2020. Period. Hard stop. In the annals of history, the year 2020 will be one that stands out. What a challenge it was for everyone, especially members of our Ataxia community. But you showed up. You didn’t back down. Your resilience, support for each other, and positivity came shining through. It’s what defines this group who all of us at the National Ataxia Foundation have the privilege of helping each and every day. Your support of our work helped make 2020 a truly remarkable year for NAF as well.

Having to cancel two research conferences and our Annual Ataxia Conference at the last moment could have been hard to handle. Instead, NAF’s series of webinars that covered the content of AAC were viewed thousands of times. Shifting our popular Walk N’ Roll events which take place around the country to an online gathering might have been disastrous for this important fundraising initiative. But you didn’t let that happen. Instead, we exceeded our goal and had a lot of fun coming together virtually. Finally, our Ataxia support groups, who so many of you rely on for connection and information, were more important than ever during the year when we couldn’t be physically together. You embraced going online, welcoming new members, and becoming Zoom experts all at the same time.

Another good thing happened for NAF in 2020. We updated the organization’s vision, mission, and key strategic goals. NAF has been funding basic Ataxia research since our founding in 1957. Those many years of investment have paid off, and now there are a large number of pharmaceutical companies that are pursuing treatments for various forms of Ataxia. It is now time to take a bold step forward and start focusing on assisting these companies in any way we can to help them get treatments to market. Asking you all to participate in genetic testing, research studies, and clinical trials will be a crucial part of that help.

We want to thank our dedicated group of generous donors and volunteers for making 2020 so very memorable. NAF is in a strong financial position because of you. You showed up like you always do. Here’s to a joyous 2021 and seeing you in person again soon.

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.
Strategic Goals:
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.
As pharmaceutical industry interest in Ataxia continues to grow, our members are integral in moving research forward to get treatments to the market. They are the first to know when there are new opportunities to participate in research or clinical trials for their specific type of Ataxia. NAF had a 52% increase in members in 2020.

**Total members** 5,569
Community Programs and Services Impact

SUPPORT GROUPS
NAF coordinates Support Groups as a way for the Ataxia community to connect and learn from others. With the pandemic changing the way that the world gathers in 2020, our Support Group Leaders stepped up to the challenge and found ways to continue to provide this valuable service to our community. Virtual support group meetings allowed us to stay connected from home. Thank you to the volunteers who make it possible.
NAF and the Friedreich’s Ataxia Research Alliance (FARA) worked together on behalf of Ataxia patients and their families to get support for the National Ataxia Awareness Resolution of 2020 (S.Res. 717). The resolution designated September 25, 2020 as National Ataxia Awareness Day in the United States. The resolution was led by U.S Senator Elizabeth Warren (D-MA) and U.S. Senator Cindy Hyde-Smith (R-MS) and passed in the US Senate in November of 2020.

ANNUAL ATAXIA CONFERENCE

For the first time in our 63 years, NAF had to cancel our most beloved event of the year. COVID-19 was in the beginning stages of the pandemic when we decided to prioritize the health and safety of our community. All of our scheduled speakers for the conference agreed to present their topics in a webinar.
Research Impact

NAF RESEARCH GRANTS

At NAF, we support researchers through our grant program, scientific meetings, collaborative initiatives, and assistance with research recruitment. We know our participation is crucial to accelerating the developments of treatment and a cure for Ataxia.

$1,080,000 Funded

27 Research Studies Supported

9 Seed Money Grants
1 Pioneer SCA3 Translational Award
7 Young Investigator SCA Awards

5 Post Doc Fellowships
2 Special Projects
3 Young Investigator Awards

Recipient of 2020 Young Investigator SCA award

“Receiving the NAF Young Investigator SCA Award made me very proud. The funding has made it possible to implement a concrete scientific project independently and autonomously...Our research has direct impact on improving trial-readiness for patients. It is a great pleasure and a great enrichment to be able to work in a field that is undergoing such a pivotal period of change... This is an incredible turning point and a strong motivation to continue research and work in this field. Together with Heike Jacobi, I founded the Ataxia Global Young Investigator Initiative. We are happy to share our passion with like-minded people and to pass it on to new young researchers. It has been very motivating to be supported on my scientific journey through funding line of the NAF Young Investigator SCA Award.”

