



**National Ataxia
Foundation**

**WALK
N'ROLL**
TO CURE
ATAXIA

National Ataxia Foundation
REATA

2018 Annual Report

WORKING TOWARDS A CURE

The National Ataxia Foundation (NAF) was founded in 1957 to search for a cause and cure for Ataxia. This continues to be at the heart of the organization today. Ataxia is a devastating disease that negatively impacts peoples' lives. NAF is a world leader in the Ataxia research field, using national and global collaboration to further research efforts.

We exist to improve the quality of life for persons with Ataxia and their caregivers through research, support group services, and education about managing their disease. NAF builds connections in the

Ataxia community and empowers people to make the best choices possible to live better.

Advances in Ataxia science are happening rapidly. The support of our community is crucial, both from our donors and families, as we come closer to having effective treatment options available. NAF is taking a leadership role in helping pharmaceutical companies and education research institutes with recruiting efforts for research studies and clinical trials.

Your support helps us move Ataxia research forward. We will not stop until there is a cure.

A special thank you to our donors, Support Group Leaders, Ambassadors, volunteers, organization partners, researchers, and clinicians.

Your impact on the Ataxia community is unparalleled and greatly appreciated. We look forward to another year of big advances in Ataxia research and support.



Bill Sweeney
President



Andrew Rosen
Executive Director

NAF Mission:

The National Ataxia Foundation is dedicated to improving the lives of persons affected by Ataxia through support, education, and research.





RESEARCH

27

Research Initiatives Funded

\$1,172,387

Spent Funding Research Initiatives

1,743

Total People Enrolled in the Ataxia Patient Registry

CLINICAL RESEARCH CONSORTIUM FOR THE STUDY OF CEREBELLAR ATAXIA

A cooperative initiative to improve Ataxia research and prepare for clinical trials. The consortium works together to study the natural progression of Ataxia and develop effective measurement guidelines for Ataxia research.

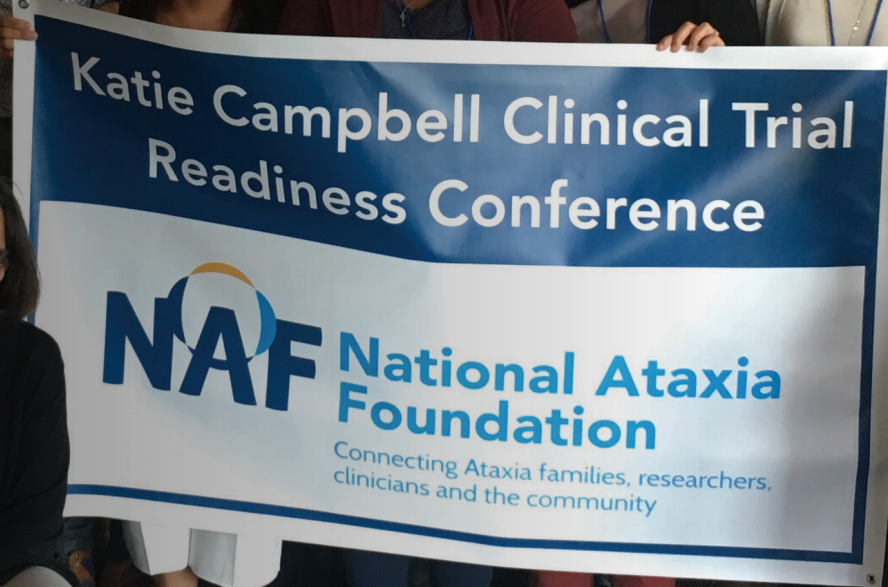


13 Sites Funded Nationwide



1 New site added in 2018

Sites: Columbia University, Emory University, Houston Methodist Research Institute, Johns Hopkins University, Massachusetts General, Northwestern University, University of Arizona, University of California, University of Chicago, University of Florida, University of Michigan, University of Minnesota, University of Utah



IMPACT

PROGRAMS AND SERVICES

26

Ataxia Awareness Events

57

Ataxia Support Groups in 41 States and 3 Countries

193

Ataxia Support Group Meetings Held

2018 ANNUAL ATAXIA CONFERENCE

Every year, NAF coordinates the world's largest annual Ataxia gathering. For two days, conference attendees meet and learn from world-leading Ataxia researchers and clinicians, network, and reunite with old friends. Hundreds of people –from patients, to caregivers, to medical professionals –attend the conference.



