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National Ataxia
Foundation

GENERATIONS

THE OFFICIAL PUBLICATION OF THE NATIONAL ATAXIA FOUNDATION

Partnering for Progress: The Time is Now

2020 AAC

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Deadline to submit materials for the Spring issue of *Generations* is February 3, 2020

Please direct correspondence to:

National Ataxia Foundation
Connecting Ataxia families, researchers, clinicians and the community

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CFC #10752

Generations Schedule:

Issue	Spring	Summer	Fall	Winter
Mail Date	April	July	October	January

NAF Update:
Letter from the Executive Director


Andrew Rosen,
Executive Director

For this first edition of Generations for the year, I thought I'd share a few thoughts on what I think is the most exciting thing happening in the Ataxia world as we prepare for a big 2020! Drum roll please...*pharmaceutical interest in the Ataxias* will reshape NAF's focus and your involvement going forward. The buzz is palpable. I saw it at the International Ataxia Research Conference that I attended in Washington, D.C., in November, where more than 100 representatives from pharmaceutical companies were presenting research, asking for meetings, and sponsoring the event. I hear it almost daily at the NAF office here in Minnesota, where we've begun to strategize about how we can best collaborate with pharmas, helping them accelerate their development of treatments for Ataxia. And I invite you all to see it with me in Denver on March 6-7 at our Annual Ataxia Conference.

Our theme for this year's conference is Partnering for Progress - The Time Is Now! This partnership among researchers, clinicians, pharmas, and patients will be what drives us toward treatments in the coming years. And let me correct myself - we prefer to call patients **Research Collaborators.** It is you who will play a larger and larger role in the many steps necessary to get treatments approved. Whether you're a person with Ataxia, a family member at risk, or a caregiver or loved one, you all are key collaborators in this partnership. In fact, you're going to have the chance to meet directly with both researchers and pharma representatives in Denver.

So what can you do now? See the box below for some specific actions you can take. And we sure hope you'll join us in March for what will be an exciting program and a chance to connect with this amazing Ataxia community.

Here's to a great 2020!
Andrew

Andrew

P.S. NAF had a solid financial year in 2019 - THANK YOU to all our donors for their generosity and support of our work. We hope to connect with you again in 2020!

Become an NAF member

Join Now:
ataxia.org/JoinNAF

Register with CoRDS

Join Now:
ataxia.org

Join a Research Study

Find Research Studies to join:
ataxia.org/help-develop-new-treatments

Collaborate with Researchers at AAC

Register Now:
ataxia.org/2020-annual-ataxia-conference

Ataxia Webinars

NAF hosted a series of educational webinars in 2019. NAF members receive early access to register and spots are limited and fill up fast. Past webinars can be viewed on our Youtube Channel.

2019 Webinars offered:

- **Dietary Consideration in Ataxia** | https://www.youtube.com/watch?v=HSyTtMuxn5Y
- **Diagnosis and Management of Pediatric Ataxia** | https://www.youtube.com/watch?v=sevFSNHfHWA
- **Clinical Trials in Ataxia** | https://www.youtube.com/watch?v=1FU1MAa66MA

Do you have a topic you'd like to see covered in a webinar?
Email your suggestions to naf@ataxia.org

Have you joined the Ataxia Patient Registry yet?

CoRDS is a centralized international patient registry for all rare diseases; it is based at Sanford Research. The goal of the CoRDS registry is to connect as many patients and researchers as possible to help advance treatments and cures for rare diseases. The CoRDS registry is free for patients to enroll and is available for researchers to access to recruit research participants.

Since 2013, NAF has partnered with CoRDS to enroll participants who have a diagnosis of Ataxia or are at-risk for Ataxia. Since that time, several researchers have accessed the Ataxia registry to help recruit research participants for their important studies.

If you have not enrolled yet, you can register today to help researchers find more answers to Ataxia and to participate in research studies and clinical trials.

