giving Fund

\$1,000 - \$2,499

Andersen Corporation
AngleTech / Cycle different
Cruisin Cajun Country, Inc.
Eagle Sprinkler Fire Protection, Inc
Federal Home Loan Bank of
Pittsburgh
Gartner, Inc.
Hunt & Viveiros, LLC
Mobius Mobility, Inc
Preferred Title
Silicon Valley Community
Foundation
V and B Farms
Weeping Beech Charitable Fund

FOUNDATIONS

NAF received grants from various foundations in 2021. We thank them for the opportunity and their support and commitment to our mission.

\$25,000+

Michael and Patricia Clementz-
Peterson Family Fund

\$2,500 - \$4,999

Evelyn S & Jim Horne Hankins Foundation
Tom & Deb Swenson Foundation

\$10,000 - \$24,999

Leader Family Foundation

\$1,000 - \$2,499

Direct Supply Foundation, Inc
Enterprise Holdings Foundation
The Ho Hing Dai Family Foundation Inc
The J M A Foundation
Ladies Who Rock for a Cause
Wells Fargo Community Support

\$5,000 - \$9,999

EveryLife Foundation
Nebraska Ataxia, Inc.

COMMUNITY GIVING PLATFORMS

NAF does not receive individual donor information from third-party giving platforms. We do want to recognize the individuals who supported us through a community giving platform. Thank you for your generous contributions in 2021!

\$50,000+

Facebook

\$2,500 - \$4,999

Burnt Hills - Ballston Lake School District
CFC TASC

\$5,000 - \$9,999

Amazon Smile
Benevity Community Fund
Chesapeake Chapter
Mississippi Chapter

\$1,000 - \$2,499

Bright Funds Foundation
Network for Good
United Way of Greater LA

INDIVIDUAL

We are humbled by our generous donors who supported our work in 2021. These individuals stepped forward to make sure that NAF can continue to lead efforts to accelerate development of treatments for Ataxia and improve the lives of those living with the disease. The caring individuals who contributed \$1,000 or more are listed below.

\$10,000 - \$1,000,000+

Anonymous
Chip Carlisle
Don Heeringa
Eric Peterson
Estate of Mark Brandt
Eugene and Margaret Klingberg
Gregory Klassen
Janet Bye
Jean Booher
Jennifer Warchol
Jing Tan
Joe Frei
John Patterson Estate
Judith Meelia
Kathleen and John Schnobrich
Lenny Pollak
Lisa Frei
Marsha Asp
Mary Bird
Michael and Patricia Brennan
Nancy and Rob Schultz
Russ & Susan Roller
Tamara and Steve Peterson
Tommy Frei

\$5,000 - \$9,999

Andrew Pickering
Brett and Melody McKay
Brian Covington
Cathleen and Rick Bethay
Dan and Stacey Strojny
Darrell Knutie
David and Becky Face
Derek Ho
Gil Robinson
James Taylor
Janet Keene
Karen Brown
Kathy and Thomas Manenti
Kathy Strand
Laura Ranum
Lonny Palubicki
Mark Machado
Maryann Sweeney
Michael and Janet Sweeney
Oscar Torres
Ruth Coffey
Scott Peterson and Lisa Ord
Suzanne and Clark Lemons
Sylvia Shelstad
Tamra Humes
Valerie Bunnell

Wendy and Richard Clemens
William Nye
William Sweeney

\$2,500 - \$4,999

Andrea Matazarro
Ashlyn Marban
Bruce Bolbock
Carolyn Straub
Cecily Jaynes
Cherie Nixon
Dan and Julie Brunnert
Daniel & Laurie Flynn
Douglas and Kimberly Brunnert
Edith Payne
Eileen Murray
Gina and Brian Bryzgalski
James Keene
Jane Jaffe and Larry
Jason Pruet
Jeannette and Matthew Viveiros
Jerry Hall
John and Lisa Dix
Karen and Barton Suchomel
Kenneth Kueny
Laurie & Tom Likai
Matt Curran
Nancy Haugen
Nicholas Pequeno
Roger and Elaine Wheeler
Ronald Mason
Sam Andrus
Sandra Johnson
Sandy and Howard Miller
Wendy Kreitman