Jennifer Faber, MD
German Center for Neurodegenerative Diseases
Bonn, Germany
NAF partnered with CureDRPLA to host an Externally-Led Patient Focused Drug Development (EL-PFDD) meeting for Polyglutamine Ataxias. An EL-PFDD meeting gives the FDA and other key stakeholders, including medical product developers, health care providers, and federal partners an important opportunity to hear directly from patients, their families, caregivers, and patient advocates about the symptoms that matter most to them, the impact the disease has on patients’ daily lives, and patients’ experiences with currently available treatments.

The Voice of the Patient Report for Polyglutamine Ataxias and DRPLA is a comprehensive document created from the feedback gathered at the meeting. It was submitted to the U.S. Food and Drug Administration. Future applications for therapy approvals will use the report as a reference to obtain the patient perspective on treatments and to understand what symptoms matter most to patients. This will serve as a guide to Industry as they develop effective and meaningful therapies for the Ataxias.

**MEETING STATS**

- **September 25, 2020**
  - 452 · Attended Live
  - 1,346 · Streamed Recording

**ATAXIA COMMUNITY PARTICIPATION**

- 29 · Speakers
- 9 · Callers
- 235 · Emailed Comments
NAF DRUG DEVELOPMENT COLLABORATIVE

We launched the NAF Drug Development Collaborative (DDC) in 2020. It is a pre-competitive pharmaceutical industry consortium 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.

Thank You DDC Members!

The Gordon and Marilyn Macklin Foundation has supported NAF through generous donations to the research program and other initiatives since 2009. Most recently, this support has been directed toward funding of the Clinical Research Consortium for the Study of Cerebellar Ataxia (CRC-SCA). Gordon and his wife, Marilyn, established their foundation to support those who are less fortunate from a health or economic perspective. When the couple passed, Gordon's nephew, Donald (Don) Dawn, assumed the role of the Foundation's President. Marilyn had Ataxia, and thus the focus on supporting those who are also impacted by the condition.

"Thanks to the important work of the CRC-SCA in working collaboratively to collect patient data, we are moving closer to finding treatments and an eventual cure for Ataxia," Mr. Dawn said.

We want to thank the Macklin Foundation for its loyal support of NAF.
The CRC-SCA is composed of fourteen Ataxia clinics across the U.S. that specialize in the diagnosis and treatment of Ataxia. These are the leading centers in the country, guided by a distinguished group of Principal Investigators (PI’s). The group is conducting a natural history study in Ataxia to better understand the factors that determine disease progression. Their goal is to improve the understanding of the disease process, current treatments, and development of disease-modifying therapies. In 2020, the CRC-SCA consortium began collecting cerebrospinal fluid as a biomarker to better understand disease progression.

- 600+ people enrolled
- Study covers: SCA 1, 2, 3, 6, 7, 8 and 10

"Continuing natural history data collection will truly make the CRC-SCA clinical trials 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
As NAF takes bold steps forward to accelerate the developments of treatments and a cure, it is our donors that make our work possible. Your generous support allows us to continue to offer community and education programs that empower people with Ataxia and their families to improve their lives.

THANKS TO OUR DONORS!