Enroll at www.sanfordresearch.org/SpecialPrograms/cords

Questions? Contact CoRDS at cords@sanfordhealth.org or (877)658-9192

KNOW THE FACTS ABOUT
SPINOCEREBELLAR ATAXIA
AND A NEW CLINICAL STUDY

About Spinocerebellar Ataxia (SCA)

SCA is an inherited form of ataxia, a rare and progressive neurological disease that develops due to damage to the cerebellum, the part of the brain responsible for coordinating movement.

Ataxia affects nearly 150,000 people living in the U.S. of which an estimated 3,200–18,000 have SCA

Symptoms of SCA may include lack of coordination, trouble with balance, difficulty swallowing, slurred speech and/or deterioration of fine motor skills

The most common types of SCA are SCA1, SCA2, SCA3, SCA6 and SCA7 which are caused by specific genetic defects

People are typically diagnosed in their mid-30s but SCA can affect all ages, genders and race

There is no cure or FDA-approved treatment for SCA

Current treatment approaches focus on symptom management to improve quality of life

SCA Study Overview

The Phase 3 randomized, controlled study is designed to evaluate troriluzole, an investigational drug that modulates the brain chemical glutamate. Brain cells communicate with each other by using chemicals, such as glutamate.

48 WEEKS Participants are enrolled in the study for 48 weeks*

** Participants who participate in the study will be eligible to continue for an additional 48 week phase where all participants receive troriluzole.*

T T : P P Participants are randomized one-to-one on troriluzole or placebo and take two pills once daily

18+ More than 18 U.S. medical centers are participating in the study

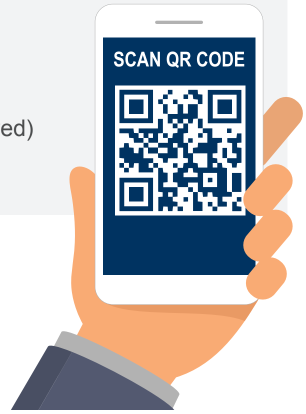
Mainly focus on disease-types SCA1 and SCA2

Study will measure if troriluzole can slow down and improve ataxia symptoms in people with SCA

Primary endpoint = measureable change in ataxia symptoms, including walking, standing, sitting and speech

Key Eligibility Criteria

- ✓ Known or suspected diagnosis of SCA1 or SCA2
- ✓ Confirmed clinical evidence of SCA diagnosis or willingness to have testing completed
- ✓ Ability to walk eight meters without human assistance (canes or other devices are allowed)
- ✓ Be physically able to complete the trial (adequate hearing, vision and language skills)



For more information about this study, visit
www.scatrial.org

The study is sponsored by Biohaven Pharmaceuticals.

MICHIGAN MEDICINE
UNIVERSITY OF MICHIGAN

SPINOCEREBELLAR ATAXIA TYPE 3 (SCA3)

UNIVERSITY OF MICHIGAN RESEARCH OPPORTUNITY

Do you or a family member suffer from SCA3?

The Neurology Department of the Medical School is currently conducting a research study for the purpose of identifying new biomarkers useful for SCA3, and your help is needed!

We are looking for:

- Healthy individuals and individuals with known SCA3 over 18 yrs. of age
- Approximately 1 hour of your time
- Involves a single lumbar puncture and blood draw
- Paid incentive for participation

Some exclusions apply - contact us at
(734) 232-6247

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Natural History Study needs SCA Research Participants

The Clinical Research Consortium for the Study of Cerebellar Ataxia (CRC-SCA) continues to recruit research participants who have a confirmed diagnosis of SCA 1, 2, 3, 6, 7, 8 or 10. This is an opportunity for anyone in the United States with those forms of SCA at any stage of the disease to participate. Contact the research coordinator at a site near you to learn more about how you might be able to help in Ataxia research efforts to discover a treatment.

The National Ataxia Foundation encourages anyone with SCAs 1, 2, 3, 6, 7, 8 and 10 to participate.

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This research is generously supported by the Gordon and Marilyn Macklin Foundation and the National Ataxia Foundation.

