



**National Ataxia
Foundation**

A large, decorative circular graphic is centered on the page. It consists of an outer ring of thin, wavy, grey lines that resemble a stylized sun or a textured border. Inside this ring is a solid orange circle. The text '2019 ANNUAL REPORT' is centered within the orange circle. The background of the page is a light grey gradient, with dark blue and orange geometric shapes in the corners.

**2019
ANNUAL
REPORT**

NOTE FROM THE EXECUTIVE DIRECTOR

2019 was the 63rd year of existence for the National Ataxia Foundation. I am proud to report that NAF's mission, "to improve the lives of persons affected by Ataxia through support, education, and research," has never rung more true than in this past year. In contrast to NAF's rich history, 2019 was my first year as Executive Director. It has been such a true honor for me to meet so many of you, whether it was at our record-setting 62nd Annual Ataxia Conference in Las Vegas, at one of the dozens of support group meetings that happen around the country every month, or at a local fundraising event that is such a critical part of our organization's funding. The resilience, commitment, and grace shown by this community and the personal stories you have shared are the motivation NAF needs as we push forward.

I have seen this same commitment from our dedicated group of Ataxia researchers and clinicians with whom we work so closely in pursuit of treatments and an eventual cure for Ataxia. Through NAF's support, these scientists and doctors have made consistent progress in understanding the disease of Ataxia and in preparing their clinics for the pharmaceutical trials that have already started and will continue. 2019 was also the year that NAF's partnership with pharmaceutical companies interested in developing treatments for Ataxia continued to evolve. There has never been more interest from pharma, and we're doing everything we can to help them accelerate their development programs.

NAF would like to thank you, our remarkable group of donors and volunteers, for your accomplishments in 2019. Whether it be dropping off a check at your local Walk n Roll, being a Support Group Leader lending a hand in your community, or making a matching gift during our annual fundraising drives, we simply couldn't do our work without you. We look forward to another year of growth for NAF in 2020 and connecting with you along the way.

A handwritten signature in white ink on a dark blue background. The signature is cursive and reads "Andrew Rosen".

Andrew Rosen, *Executive Director*

MEMBERSHIP



NAF MEMBERSHIP

For 62 years, NAF has been a member-based organization. In our earlier days, membership dues helped fund research and keep operations going. With more diverse fundraising opportunities, NAF was able to begin offering free membership in 2019. With that change, we saw the largest growth in NAF membership in our history. We are proud to announce that our membership more than tripled in 2019 – with a record 3,665 active members of NAF.

224%

increase
in members



NAF Mission:

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

COMMUNITY PROGRAMS AND SERVICES IMPACT



ATAXIA SUPPORT GROUPS

Connecting with other individuals affected by Ataxia is an important service that NAF offers. Thousands have learned more about their disease and been connected to services and specialists in their communities from networking at a local support group. We value the leaders who volunteer their time to help coordinate these important Ataxia Support Groups.



2019 Ataxia Support Groups

▶ 63 Ataxia Support Groups

10 new support groups in 2019



10% increase

▶ 605 Support Group Meetings



213% increase



Groups in 41 states and 4 countries

ADVOCACY

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 your stories to policy makers and pharmaceutical companies to grow awareness, accelerate drug development, and ensure access to care and treatment services.



Awareness Events

▶ 180 Awareness Events



6x more than previous years

FIRST EVER UNITED AGAINST ATAXIA HILL DAY ON CAPITOL HILL

● Held September 25, 2019

● 13 Ataxia advocates attended

● Met with 14 US Senators' Offices



OUTREACH TO A YOUNGER GENERATION

A brand-new support group was formed this year – one that addresses issues that are specific to young adults with Ataxia. Under 30 with Ataxia, a virtual group using the Facebook platform, began after Lauren Sormani attended NAF's Annual Ataxia Conference and wished to maintain the connections that she formed with others. She stepped up to be a Support Group Leader for NAF and a voice for younger people affected by Ataxia.



