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.

Andrew Rosen, Executive Director
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.

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.

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.

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

FIRST EVER UNITED AGAINST ATAXIA HILL DAY ON CAPITOL HILL

- Held September 25, 2019
- 13 Ataxia advocates attended
- Met with 14 US Senators’ Offices

180 Awareness Events

- 6x more than previous years
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
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.

**ANNUAL ATAXIA CONFERENCE**

- **683 attendees**
  - Representing 41 states and 13 countries
- **29% increase**
- **30 Travel Grant Recipients**
- **21 Sponsors**
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.
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 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.

NUMBER OF DONORS BY AVERAGE GIFT SIZE

$2,921,016
Total Number of Gifts
9,041
Total Donors
6,355
CORPORATE PARTNERS

A generous group of corporations chose to partner with NAF in 2019, providing much needed support.

$25,000+
Cadent Therapeutics
Ionis Pharmaceuticals
Exicure

$10,000 - $25,000
Reata Pharmaceuticals Inc.
Albert Frei & Sons, Inc.
Cydan II, Inc
PTC Bio
uniQure

$5,000 - $9,999
Lacerta Therapeutics
Massachusetts Mutual Life Insurance Company

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

$100,000+
Anonymous

$25,000+
Michael and Patricia Clementz-Peterson Family Fund

$10,000 - $25,000
Novaspace.com, LLC
Cossock Foundation
Babcox Family Foundation
Leader Family Foundation

$5,000 - $9,999
Minnesota Medical Foundation-BAARC

$2,500 - $4,999
Los Alamos National Security, LLC
B. Braun CeGaT, LLC
Torres Electrical Supply Co, Inc.
Willington Construction, LLC

$1,000 - $2,499
Federal Home Loan Bank of Pittsburgh

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

$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 Osspanik and SP Robbins Fund
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
Marcia Neugebauer

$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
Edward and Susan Ciolkosz
Brian Covington
Anonymous
Carolyn Straub
Cathleen and Rick Bethay
Susan Perlman
Andrew Haluska
Carolyn Allen
Trois Chevau
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 Anthone
Lawrence Adair
William Maitland
Mike Estabrook
Linda Sidwell
Robert Fink
Marcie Anthone
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 Gilliland
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 Rolleri
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 Boorer
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 Rinaldo
William and Elizabeth Schlueter
Julie Schur
Adam Schwarz
David Spotts
Mark and Jill Steppe
Marilyn Teske
Adina Tococi Tococi
Lodewijk Toonen
Astrid Valles Sanchez
Knene Van Dijk
Hao Wang
Ling-Mei Wang
Ing Liong Wong
Irene Wu
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.

**COMMUNITY FUNDRAISING**

**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

**Go The Extra Mile**

- 15 Fundraisers
- $25,181 Raised

**Passion Fundraising**

- 16 Fundraisers
- 100% increase
- 627 Donors
- $148,799 raised
- 180% increase
## WORKING TOWARDS A CURE

### SUPPORT & REVENUE

<table>
<thead>
<tr>
<th>Category</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contributions</td>
<td>2,572,793</td>
</tr>
<tr>
<td>Memberships</td>
<td>20,349</td>
</tr>
<tr>
<td>Conference Income</td>
<td>357,654</td>
</tr>
<tr>
<td>Other Income</td>
<td>194,353</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>3,145,149</strong></td>
</tr>
</tbody>
</table>

### EXPENSES

<table>
<thead>
<tr>
<th>Category</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Research</td>
<td>1,737,512</td>
</tr>
<tr>
<td>Education and Service</td>
<td>331,633</td>
</tr>
<tr>
<td>Management and General</td>
<td>558,982</td>
</tr>
<tr>
<td>Fundraising</td>
<td>422,964</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>3,051,091</strong></td>
</tr>
</tbody>
</table>

### NET ASSETS

<table>
<thead>
<tr>
<th>Description</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Change in Net Assets</td>
<td>94,058</td>
</tr>
<tr>
<td>Net Assets, beginning</td>
<td>3,503,680</td>
</tr>
<tr>
<td>Net Assets, ending</td>
<td>3,597,738</td>
</tr>
<tr>
<td>Total Assets</td>
<td>3,885,975</td>
</tr>
<tr>
<td>Total Liabilities</td>
<td>288,237</td>
</tr>
<tr>
<td><strong>Total Net Assets</strong></td>
<td><strong>3,885,975</strong></td>
</tr>
</tbody>
</table>

### HOW WE SPEND OUR MONEY

- **Research**: 57% (1,737,512)
- **Education & Services**: 18% (331,633)
- **Fundraising**: 11% (558,982)
- **Management & General**: 14% (422,964)

Pie chart showing the distribution of revenue and expenses.
**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