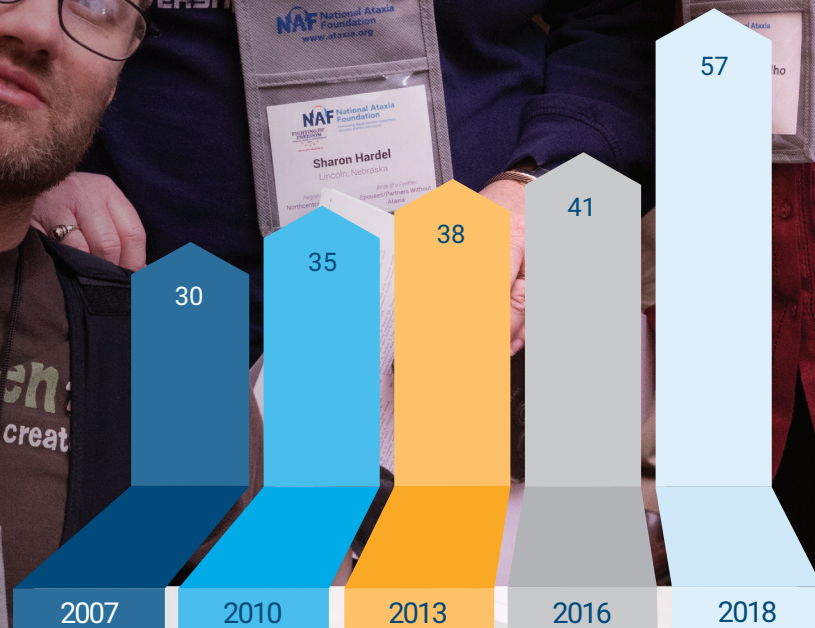
531 Attendees | from 37 States | 6 Countries