“Navigating high school and college with Ataxia was no walk in the park. The entire time I was forging my path blind—I did not know anyone who had recently paved that path before me. Over the years I came up with my own modifications for most of college life. While my friends are amazing and very supportive, it was hard for them to understand what I was going through and how to best help me. After all, how could they if they were not living with Ataxia themselves? Looking back over the last few years, my life would have been immensely easier if I had other college-aged Ataxians to bounce ideas off of or to ask for advice in certain social situations. While I am extremely grateful for the information I have gathered from all the Ataxians I have met, I felt there was a gap that needed to be filled.

I was elated to be able to give advice to others, especially those who are younger than me, about my tips and tricks for navigating high school and college with Ataxia, and I know others were as well. Many gained new friends, including myself. We all agreed that there is a need for more involvement from the younger generation of people living with Ataxia. The Under 30 with Ataxia Facebook Support Group was created shortly after.”

Lauren Sormani, SCA8

ANNUAL ATAXIA CONFERENCE

Every year, we coordinate 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. We had record-breaking attendance at NAF's 2019 Annual Ataxia Conference.



683 attendees
Representing 41 states
and 13 countries



29% increase



30 Travel Grant Recipients



21 Sponsors



RESEARCH IMPACT



NAF RESEARCH GRANTS

We are committed to funding the best science relevant to hereditary and sporadic types of Ataxia – it is at the core of our mission. NAF offers various types of research grants to encourage further investigation into therapy development for Ataxia.



26

Research
Initiatives
Funded



Nearly
\$1 MILLION

Spent Funding
Research
Initiatives



2,088

Total People
Enrolled in the
Ataxia Patient
Registry



“I have been a big supporter of the NAF for many years, and they have supported me. I’ve had a Pioneer Investigator Award that led us to some of the discoveries we made about SCA3. And several investigators in my own laboratory have won Post Doc Awards or Young Investigator Awards. I think what they’ve been able to do with a fairly small amount of money has had a huge impact. Particularly for the SCAs.”

– **Henry Paulson, MD, PhD,**
University of Michigan

HOW DONATIONS TO NAF LEAD TO A BETTER UNDERSTANDING OF ATAXIA

Each year, NAF accepts Ataxia research proposals from all over the world. A team of the top Ataxia scientists review the research and select the best, most promising studies for funding from NAF. It is a long process, but one that NAF and our volunteer scientists take very seriously. We know that these studies can lead to big breakthroughs for Ataxia. One day, they could lead to a cure.

Giorgio Grasselli, Ph.D, was the recipient of a research grant from NAF. His study, which was funded in part by the generous donations that individuals make to NAF, led to new understandings in Ataxia. Grasselli recently published the results of his study, titled, “SK2 channels in cerebellar Purkinje cells contribute to excitability modulation in motor-learning-specific memory traces.” His work showed that knocking-out SK2 specifically in cerebellar Purkinje cells causes only a subtle but significant alteration of locomotor strategy (longer steps, reminiscent of dysmetria that is typical in ataxic patients), while a constitutive SK2 mutation causes dramatic tremors.

With help from our donors, NAF is proud to offer support to researchers, such as Grasselli. Their work is critical to developing effective treatments.

“I would like to express again my gratitude to the NAF for the support that was essential to conduct this study which gave a significant contribution to better understand the pathophysiology underlying ataxic symptoms.”

Giorgio Grasselli, Ph. D.