Thank you to Dr. Henry Paulson, University of Michigan, who has provided hours of counsel and leadership to make this a successful research endeavor. And, thank you to each of the sites clinical researchers and research coordinators who perform the research necessary to move the field closer to treatments and a cure.

For more information on the study, you may contact Sue Hagen at susan@ataxia.org or 763-231-2742

Disappointed that you don't qualify for this research study?

Take an important step to make sure that you are notified of future studies for which you might qualify. Enroll in the CoRDS Ataxia Patient Registry.

If you are affected with any type of Ataxia, enroll in the registry by going to the website: https://cordsconnect.sanfordresearch.org/BayaPES/sf/screeningForm?id=SFSFL. If you have questions about enrollment in the registry, contact the CoRDS staff at 877-658-9192.

NAF Funded Research

RESEARCH SEED MONEY AWARD

Dr. Da-Qing Yang | University of Minnesota | Minneapolis, MN

Function of ATM in Neuronal Survival in Response to Growth Factor Signaling

Ataxia-telangiectasia (A-T) is an inherited childhood disorder characterized by progressive cerebellar ataxia and oculocutaneous telangiectasias. The main characteristic of A-T disease is the progressive neuronal degeneration of cerebellar Purkinje and granular cells. Patients with A-T and cell lines derived from A-T patients also exhibit various growth abnormalities ranging from insulin resistance, glucose intolerance, growth retardation, to high serum requirements for optimal cell growth in culture. However, the reason for progressive neuronal degeneration in A-T patients remains unclear.

Although ATM, the protein kinase deficient in A-T disease, is traditionally considered a nuclear protein that functions as a sensor of DNA damage, it is known that ATM is predominantly cytoplasmic in human Purkinje cells and mouse cerebellum neuronal cells. Our previous studies have shown that ATM translocates from the nucleus to the cytoplasm after human SH-SY5Y cells differentiate into neuron-like cells. Our previous findings have also shown that cytoplasmic ATM is an insulin responsive protein that stimulates Akt phosphorylation at Ser473. Akt has been well documented in promoting cell survival in a variety of apoptotic paradigms. Based on these results, we hypothesize that ATM, through activation of Akt, promotes neuronal survival in response to insulin and other neural growth factors.

The goal of this proposal is to further examine the functional link between the ATM protein kinase and neuronal survival in response to insulin and other neural growth factors. As many of the ataxia or neuronal degeneration disorders are closely related to insulin resistance and type 2 diabetes, our research may provide an overall better understanding of the ataxia and neuronal degeneration process and may lead to the discovery of novel therapeutic targets for the neuronal degeneration of human A-T and other human ataxia disorders. who receive ASO therapy.

BRAIN TISSUE DONATION PROGRAM

Ataxia researchers have made many discoveries because of donations of brain tissue from those affected with Ataxia. NAF's Brain Donation Program was established to allow those who desire to donate their brain upon death so that researchers can find more answers.

If you are interested in learning more about brain donation, you may contact Mary Ann Peterson, NAF Research Assistant, at ***mary@ataxia.org*** or **763-231-2750**.

2019 Katie Campbell Clinical Trial Readiness Conference Held in Minneapolis

Kelsey Trace, NAF Research Associate

Ataxia Researches from the 2019 CRC SCA

It was an exciting couple of days in Minnesota when prominent Ataxia clinical researchers and research coordinators met in Minneapolis in September for the annual Katie Campbell Clinical Trial Readiness Conference. This conference focuses on the work of the Clinical Research Consortium for the Study of Cerebellar Ataxias (CRC-SCA). It is supported by the family of Katie Campbell, who lost her battle with ataxia in 2016. Their generous donations make it possible for principal investigators and research coordinators from the CRC-SCA sites to gather once a year to share advancements, set-backs, and new discoveries that will move the entire field toward treatments for the Cerebellar Ataxias.