32 Travel Grant Recipients



22 Birds of a Feather Sessions Provided

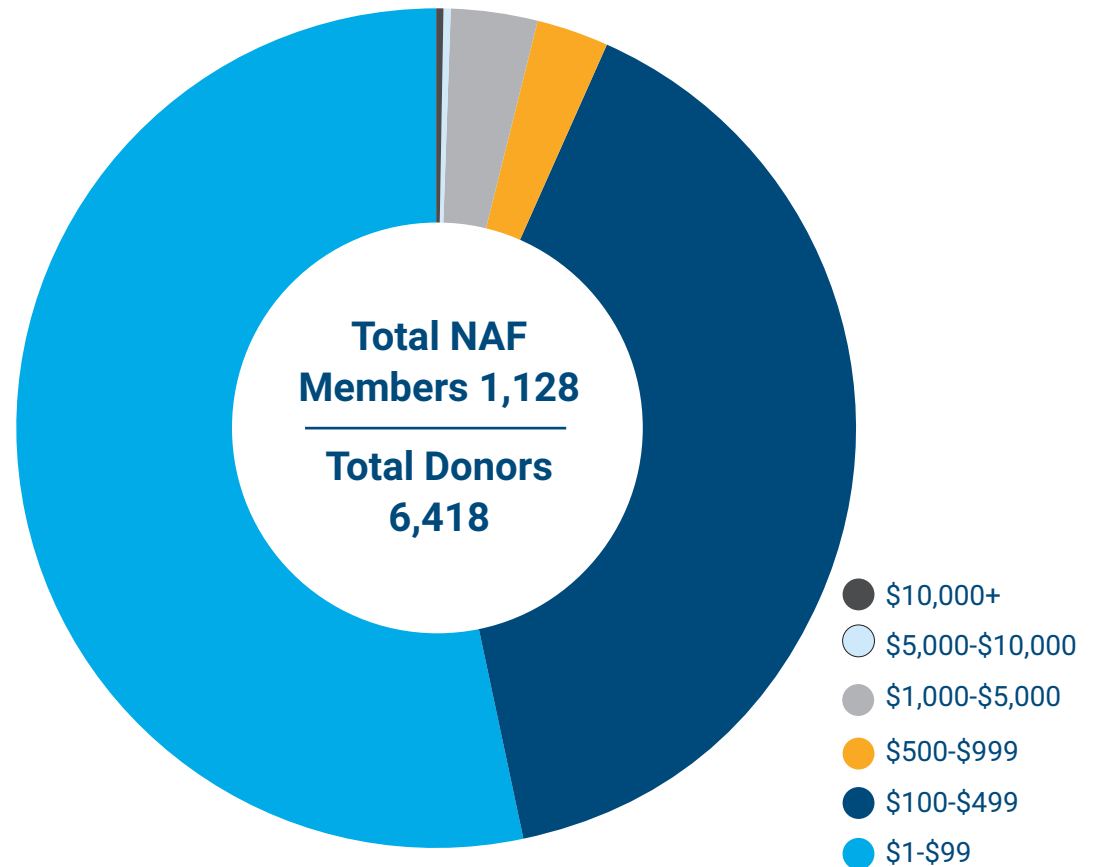


SUPPORT GROUP GROWTH





Our donors make it possible to fund Ataxia research and offer support and education services to the Ataxia community. We are grateful for our supporters and will continue to utilize your donations to fulfill our mission to improve the lives of persons affected by Ataxia.



Corporate Partners

A generous group of corporations chose to partner with NAF in 2018, providing much needed support.

\$25,000+

Biohaven Pharmaceuticals

\$10,000 - \$25,000

Albert Frei & Sons
Biogen
Cadent Therapeutics
Novaspace.com
Priority Courier Experts
Reata Pharmaceuticals

\$5,000 - \$9,999

BioMarin
Burnt Hills - Ballston Lake School District

A-T Children's Project
Cydan II
Edwards Lifesciences
FGX International
Friedreich's Ataxia Research Alliance
Ionis Pharmaceuticals
Massachusetts Mutual Life Insurance Company
Takeda Pharmaceutical Company

\$2,500 - \$4,999

Greenways Landscape Services
Hometrust Mortgage
Retrophin

\$1,000 - \$2,499

APDM
Amazon Smile Shopping program
Ataxia UK
Cetera Advisor Networks
CML Wealth Management
Cruisin Cajun Country
Fiber Optic Center
First Eagle Investment
Fragasso Financial Advisors
Hoffmann, Hoffmann & Gebhard
Hunt & Viveiros
Ingle Law Office
Keches Law Group
Law Offices of Brent A. Duque
Medical Neurogenetics

Advanced Masonry Restoration
Mississippi Polymers
Silicon Forensics
Steminent Biotherapeutics
Tegra Medical
Torres Electrical Supply Co

Foundations

NAF was awarded numerous grants from foundations in 2018. We thank them all for their generous support and commitment to our mission.

\$100,000+

Gordon & Marilyn Macklin Foundation

\$25,000+

Anonymous
Clementz Foundation

\$10,000 - \$25,000

Babcox Family Foundation
Leader Family Foundation

\$5,000 - \$9,999

The Marcon Foundation Inc.
Rotary Foundation

\$2,500 - \$4,999

JP Morgan Chase Foundation
The Saint Paul Foundation

\$1,000 - \$2,499

The CarMax Foundation
The Community Foundation
Evelyn S & Jim Horne Hankins

Foundation
Exelon Foundation
Marcie L Anthonie Charitable Fund

The J M A Foundation
PVH Foundation
Virginia Lucas Charitable Fund

Community Giving Platforms

Although NAF does not receive individual donor information, we do want to recognize these Community Giving Platforms that contributed to us in 2018.