CLINICAL RESEARCH CONSORTIUM FOR THE STUDY OF CEREBELLAR ATAXIA



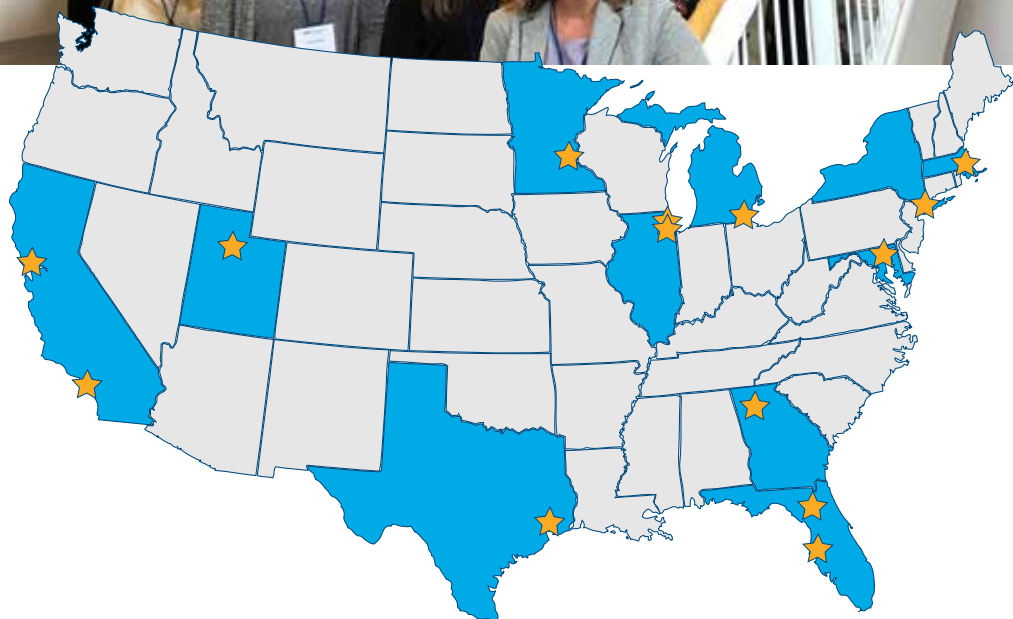
14 Sites Funded Nationwide

CRC-SCA is a group of researchers and clinicians working together to accelerate research and prepare our community for clinical trials. They work together to study the natural progression of Ataxia to help develop effective measurement guidelines for Ataxia research and therapies.



CRC-SCA Mission:

To better understand the factors that determine disease progression among Cerebellar Ataxia with the goal of improving the understanding of the disease process, current treatments, and development of disease-modifying therapies.



SCA GLOBAL



▶ 123 Attendees

SCA Global is an international collaborative in clinical research efforts for the Spinocerebellar Ataxias.

Launched in 2018, NAF is proud to be an integral piece of forming this important group. NAF helped host the first SCA Global Conference in 2019.