Additionally, as a new staff member of NAF, it was my first time meeting the attendees in-person. Let me tell you, they are quite the group of dedicated, congenial, and motivated individuals! It was so nice to be able to put faces to email addresses.

Key Points Discussed by Researchers

The focus of the meeting was to continue advancing the field to provide the tools that pharmaceutical companies need to develop treatments and therapies. With over 65 attendees, including clinician researchers and coordinators, NAF staff, and pharmaceutical companies; it was an empowering and collaborative two days. It was a great opportunity for me to learn more about the goals of the consortium. Highlights from this conference include:

The introduction of new leadership for the consortium (Drs. Kuo, Shakkottai, and Rosenthal) for whom there was enthusiastic support. Leadership presented an updated working mission statement, discussed future focus of CRC-SCA, and utilization of increased stakeholder interest, in particular, industry partners.

The concept that patients are the most important aspect of a research study in order to find treatments for Ataxia. Patients are research collaborators and researchers realize that their donation of biospecimens is an altruistic and precious act.

The necessity of collecting biospecimens such as blood and cerebral spinal fluid (CSF) to be used as potential biomarkers. Biomarkers can be used to see how well the body responds to a treatment.
An in-depth discussion regarding data access and its use to promote increased research in SCAs, ensure quality of research, and avoid duplication of research efforts.

Become a Research Collaborator

In summary, the CRC-SCA Natural History Study and biomarker development is growing and morphing during this exciting new era in Ataxia research as pharmaceuticals are advancing to therapy development for the Ataxias. CRC-SCA is anticipating adding specific clinical end-point assessments and biospecimen collection to increase the strength of this study and collaborate with stakeholders in a meaningful way that includes patients as research collaborators.

> **"We would like to take the opportunity to thank the National Ataxia Foundation for your contribution as a sponsor to the 6th International Meeting on Spastic Paraparesis and Ataxia. It has been a great success and we couldn't thank you enough for your high contribution."**
>
> **— Alexandra Durr & Giovanni Stevanin**

160 scientists and patients from 21 countries and from 4 continents attended the SPATAX meeting held in Nice, France on September 19-20, 2019.

Joint Mission Bataan to Cure Ataxia 2020

Joint Mission Bataan to Cure Ataxia or JMB is an expansion of last years' effort led by North Carolina resident, Mike De Rosa and Ed Brand from New York. Mike and Ed took part in the 2019 Bataan Memorial Death March, a 26.2-mile walk/hike through the desert highlands, near the White Sands Missile Base in New Mexico. Through their combined efforts Mike and Ed raised more than $35,000 in support of NAF. The Joint Mission Bataan is an exciting opportunity to support the Ataxia community, and veterans, at the same time. Close to 30 individuals from around the country have committed to hiking 26.2 miles in the New Mexico desert as part of the Bataan Memorial Death March on March 15, 2020.

Meet a couple of marchers taking part in JMB 2020

Mark Minkin

"Supporting family is my #1 priority. My beautiful wife Leah is my rock, and I have 2 amazing kids: Anna, a freshman at the University of Wisconsin Madison, and my son Daniel, a Junior in high school. Rounding out our family is our wonderful Goldendoodle, Gordo. Currently, I am a Senior Account Manager for Direct Supply. I am active in our church choir and enjoy performing in musical theater productions whenever time allows. My wife, Leah was diagnosed with Cerebellar Ataxia Type unknown at this time. This rare neurological disease that my wife has been battling has changed my perspective on life and provided me with a new purpose: to help raise awareness about this terrible disease, and to raise funds for research. I am doing this for all those suffering from this terrible disease and everyone who is touched by Ataxia. One step at a time to raise awareness!"

Nathan Oliver

"It's my extreme honor to have the opportunity to represent Arkansas in the Joint Mission Bataan. Having the chance to pay tribute to our active duty and veteran military personnel, and everyone affected by Ataxia, is amazing. The Joint Mission Bataan will be a challenge and one I look forward to accomplishing."