\$1,000 - \$2,499

Adam Daggy
Amy Lau
Anna Matykowski
Anonymous
Anthony and Robyn Zeller
Ben Frei
Beverly Davidson
Bill Budris
Bill Laine
Bob Schlickbernd
Bob Sullivan
Bonnie Bunch
Bruce Ruehl
Carolyn Pierce
Charles and Anne Ludvik
Charlotte Depew
Cheri and Gil Bearman
Christopher Delagrange

Connie Warne
Coreen Gililand
Daniel and Sheila Irwin
David Perme
Deanna Povolny
Denise Kolpack
Dick and Robin Manley
Donald and Virginia Van Voorhis
Earl McLaughlin
Francis and Theresa Klitz
Frederick Hensel
Gerald and Candice Matykowski
Harlan Lindberg
Harry Orr
Hugh and Christine Hohe
Ingrid Mealer
James and Sheila Lemire
James Harrington
James Schaal
Janice and John Gisler
Jason Gale
Jeff and Karen Wedge
Jeff Barr
Jenny Parker
Jesse Hughes
John and Dana Mauro
John and Deborah Hazlin
John Asp
John Collin
John Smithers
Jon Nadler
Joseph and Joan Cronin
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Julie Schuur
K. C. and Nancy Turnbull
Karen and Thomas Ganey
Katharine Adams
Katherine Sweeney
Kathryn Youngblood
Katie and Ted Clark
Keith Bottorff
Kelly and Luke Rutledge
Kerry Enright
Kristina Nave
Laddy Ospanik
Larry and Joyce Stobbs
Laura Ospanik
Lauren Anthonie
Lawrence Adair
Linda Hunnius
Lindsay Basciotta
Lucille Lundquist
Luke and Pamela Hankins

Maggie & Wally Ducayet
Marc and Carolilne Heilweil
Marcie Anthonie
Margaret Kennedy
Marilyn Teske
Mark and Jill Steppe
Mark Robinson
Mary Ann Tucci
Mary Harrold
Meg McLane
Melissa Clausen
Michael and Janet Hensley
Michael and Teresa McCombe
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Patsy Gaffney
Paul and Karen Silva
Paul Mugnier
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Randall and Anne Rice
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Rhonda Holt
Richard and Carole Carr
Richard and Marie Brand
Richard Berkins
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RT and JP Ramsay
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Sandra Deane
Sarah McNaughton
Scott Walters
Shannon Brown
Sharon Ephraim
Sherri and Jason Hubbard
Sid Lawton
Socorro Cavazos
Spencer Giddings
Stephen Krasner
Steve and Judith McPhail
Stuart Emery
Sylvia Bartfalvi
Tetsuo Ashizawa
Theresa Zesiewicz
Thomas and Elsie Hogan
Thomas Malia
Thomas Underwood
Valerie Arias
Vicki Merrill
William Maitland

“

“I specifically donate to NAF because in attending meetings in the past I saw members who experience much greater difficulties than myself and I feel it is my responsibility as a member of the Ataxia community to help. I also believe that I have a responsibility to help the human community. I do have a selfish reason that I contribute concerning my sons, my understanding of genetics is that both of my sons are at risk of inheriting my gene for Ataxia. In my lifetime there have been many advances in the understanding of Ataxia and I wish this to continue as it will benefit all those affected by Ataxia and future generations that could be affected. From someone who has Ataxia, thank you to all those people that help us.”

— Richard, Impact Partner

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. Impact Partners are people who give what they can to help us offer Ataxia research grants, provide educational programs for Ataxia families, and offer support services in local communities around the country. Thank you for your consistent support in 2021!

126 → monthly donors

\$38,971 → raised by Impact Partners in 2021

WALK N’ ROLL TO CURE ATAXIA

Walk N’ Roll to Cure Ataxia is a fundraiser organized by volunteers in their local communities. In 2020, a single national virtual event was held since the pandemic prevented gatherings. In-person events returned in 2021.

Some event organizers decided to get together again, while others participated in a virtual Walk. Thank you to everyone who organized, donated, and/or attended these impactful events!

Virtual Walk N’ Roll Stats
October 16, 2021

115 → Attended Live

\$71,093 → Raised

391 → Donations

Community Walk
N’ Roll Stats

8 → Walks

\$188,153 → Raised

1,203 → Donations

PASSION FUNDRAISING

Many thanks to the individuals or groups who turned their passions into a community fundraising event for a good cause! These events raise money in support of NAF’s mission to accelerate the development of treatments while improving the lives of those living with Ataxia. Thank you for the generous donations and time spent organizing the events.