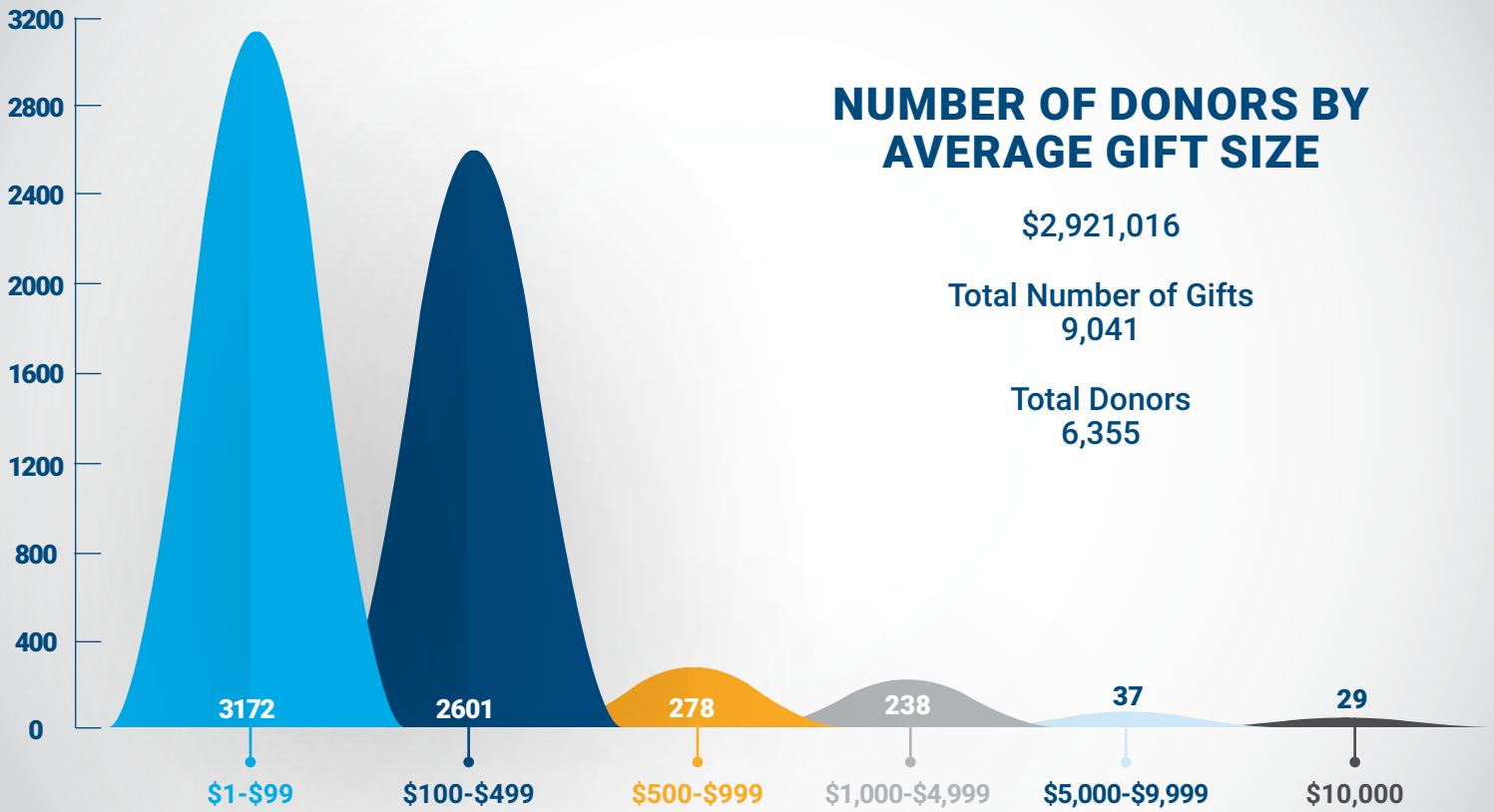
GOALS OF SCA GLOBAL

- 1** Better understand the manifestation, evolution, and impact of various SCA's
- 2** Develop and validate biomarkers which can be used in future interventional trials
- 3** Facilitate access to people with SCA's who are willing to participate in clinical trials



THANKS TO OUR DONORS

Our donors make it possible to fund Ataxia research and offer support and education services to the Ataxia community. We are grateful for your overwhelming support 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 2019, providing much needed support.

\$25,000+

Biohaven Pharmaceuticals
Cadent Therapeutics
Ionis Pharmaceuticals
Exicure

Ixico
Greenways Landscape Services, LLC
California Analytical Instruments, Inc.
Charter West Bank
FGX International
Takeda Pharmaceuticals USA, Inc.
Wave Life Sciences

TD Ameritrade Clearing
Country Meadows Associates
Morgan Stanley
First Eagle Investment
Enterprise Holdings
Technical Assessments
Fiber Optic Center, Inc
Herb Chambers Honda of Burlington
Hoffmann, Hoffmann & Gebhard
Hunt & Viveiros, LLC
Keches Law Group, P.C.
ME Tonka, Inc.
Medical Neurogenetics, LLC
Silicon Forensics, Inc.
Woodlake Wealth Management