An Ataxia Journey: Finding Hope Despite a Debilitating Disease

Samantha Kuhn, Paulding Putnam Electric Cooperative Communications Coordinator

What would it be like to have a rare disease that progressively inhibits your ability to walk, causes tremors, loss of balance, and difficulty speaking? Paulding Putnam Electric Cooperative member Cheri Bearman of Hoagland, Indiana, knows the answer all too well.

"Ataxia has definitely taken a toll on me," she says. A dozen dark memories cloud her eyes. "I'm not a person who likes to sit, but I'm probably going to end up in a wheelchair."

Bearman, 62, suffers from spinocerebellar ataxia type 3 (SCA3), a degenerative neurological disease. In fact, three of her five siblings have it, too, passed on from her mother. Though the age when symptoms begin can vary, complications are often serious, debilitating, and life-shortening. There is no cure.

"Go forward with slow, gentle steps"

As many as 150,000 people in the U.S. are affected by ataxia, and each child of an affected parent has a 50% chance of inheriting the disease. One of Bearman's three children began experiencing symptoms at age 33 and recently tested positive, but due to insurance complications, it is common to forgo the test.

"I am still able to walk unassisted for the most part, but I am becoming more and more unstable," Bearman says. "I was always very active, athletic, coordinated, and agile, so as the disorder progresses, it's becoming more and more difficult for me to do the things I have always enjoyed."

For Bearman, the change was gradual, starting in her early 50s. A hardcore athlete, she ran and biked long distances, did yoga, and loved soaking up nature. But as the disease progressed, she was soon unable to run — just walking alone required trekking poles for stability. Traditional two-wheel cycling wasn't an option either; she now rides a TerraTrike, an eight-speed recumbent tricycle, to avoid the danger of falling while stopping or starting. Because of her increasing lack of balance, she can no longer perform her favorite yoga poses; chair yoga is now part of her routine. She also suffers from double vision, experiences muscle weakness and severe overall fatigue, and has severe neuropathy in her feet and legs that interrupts sleep.

She's tried chiropractic treatments, acupuncture, medications, and massage therapy. But nothing has seemed to help.

"In public, I seem very positive, but at home, my worst side comes out," she says. "I used to be able to clean my house in one day, but now, it takes a day to clean one room. It's very frustrating. You vent, you yell, and you ask 'why?' But I have to be a rock for my children and grandchildren. I have to be strong."

What Bearman has accomplished is incredible. In 2014, she started an ataxia support group in

Indiana and got involved with the National Ataxia Foundation, helping with their quarterly magazine, Generations, to spread awareness. Once a year, she sees her neurologist at the University of Michigan in Ann Arbor and participates in various ataxia research studies involving MRIs, lumbar punctures, blood draws, and skin biopsies.

When her ataxic gait ("walking like you're drunk") feels overwhelming, the dizzying sensation takes over, or she remembers she can't drive at night, it's easy to become discouraged. But three little M's (mindfulness, meditation, and movement) and F's (faith, family, and friends) keep her motivated. She's determined to live a "glass half full" lifestyle.
"I'm known as the card lady because I like to inspire others. I send people Bible verses and inspirational quotes … I need to remember to take that to heart myself," Bearman says. "I know there are a lot of worse diseases than ataxia. Though there is no cure or treatment presently, experts agree the best thing to do is to keep moving."

And move she does. The Fort Wayne Walk n' Roll to Cure Ataxia – an annual fundraiser and two-mile walk – is a large part of her life. Currently, there are 17 Walk n' Roll events nationwide that have collectively raised more than three million dollars for ataxia research and support. This year's Rock n' Roll is Oct. 5 at Foster Park in Fort Wayne.

Bearman's husband, Gil, has been by her side through it all. He helps with endless encouragement, makes sure their scenic rural property is well-kept, installs railings around their home, and fights for continued ataxia research.