\$100,000+

Facebook

\$25,000+

United Way

\$5,000 - \$9,999

Benevity Community Fund
YourCause

\$2,500 - \$4,999

Combined Federal Campaign
Network for Good

\$1,000 - \$2,499

Paypal Giving Fund
Schwab Fund for Charitable Giving
TRUIST

\$1,000 - \$2,499

Allstate Giving Campaign
Community Health Charities

Cybergrants StateStreet
Thrivent Choice
Travelers Community Connections



Individuals

Our generous donors allow NAF to continue our important work funding critical research and support services. These caring individuals who contributed at least \$1,000 are listed below

\$50,000+

Anonymous
Anonymous
Estate of Brenda L. Gourdin
Myron and Army Haugen
Marcia Neugebauer
Carol Stabenow

Laura Ospanik
Ed Ringer
Debbie Ringer
Carolyn Straub
William Sweeney
Janet Sweeney
Elaine Wheeler
Joan Wisniewski

Thomas Frei
Joseph & Amber Frei
Lisa Frei
Yuko Gee
Martine Geraerts
Coreen Gililland
Janice and John Gislser
Gerard & Janet Glinsky
Russell Godbersen
Mark Graham
Terry Greenwood
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Jerry Hall
Andrew Haluska
Rhonda Holt
Donald Huebner
Linda Hunnius
Daniel and Sheila Irwin
Clyde and Denise Jackson
Richard Jones
Margaret Kennedy
Gene Klingberg
Eugene Klingberg
Conrad Koch Jr.
Mary Kohfeld
Jerry & Cecelia Lange
Amy Lau
Harlan Lindberg
Joe and Anne Linnen
Robert & Lynda Loigman
Sarah Luchansky
Lucille Lundquist
Thomas Malia
Dick Manley
Jim Martin
Cherie Marvel
Bruno and Rhonda Mastroprimiano
Meg & Jamie McLane
Earl McLaughlin
Vicki Merrill
Gregory Messigian
Uwe Meya
Eileen Millburg Estate
Hoit Miller
Sandy Miller
William Milligan
Gay Monaco
John & Jane Moore
Patty Myers
Eric Newman

Roy Francis O'Connor
Puneet Opal
Harry Orr
Jamee Pau
Edith Payne
Michael & Mary Beth Peabody
Joan and Harold Peper
Bill Pierro
John Plut
Deanna Povolny
R. T. & J. P. Ramsay
Scott & Emily Ray
Wilson Romero
Jonathan Rubin
Jack Sandoe
Noreen Scherer
Michael Schleyhahn
Paul & Kandace Schneider
Robert & Nancy Schultz
Julia Schuur
Sylvia Shelstad
Ludy Shih
Rollie Sivyver
Linda Snider
Mary Beth Snyder
Suzanne Spicer
George Stone
Kathy Strand
Robert & Ashley Sturdevant
Niels Svenstrup
Maryann Sweeney
Pei Tang
Robert Taylor
Marilyn Teske
Mary Ann Tucci
K. C. & Nancy Turnbull
Nan Vail
Koene Van Dijk
Paul and Tracey Van Hoof
Elizabeth Wagner
Priscilla Wallack
Russell Wantland
Michael Willard
Robert Wilson
Ing Liong Wong
Irene Wu
Anthony & Robyn Zeller
Dave Zilles
Jon Zilles