\$10,000 - \$25,000

Reata Pharmaceuticals Inc.
Albert Frei & Sons, Inc.
Cydan II, Inc
PTC Bio
uniQure

\$2,500 - \$4,999

Los Alamos National Security, LLC
B. Braun CeGaT, LLC
Torres Electrical Supply Co, Inc.
Willmington Construction, LLC

\$5,000 - \$9,999

Lacerta Therapeutics
Massachusetts Mutual Life Insurance
Company

\$1,000 - \$2,499

Federal Home Loan Bank of Pittsburgh
Rock County Red Arrow

FOUNDATIONS

NAF was awarded grants from foundations in 2019. We thank them for their generous support and commitment to our mission.

\$100,000+

Gordon & Marilyn Macklin Foundation

\$25,000+

Michael and Patricia Clementz-
Peterson Family Fund

\$10,000 - \$25,000

Novaspace.com, LLC
Cossack Foundation
Babcox Family Foundation
Leader Family Foundation

\$5,000 - \$9,999

Minnesota Medical Foundation-BAARC

\$2,500 - \$4,999

Cerebellar Ataxia Australia Inc.
Burnt Hills - Ballston Lake School
District
Nebraska Ataxia, Inc.
Ataxia UK
AISA
Mennonite Foundation
Stuart and Joy Stein Family Legacy
Fund
The Minneapolis Foundation

\$1,000 - \$2,499

Exelon Foundation
JP Morgan Chase Foundation
Cruisin Cajun Country, Inc.

Evelyn S & Jim Horne Hankins
Foundation
Friedreich's Ataxia Research Alliance
(FARA)
Estate of Parson's Trust
Charitable Adult Rides and Services, Inc.
PSEG Foundation
Direct Supply Foundation, Inc.
Cardinals Care
Elsevier Foundation
EveryLife Foundation
Tom and Deb Swenson Foundation
Greater KC Community Foundation
United Food and Commercial Workers
1546

COMMUNITY GIVING PLATFORMS

Although NAF does not receive individual donor information, we do want to recognize those who gave through a Community Giving Platform. Thank you for your contributions in 2019.

\$100,000+

Facebook

\$25,000+

Fidelity Charitable Gift Fund

\$5,000 - \$9,999

Benevity Community Fund
YourCause, LLC

CFC TASC
Mississippi Chapter of NAF
United Way of Capital Region

\$2,500 - \$4,999

Charities Aid Foundation of America
Schwab Fund for Charitable Giving
Chesapeake Chapter

\$1,000 - \$2,499

Amazon Smile
TRUiST
United Way of Greater LA
United Way of Chicago Area
Northern California Ataxia Support
Group
LF Ospanik and SP Robbins Fund

INDIVIDUALS

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

\$50,000+

Anonymous
Anonymous
Clair and Marilyn Hoblit
Anonymous
Marcia Neugebauer

\$25,000 - \$49,999

Eric Peterson
Tamara and Steve Peterson

\$10,000 - \$24,999

Susan Huffman
Anonymous
Judy Meelia
Arthur and Mildred Walsh
Barry Hyman

\$5,000 - \$9,999

Anonymous
Madalyn and Jeff Gottschalk
Brett Grossman
Mary Bird
David Jr Henry
Lisa Ord
Maryann Sweeney
Neil and Linda Peterson
William Sweeney
Ruth Coffey
Nancy Haugen
Tamra Humes
Sergio Damasio
Darrell Knutie
Michael and Karen Leader
Gil L'italien
Emmett Mosley
James Keene
Judith Chronister
Ashlyn Marban
William Nye
Laura Ranum
Kathleen Schnobrich

\$2,500 - \$4,999

Jeffrey Gottschalk
Joseph and Catherine
Decrescenzo
Paul Bellamy
Camille Daglio
Roger and Elaine Wheeler
Laurie and Tom Likai
Adam Tabor
Harry Pilvinis
Kathleen Gingerelli
Jane Jaffe
Jodi Iverson
Philip Allison
Barton Suchomel
Rhonda Holt