"Cheri isn't a quitter," Gil says. "She doesn't back away from a challenge. She knows what's ahead from watching her own mother, but she'll keep pushing on. She's going to walk as long as she possibly can."
Cheri's favorite quote from Thich Nhat Hanh sums it up perfectly: "Be like a lion, going forward with slow, gentle, and firm steps." Rather than focusing on what's missing, she finds joy in discovering what's been there all along.

Become an Ataxia Advocate

Visit our NEW Advocacy webpage www.ataxia.org/advocacy for advocacy tools, events, and resources.

On the advocacy webpage you can:
- Download the Advocacy Toolkit
- Learn how to contact your local representatives to request a Proclamation for International Ataxia Awareness Day (IAAD).
- Check out advocacy events happening around the country.
- Get the latest news on legislative issues impacting the Ataxia community.

We want to hear from you if you have a relationship with a US Congressman or Senator to further support the legislative issues impacting the Ataxia community.

Contact Lori Shogren, Community Program and Services Director at **lori@ataxia.org.**

PARTNERING FOR PROGRESS

The Time is Now!

63RD ANNUAL ATAXIA CONFERENCE

MARCH 6-7, 2020
SHERATON DENVER
DOWNTOWN HOTEL

VISIT **WWW.ATAXIA.ORG** FOR ADDITIONAL EVENT DETAILS.

As interest from the pharmaceutical industry in developing drugs to treat Ataxia continues to grow, we at NAF believe that collaboration among researchers, clinicians, pharmaceutical companies, and Ataxia patients has reached a critical moment. We all must work together, as partners, to advance progress toward better patient care and more effective treatments for Ataxia. **The Time is Now!**

Keynote Speaker - Jeremy D. Schmahmann, MD is Professor of Neurology at Harvard Medical School, and a Neurologist at the Massachusetts General Hospital where he is the Founding Director (1994) of the Ataxia Unit, Director of the Laboratory for Neuroanatomy and Cerebellar Neurobiology, and a member of the Cognitive Behavioral Neurology Unit. His research and clinical practice focus on the neurology and basic science of the Ataxias and other cerebellar disorders, and he pioneered the role of the cerebellum in cognition and emotion.

Other sessions not to miss!

- Drug Development: Ataxia Drug Discovery Pipeline
- Ataxia Research Comes Full Circle
- Patients as Research Collaborators
- Living Well with Ataxia: A Palliative Care Approach
- Networking with Ataxia Researchers
- Pharma Consortium Panel
- Clinical Care of Ataxia
- A Wholehearted Life: One Step at a Time
- Living and Coping with Ataxia Panel

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Things to Know About ACC

When: March 6-7, 2020
Where: Sheraton Denver Downtown, 1550 Court Place, Denver CO 80202
Register: Online at ataxia.org/2020-annual-ataxia-conference
Cost:

Before January 24, 2020 - $150

January 25 – February 21, 2020 - $175

Onsit available March 5, 2020 - $225

Registration covers access to:

- All areas of the conference: General sessions, small sessions, Birds of a Feather sessions, Friday evening reception (light snacks), Saturday banquet (plated dinner), exhibit hall.
- You're in control! Pick and choose which sessions or event you'd like to attend. Note: Registration cost does not change if you opt not to attend the reception or the banquet.
- Conference Registration cost DOES NOT include hotel or transportation.

Featured Highlights of the 2020 AAC

Register now for the 2020 AAC! Whether you are a first-time attendee or you have joined us before, we can't wait to see you in Denver this year. Our 2020 Annual Ataxia Conference is packed full of great topics, fun activities, and renowned speakers for you. For those of you who have never joined us before, get ready for a two-day social and educational experience like you've never seen. Here are just a few highlights of the upcoming 2020 AAC.

Saturday Banquet

Join us on Saturday night for a banquet that features a plated dinner, award ceremony, and dance. Your registration fee includes the meal – cash bar will also be available. It's a night of fun and great conversation that you won't want to miss!

Ataxia Market Place

Interested in research opportunities, accessible equipment, activities, and resources? Visit the Ataxia Marketplace during the conference to find out more about those areas of interest and participate in other activities and bonus sessions.