Revenue and Fundraising

DONORS BY GIFT SIZE

Total Donors 4,603  Total Donated $2,232,007

- $500-$999
- $100-$499
- $1-$99
- $1,000-$4,999
- $5,000-$9,999
- $10,000+
**CORPORATE PARTNERS**

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

<table>
<thead>
<tr>
<th>Amount</th>
<th>Company Names</th>
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| $25,000+   | Albert Frei & Sons, Inc.  
F. Hoffman-LaRoche Ltd.  
Ionis Pharmaceuticals  
Reata Pharmaceuticals Inc.  
Seelos Therapeutics  
Takeda Pharmaceuticals USA, Inc.  
uniQure  
Vico Therapeutics B.V. |
| $5,000 - $9,999 | Duke University  
APDM, Inc.  
Charter West Bank  
Chondrial Therapeutics, Inc.  
Exicure  
Lacerta Therapeutics  
PTC Therapeutics |
| $10,000 - $24,999 | Biogen  
Cadent Therapeutics |
| $2,500 - $4,999 | Eagle Ridge  
Gulf Ford Robinson Charitable Account |
| $1,000 - $2,499 | Kennebunk Savings Bank  
Live Nation  
Minoryx Therapeutics  
Torres Electrical Supply Co, Inc. |

**FOUNDATIONS**

NAF received grants from various foundations in 2020. We thank them for their support and commitment to our mission.

<table>
<thead>
<tr>
<th>Amount</th>
<th>Foundation Names</th>
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| $25,000+   | Cossack Foundation  
Gordon & Marilyn Macklin Foundation  
The Clementz Foundation |
| $5,000 - $9,999 | Brett and Melody McKay  
Leader Family Foundation  
The Bob Allison Ataxia Research Center |
| $10,000 - $24,999 | CureDRPLA  
The Tom, Mary, and Becky Babcox Family Foundation |
| $2,500 - $4,999 | Ataxia UK  
Nebraska Ataxia, Inc. |
| $1,000 - $2,499 | Bierley Charity  
Elsevier Foundation  
Enterprise Holdings Foundation  
EveryLife Foundation  
Fidelity Charitable  
Greater KC Community Foundation  
The Bob Allison Ataxia Research Center |

**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 2020!

<table>
<thead>
<tr>
<th>Amount</th>
<th>Platform Names</th>
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</table>
| $100,000+ | Benevity Community Fund  
Facebook |
| $2,500 - $4,999 | Amazon Smile Shopping Program  
Charities Aid Foundation of America |
| $1,000 - $2,499 | Cybergrants 3M Foundation  
Paypal Giving Fund  
Shell & Motiva Employee Giving  
United Way of Chicago Area |
| $5,000 - $9,999 | CFC TASC  
Chesapeake Chapter of NAF  
Community Health Charities  
Mississippi Chapter of NAF  
United Way of the Capital Region |
INDIVIDUALS

We are humbled by our generous donors who supported our work in 2020. Despite the uncertainty in the world due to the pandemic, these individuals stepped forward to make sure that NAF can continue to lead efforts to accelerate development of treatments for Ataxia. The caring individuals who contributed $1,000 or more are listed below.

$50,000+
- Anonymous
- Anonymous
- Anonymous
- Joseph Frei
- Marcia Neugebauer
- Terrence Fort Estate

$25,000 - $49,999
- Kathleen and John Schnobrich

$10,000 - $24,999
- Anonymous
- Anonymous
- Anonymous
- Gregory Klassen
- Jean Booher
- Jennifer Warchol
- Judy Meelia
- Lisa Frei
- Ruth Coffey
- Thomas Frei

$5,000 - $9,999
- Bob Schlickbernd
- Cherie Nixon
- Darrell Knutie
- Douglas and Kimberly Brunnett
- James Keene
- Laura Ranum PhD
- Mark Pejokovich
- Russel Derickson
- Tamra Humes
- Thomas Keene
- William Nye
- William Sweeney