Edward and Susan Ciolkosz
Brian Covington
Anonymous
Carolyn Straub
Cathleen and Rick Bethay
Susan Perlman
Andrew Haluska
Carolyn Allen
Trois Chevaux
Laura Cobb
Matthew Viveiros
Anne and Don Griswold
Ronald Mason

\$1,000 - \$2,499

Rolf and Lisa Schumann
Krzysztof Drzewiecki
Bernard Frei
Tetsuo Ashizawa
William and Nancy Brookhart
Daniel and Sheila Irwin
Richard and Carole Carr
Tim and Karen Miller
K. C. and Nancy Turnbull
Anthony and Robyn Zeller
Priscilla Wallack
Dorothy Bowdon
Russell Jordan
Vicki Merrill
Sylvia Shelstad
Helena Teixeira
Dave Zilles
Joseph Frei
Charlotte Depew
Laura Ospanik
Delano Brazil
Eric and Alexander Piper
R. T. & J. P. Ramsay
Thomas Frei
Doug Place
Michael Anderson
Lauren Anthonie
Lawrence Adair
William Maitland
Mike Estabrook
Linda Sidwell
Robert Fink
Marcie Anthonie
Karen Brown
Christopher Otley
Cathryn West
Leah and Mark Minkin
Lori Grigg
John Dwyer
Jeremiah Hume
Lisa Cole
Melinda Reese
Wilson Romero
Traci Schilling

Larry Schut
Coreen Gililand
Ed Ringer
Deanna Povolny
Dawn and Minkz Ngo
Richard Jones
Debbie Ringer
Daniel and Pamela Carr
Joseph Brown
Douglas and Kimberly
Brunnert
Dick Manley
Socorro Cavazos
Yun Roller
Bob Sturdevant
Efrem Mcadoo
Mary Ann Tucci
Mark Minkin
Lucille Lundquist
Randy and Pamela Perault
Cherie Nixon
Andrew Moss
John and Lisa Dix
Rey Dunca
Vincent Laugh
Janet and John Oshea
Derek Ho
Ethel Gilbert
Thomas Jones
Jane Olson
Marc Soares
Brian Spencer
Kristian Adair
Doug Brunnert
Jordan Combs
Greg Conger
Scott Dillingham
Lisa Drake
Brandon Farris
Gerard & Janet Glinsky
Allen J. Gula
Nancy Herndon
Lisa Krogulecki
Jon Larson
Anna Matykowski
Teresa McCombe
Earl McLaughlin
Gregory Messigian
Giovanni Morgano
Leonel and Janet Noia
Linda and Randal Pagel
Ronald Pamachena
Edith Payne
Carolyn Pierce
Nancy Schultz
Glenda Sheffield
Tenisha Williamson
Thelma Winston
Paschal and Sarah Guercio

Michael Derosa
Anne Leader
Kathy Davis
Beverly Davidson
Katharine Adams
Angie Almony
Moore Arnold
Nancy Atha
Thomas Baker
Peter Bialek
Jean Booher
Bret Bostwick
Melissa Clausen
Bob and Jane Collacchi
Richard and Betty Furton
Alex Harding
Frederic Heerinckx
Jesse Hughes
Serena Hung
Linda Hunnius
Mike and Carol Ingram
Gary Kay
Gregg Keaney
Margaret Kennedy
Dr. Mark and Terry Koller
Thomas Kremer
David and Liesa Leader
Harlan Lindberg
Rebecca Lipner
Yuanjing Liu
Melinda Maguire
William Milligan
Jodie Morrison
Benjamin Nystrom
Roy Francis O'Connor
Kathie Pierce
William Pierro
Steven and Pamela Ramsey
Mike and Toni Rosen
Bruce Ruehl
William and Elizabeth
Schluemer
Julie Schuur
Adam Schwarz
David Spotts
Mark and Jill Steppe
Marilyn Teske
Adina Tocoian Tocoian
Lodewijk Toonen
Astrid Valles Sanchez
Koene Van Dijk
Hao Wang
Ling-Mei Wang
Ing Liong Wong
Irene Wu