\$25,000 - \$49,999

Anonymous
Richard and Lois Bierschbach
Estate of David J Liva

\$1,000 - \$2,499

Larry Adair
Kristian Adair
Katharine Adams
Lauren Anthonie
Moore Arnold
Nancy Atha
Cheryl Bearman
Carole Ben-Maimon
Don and Sheri Benninghoven
Rob Berman
Thomas Billings
Daniel Bradley
Tammy Brazil
David & Holly Brunnert
Doug Brunnert
Douglas and Kimberly Brunnert
Marc and Janis Bush
Michael Cammer
Blayne and Karen Cannon
Richard & Carole Carr
Randy Castle
Ryan Chang
Trois Chevaux
Kathryn Collier
Brian Covington
Derek Coyne
Ibrahim Dagher
Anderson Dahlen
Beverly Davidson
Rushika de Silva
Sandra Deane
Christopher DeHaven
Charlotte L. Depew
Krzysztof Drzewiecki
Clint Duke
Michelle Fateh
Antonio Fernandes
Shawn Firebaugh
Bernard Frei
Al & Laura Frei

\$10,000 - \$24,999

Anonymous
Nelía Aguiar
Ruth Coffey
Stephan Cossack
Sergio Damasio
Janet Keene
Darrell Knutie
John and Kathleen Schnobrich

\$5,000 - \$9,999

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Roger & Peggy Furton
Jeff & Kim Gottschalk
James Keene
Thomas Keene
Gregory Klassen
Brett and Melody McKay
Eric Peterson
Laura Ranum
Tammy Trenkmann-Perry

\$2,500 - \$4,999

Dorothy Bowdon
Socorro Cavazos
Edward & Susan Ciolkosz
Camille Daglio
Estate of Marvin G. Way
Erica Flora
Brent and Penny Hays
Tamra Humes
Jane Jaffe
Michael & Karen Leader
Ronald Mason
Cherie Nixon
William Nye

COMMUNITY FUNDRAISING

Each year, volunteers that want to take an active role in supporting NAF's mission dedicate their time to organize fundraising events across the country. Their time and efforts allow NAF to continue leading the fight against Ataxia.

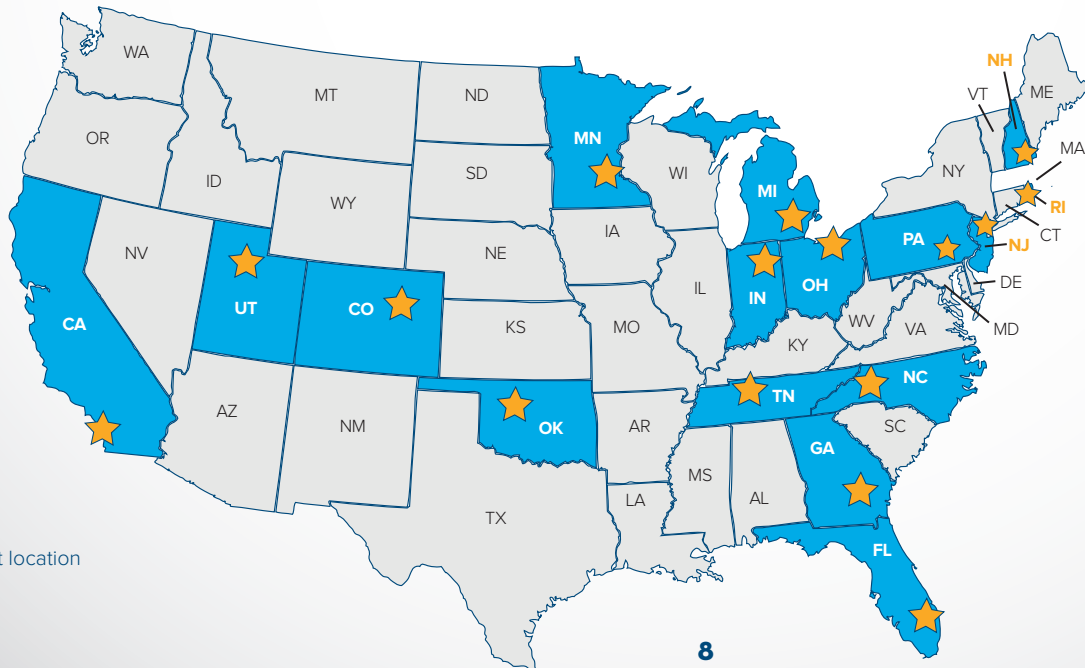


WALK N' ROLL

Walk N' Roll to Cure Ataxia is NAF's largest grassroots fundraising event. Coordinated entirely by volunteers, Walk N' Roll brings together thousands of people each year to help fight Ataxia. Our volunteers, walkers, rollers, and donors have raised more than **\$3,120,000** since 2007! Thank you for your support and commitment to support NAF's mission.