$2,500 - $4,999
- Alex and Marlys Meyer
- Andrea Matarazzo
- Andrew Pickering
- Anonymous
- Barton Suchomel
- Brian Covington
- Janet, Mike, and Brynn Dyer
- Karen Brown
- Katherine Sweeney
- Mike and Toni Rosen
- Noorin Bhanji
- Roger and Elaine Wheeler
- Ronald Mason
- Sergio Damasio
- Sylvia Shelstad
- Tim and Karen Miller
- Georgia Trujillo
- Gerald Matykowski
- Gerard D. Hont
- Greg Rooks
- Gregory Messigian
- Harlan Lindberg
- Harriet Rosen
- Isabella Carvara Jr.
- Jane and Larry Jaffe
- Jason Dillon
- Jason Pruett
- Jay and Meg Larson
- Jeannette and Matthew Viveiros
- Jeff Stark
- Jennifer Gutwein
- Jenny Parker
- John Brittain
- John Teget
- Judith Chronister
- K. C. and Nancy Turnbull
- Karter Edwards
- Katharine Adams
- Kenneth Kueny
- Kenneth Neff
- Kerry Enright
- Kevin Forrest
- Krisie Nave
- Laura Ospanik
- Lauren Anthone
- Laurie Duncan
- Lawrence Adair
- Leah and Mark Minkin
- Linda Snider Sidwell
- Lucille Lundquist
- Maggie & Wally Ducayet
- Marcia Murto
- Margaret Kennedy
- Mariam Bahrmane
- Marilyn Teske
- Mark and Laneta Graham
- Mark and Rebecca Massman
- Mark Robinson
- Mary Ann Tucci
- Mary Bird
- Maryann Sweeney and John Dyer
- Matt Curran
- Melissa Clausen
- Michelle Serrano
- Mike Estabrook
- Nancy Haugen
- Nancy Schultz
- Neal & Kath Verga
- Patricia Thomas
- Paul & Susan Graseck
- Paul Elmore
- Perry Giles
- Priscilla Wallack
- Ray and Jane Dunkelberg
- Rebecca Lipner
- Renee DuShane
- Rhonda Holt
- Richard and Carole Carr
- Richard Jones
- Robert Baker
- Robert Hartmann
- Ronald Phelps
- Ross Way
- Roy Francis O’Connor
- Samuel Kirton
- Sandra Deane
- Sandra Johnson
- Sandy Miller
- Socorro Cavazos
- Susan Huffman
- Tamara and Steve Peterson
- Teann Nash
- Terrance Carr
- Terry and Cynthia Kinney
- Terry Dougan
- Thomas Jones
- Thomas Malia
- Valerie Arias
- Vicki Merrill
- Virginia Lucas
- William Pierro
VIRTUAL WALK N’ ROLL TO CURE ATAXIA

For the first time since Walk N’ Roll to Cure Ataxia began in 2007, a single national event was held virtually! Our event organizers were not able to put together in-person Walks in their communities, so they joined us online for live-streamed entertainment and fun instead. Thank you to all who attended, fundraised, and/or donated to the campaign!

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.
## WORKING TOWARDS A CURE

### SUPPORT & REVENUE

<table>
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<th>Source</th>
<th>Amount</th>
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<tr>
<td>Contributions</td>
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<td>Research Collaborative</td>
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<td>Conference Income</td>
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### EXPENSES

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<td>Management and General</td>
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### NET ASSETS

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<tr>
<td>Net Assets, beginning</td>
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<tr>
<td>Net Assets, ending</td>
<td>$3,862,203</td>
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<tr>
<td>Total Assets</td>
<td>$4,138,714</td>
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<tr>
<td>Total Liabilities</td>
<td>$276,511</td>
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<tr>
<td>Total Net Assets</td>
<td>$4,138,714</td>
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</tbody>
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### HOW WE SPEND OUR MONEY

- Research: 54%
- Education and Services: 23%
- Management and General: 14%
- Fundraising: 9%
Organization Leadership

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Thanks from the NAF Staff! To our donors, community members, partners, and Ataxia professionals, we thank you for making 2020 a successful year with much progress made towards NAF’s mission. Your support and participation are key to accelerating the development of treatments for Ataxia.