COMMUNITY FUNDRAISING



Passion Fundraising

▶ 16 Fundraisers



100% increase

▶ 627 Donors
\$148,799 raised



180% increase



Go The Extra Mile

▶ 15 Fundraisers

▶ \$25,181 Raised

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 effort allow NAF to continue leading the fight against Ataxia.

PASSION FUNDRAISERS

- Spacefest — Sally, Kelsey, and Nate Poor
- Cars of Summer — John Mauro
- Spaghetti Dinner — Teresa Bredberg
- Tea Time for a Cure — Jane Jaffe
- WPA Golf Outing — Madalyn Gottschalk
- Festival of International Flavor — Joe and Kathy Decrescenzo
- Brad's Fundraiser — Kim Stevenson
- Cameryn's Call for a Cure — Laura, Devin, Cameryn Cobb, Tammy Brazil
- Eat for a Cure — Mary Fuchs, Angela Li
- Lap the Lake — Wisconsin Ataxia Warriors- Dick Manley
- Kaffke Collective — Alicia Knopp
- NAF Poker Walk — Joel Sutherland
- Ataxia Awareness — Susan Kresnye



WORKING TOWARDS A CURE

SUPPORT & REVENUE

Contributions	2,572,793
Memberships	20,349
Conference Income	357,654
Other Income	194,353
Total	3,145,149

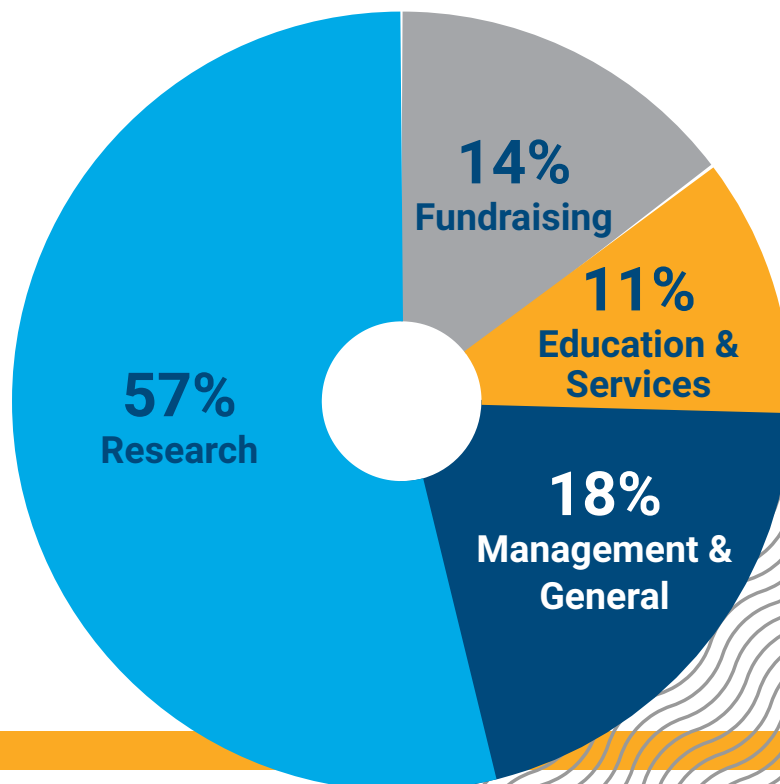
EXPENSES

Research	1,737,512
Education and Service	331,633
Management and General	558,982
Fundraising	422,964
Total	3,051,091