13 → Passion Fundraisers

\$119,963 → Raised



WORKING TOWARDS A CURE

SUPPORT & REVENUE

Contributions	\$1,954,070
Research Collaborative	\$499,995
Conference Income	\$212,609
Other Income	\$241,501
Total	\$2,908,175

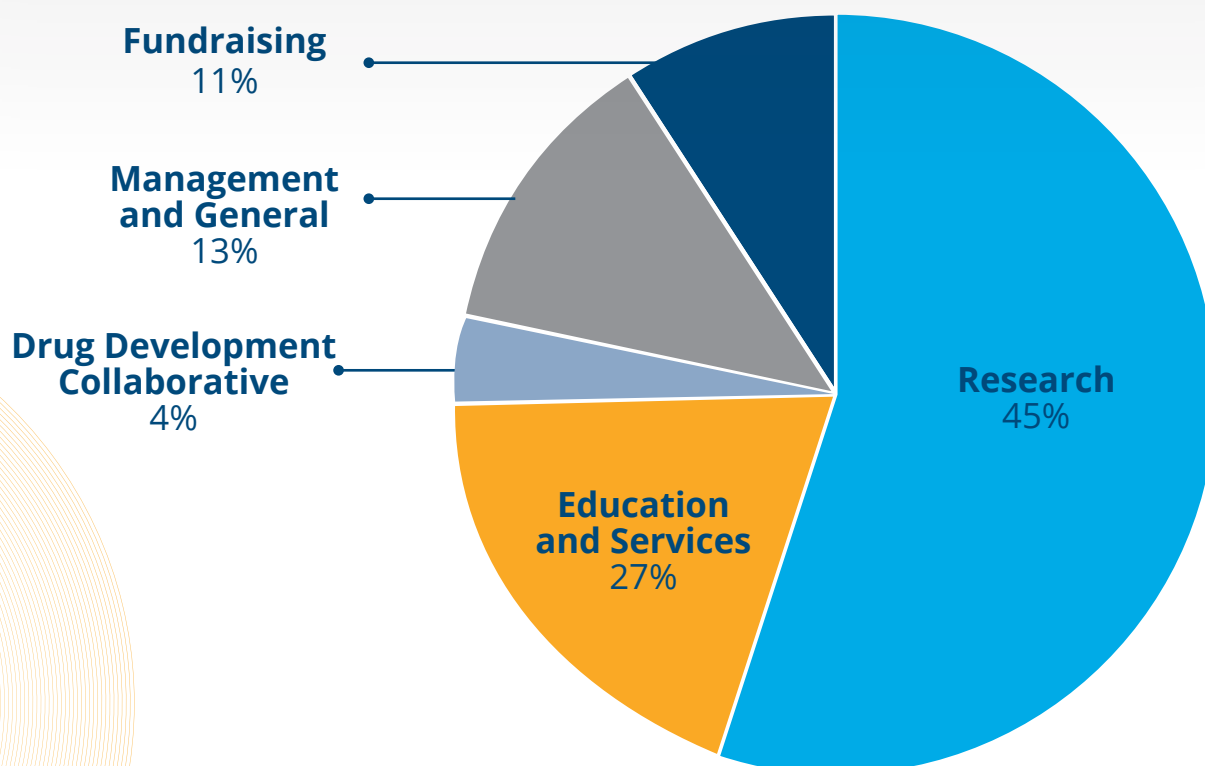
EXPENSES

Research	\$1,175,717
Education and Service	\$700,800
Drug Development Collaborative	\$106,754
Management and General	\$343,800
Fundraising	\$283,086
Total	\$2,610,157

NET ASSETS

Change in Net Assets	\$298,018
Net Assets, beginning	\$3,862,203
Net Assets, ending	\$4,160,221
Total Assets	\$4,160,221
Total Liabilities	\$246,072
Total Net Assets	\$4,406,293

HOW WE SPEND OUR MONEY



ORGANIZATIONAL LEADERSHIP



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University of Florida

George "Chip" Wilmot, MD, PhD
Emory University

Robert B. Wilson, MD, PhD
University of Pennsylvania



NAF Staff

To our donors, community members, partners, and Ataxia professionals, we thank you for making 2021 a successful year. Your support and participation are key to accelerating the development of treatments for Ataxia.

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