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.

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.
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.
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
$1 MILLIONNearly 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.
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
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.

THANKS TO OUR DONORS

NUMBER OF DONORS BY AVERAGE GIFT SIZE

Total Number of Gifts
9,041

Total Donors
6,355

$2,921,016
### CORPORATE PARTNERS

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

<table>
<thead>
<tr>
<th>Amount</th>
<th>Company Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>$25,000+</td>
<td>Cadent Therapeutics</td>
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<tr>
<td></td>
<td>Ionis Pharmaceuticals</td>
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<tr>
<td></td>
<td>Exicure</td>
</tr>
<tr>
<td>$10,000 - $25,000</td>
<td>Reata Pharmaceuticals Inc.  Albert Frei &amp; Sons, Inc.</td>
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<tr>
<td></td>
<td>Cydan II, Inc</td>
</tr>
<tr>
<td></td>
<td>PTC Bio</td>
</tr>
<tr>
<td>$5,000 - $9,999</td>
<td>Lacerta Therapeutics</td>
</tr>
<tr>
<td></td>
<td>Massachusetts Mutual Life Insurance Company</td>
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<tr>
<td></td>
<td>Ixico</td>
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<td></td>
<td>Greenways Landscape Services, LLC</td>
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<tr>
<td></td>
<td>California Analytical Instruments, Inc.</td>
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<td></td>
<td>Charter West Bank</td>
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<td>FGX International</td>
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<td>Takeda Pharmaceuticals USA, Inc.</td>
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<tr>
<td></td>
<td>Wave Life Sciences</td>
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<tr>
<td>$2,500 - $4,999</td>
<td>Los Alamos National Security, LLC  B. Braun CeGaT, LLC</td>
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<td>Torres Electrical Supply Co, Inc.</td>
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<tr>
<td></td>
<td>Willington Construction, LLC</td>
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</tbody>
</table>

### FOUNDATIONS

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

<table>
<thead>
<tr>
<th>Amount</th>
<th>Foundation Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>$100,000+</td>
<td>Gordon &amp; Marilyn Macklin Foundation</td>
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<tr>
<td>$25,000+</td>
<td>Michael and Patricia Clementz-Peterson Family Fund</td>
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<tr>
<td>$10,000 - $25,000</td>
<td>Novaspace.com, LLC  Cossack Foundation  Babcox Family Foundation  Leader Family Foundation</td>
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<tr>
<td>$5,000 - $9,999</td>
<td>Minnesota Medical Foundation-BAARC</td>
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<tr>
<td></td>
<td>Ixico</td>
</tr>
<tr>
<td></td>
<td>Greenways Landscape Services, LLC</td>
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<td>California Analytical Instruments, Inc.</td>
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<td>Federal Home Loan Bank of Pittsburgh</td>
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### 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.

<table>
<thead>
<tr>
<th>Amount</th>
<th>Platform Name</th>
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<tbody>
<tr>
<td>$100,000+</td>
<td>Facebook</td>
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<tr>
<td>$25,000+</td>
<td>Fidelity Charitable Gift Fund</td>
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<tr>
<td>$5,000 - $9,999</td>
<td>Benevity Community Fund  YourCause, LLC</td>
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<td></td>
<td>CFC TASC</td>
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<td></td>
<td>Mississippi Chapter of NAF</td>
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<tr>
<td></td>
<td>United Way of Capital Region</td>
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| $2,500 - $4,999 | Charities Aid Foundation of America  Schwab Fund for Charitable Giving  Chesapeake Chapter  Amazon Smile  TRUST  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+

<table>
<thead>
<tr>
<th>Amount</th>
<th>Donors</th>
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<tr>
<td>$50,000+</td>
<td>Anonymous, Anonymous, Clair and Marilyn Hoblit, Marcia Neugebauer</td>
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### $25,000 - $49,999

<table>
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<th>Amount</th>
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<tbody>
<tr>
<td>$25,000 - $49,999</td>
<td>Eric Peterson, Tamara and Steve Peterson</td>
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### $10,000 - $24,999

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<th>Donors</th>
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<td>$10,000 - $24,999</td>
<td>Susan Huffmann, Anonymous, Judy Meelia, Arthur and Mildred Walsh, Barry Hyman</td>
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### $5,000 - $9,999

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<th>Amount</th>
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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

**PASSION FUNDRAISING**

- 16 Fundraisers
- 100% increase
- 627 Donors
- $148,799 raised

**Go The Extra Mile**

- 15 Fundraisers
- $25,181 Raised
WORKING TOWARDS A CURE

SUPPORT & REVENUE

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<th>Source</th>
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<td>Memberships</td>
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<tr>
<td>Conference Income</td>
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<td>Other Income</td>
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EXPENSES

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<td>Education and Service</td>
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<td>Management and General</td>
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<td>Fundraising</td>
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NET ASSETS

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<td>Change in Net Assets</td>
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<td>Net Assets, beginning</td>
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<tr>
<td>Net Assets, ending</td>
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<tr>
<td>Total Assets</td>
<td>3,885,975</td>
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<tr>
<td>Total Liabilities</td>
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<tr>
<td><strong>Total Net Assets</strong></td>
<td><strong>3,885,975</strong></td>
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</table>

HOW WE SPEND OUR MONEY

- **57%** Research
- **18%** Management & General
- **11%** Education & Services
- **14%** Fundraising
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Northwestern University Feinberg School of Medicine
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Houston, TX