NET ASSETS

Change in Net Assets	94,058
Net Assets, beginning	3,503,680
Net Assets, ending	3,597,738
Total Assets	3,885,975
Total Liabilities	288,237
Total Net Assets	3,885,975

HOW WE SPEND OUR MONEY



ORGANIZATION LEADERSHIP



Board of Directors

President

William P. Sweeney*
Minneapolis, MN

Vice President

Camille Daglio*
Hattiesburg, MS

Treasurer/Secretary

Charlene Danielson*
Minnetonka, MN

Executive Committee Members

David Brunnert
Houston, TX

Joseph DeCrescenzo
Bear, DE

Sam Kirton
Fairfax, VA

John Mauro
Auburn, MA

Greg Rooks
Atlanta, GA

Medical Liaison

Lawrence Schut, MD
Maple Lake, MN

NAF Research Director

Harry T. Orr, PhD
Minneapolis, MN

NAF Medical Director

Susan Perlman, MD
Los Angeles, CA

Associate Research Director

Laura Ranum, PhD
Gainesville, FL

Directors

Michael Cammer
Downington, PA

Harold Crawford
Terry, MS

Cindy De Mint
Yorba Linda, CA

Mike Leader
Hummelstown, PA

Wilson Romero
New Iberia, LA

Marilyn Schut Lee
St. Cloud, MN

Linda Snider, MD
Omaha, NE

Dave Zilles
Atlanta, GA

*Executive Committee Members



Medical and Research Advisory Board

Research Director

Harry T. Orr, PhD
Director of Institute
for Translational
Neuroscience
Tulloch Professor of
Genetics
University of Minnesota
Minneapolis, MN

Associate Research Director

Laura Ranum, PhD
Professor of Molecular
Genetics and
Microbiology
Director, Center for
Gene Discovery and
Neurological Disease
University of Florida,
College of Medicine
Gainesville, FL

Medical Director

Susan Perlman, MD
Clinical Professor
UCLA Neurological
Services
David Geffen School of
Medicine
Los Angeles, CA

Medical Liaison

Lawrence Schut, MD
Maple Lake, MN

Tetsuo Ashizawa, MD, FAAN

Methodist Hospital
Research Institute
Houston, TX

Khalaf Bushara, MD, MRCP

University of Minnesota
Minneapolis, MN

Beverly Davidson, PhD

Children's Hospital of
Philadelphia
Philadelphia, PA

Brent L. Fogel, MD, PhD

David Geffen School of
Medicine
University of California,
Los Angeles
Los Angeles, CA

Christopher M. Gomez, MD, PhD

University of Chicago
Chicago, IL

Pravin Khemani, MD

Swedish Neuroscience
Institute
Seattle, WA

Sheng Han Kuo, MD

Columbia University
New York City, NY

Albert La Spada, MD, PhD, FACMG

Duke University School of
Medicine
Durham, NC

David Lynch, MD

University of Pennsylvania
Philadelphia, PA

Puneet Opal, MD, PhD

Northwestern University
Feinberg School of
Medicine
Chicago, IL

Gülin Öz, PhD

Center for Magnetic
Resonance Research
University of Minnesota
Minneapolis, MN

Liana Rosenthal, MD

Johns Hopkins University
Baltimore, MD

Henry Paulson, MD, PhD

University of Michigan
Medical Center
Ann Arbor, MI

Stefan Pulst, MD

University of Utah Health
Sciences Center
Salt Lake City, Utah

Jeremy D. Schmahmann, MD

Harvard Medical School
Boston, MA

Vikram Shakkottai, MD, PhD

University of Michigan
Ann Arbor, MI

S.H. Subramony, MD

University of Florida
Gainesville, FL

George "Chip" Wilmot, MD, PhD

Emory University
Atlanta, GA

Robert B. Wilson, MD, PhD

University of Pennsylvania
Philadelphia, PA

Huda Zoghbi, MD

Baylor College of
Medicine
Houston, TX