16 Walk N' Roll to Cure Ataxia Events Held
2,703 Donations
\$443,890 Raised

- Atlanta, GA
- Denver, CO
- Ft. Wayne, IN
- Ann Arbor, MI
- Minneapolis, MN
- Lakewood, OH
- Bristol, RI
- Londonderry, NH
- Yorba Linda, CA
- Nashville, TN
- Port St. Lucie, FL
- Jersey City, NJ
- Asheville, NC
- Hershey, PA
- Salt Lake City, UT
- Oklahoma City, OK



★ Indicates event location



Go the Extra Mile
479 Participants
\$73,482 Raised



Passion Fundraising
8 Events
\$53,075 Raised

WORKING TOWARDS A CURE

SUPPORT & REVENUE

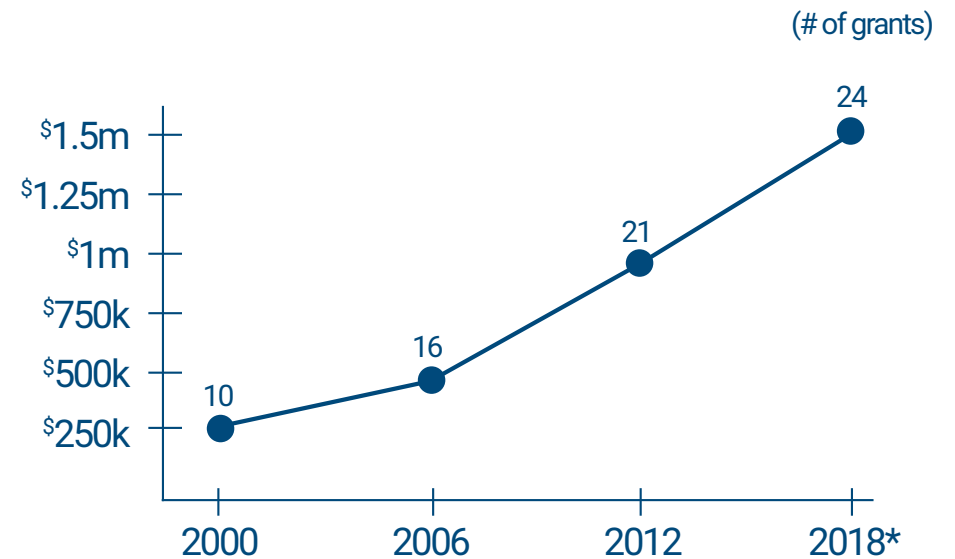
Contributions	2,197,456
Memberships	78,371
Conference Income	218,595
Other Income	(38,148)
Total	2,456,274

EXPENSES

Research	489,575*
Education and Service	515,613
Management and General	348,965
Fundraising	357,103
Total	1,711,256*

NET ASSETS

Change in Net Assets	745,018
Net Assets, beginning	2,758,662
Net Assets, ending	3,503,680
Total Assets	3,678,521
Total Liabilities	174,841
Total Net Assets	3,503,680



RESEARCH FUNDING GROWTH CHART

*Due to a change in the timing of NAF's research grant approval process, \$1,079,500 of 2018 research grant awards were not paid until Q1 2019. This resulted in a positive net income for the organization in 2018. This is a one-time event.





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2018 Board of Directors Meeting - Minneapolis, MN



2018 Ataxia Investigators Meeting - Philadelphia, PA

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