Birds of a Feather Sessions

These small breakout groups are facilitated by experienced clinicians. Rather than presentations, they are interactive conversations where all individuals share concerns, ask questions, and discuss topics relevant to the group.

Lunch N' Learn Sessions

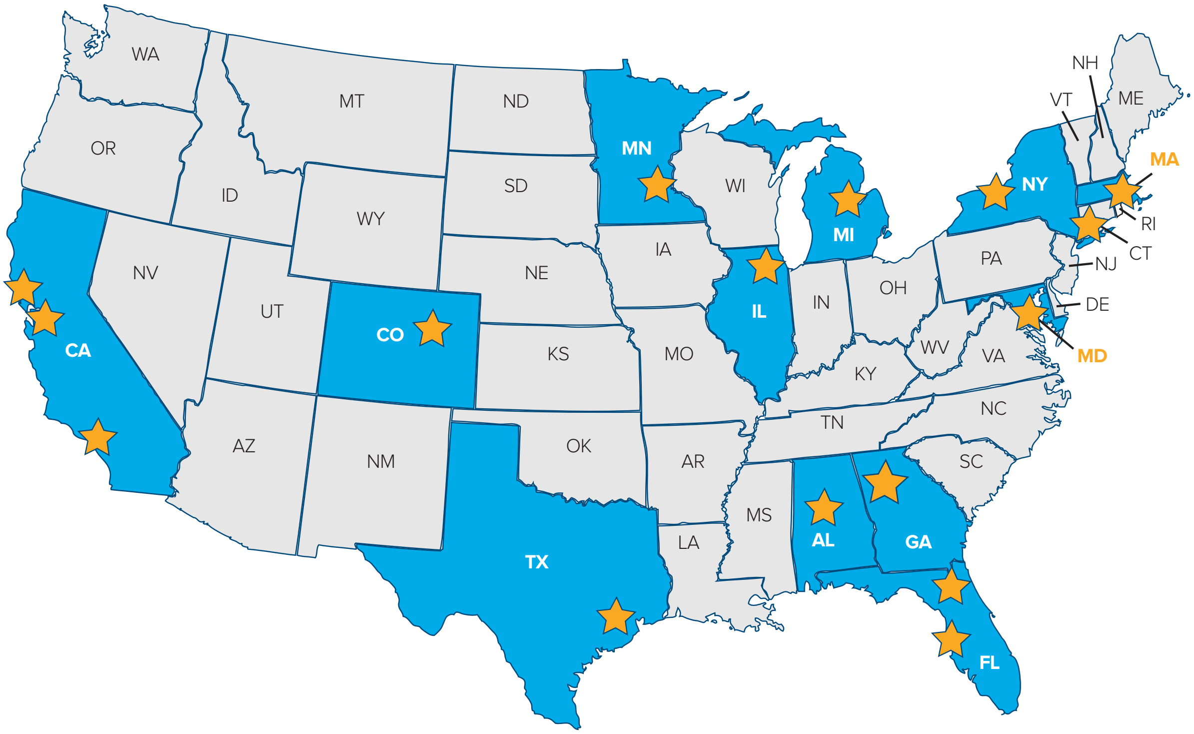
Grab your lunch and join one of the many informative bonus sessions being offered each day. Check the schedule for room location. Lunch concessions will be offered for purchase.

Location

Sheraton Denver Downtown is located on the 16th Street Mall – which is a mile-long strip of bistros, microbreweries, shopping, and entertainment. The 16th Street Mall offers a free and accessible bus that travels 16th Street on a regular basis daily.

READISCA Observational Study for SCA 1 & 3

Looking for participants with SCA1 and SCA3 to help with the READISCA study at any of the sites across the US. One of the main goals of this study is to get ready for treatment trials. READISCA does not involve medication or treatment therapy, but it will collect crucial data that will help future clinical trials. The main goals of this study are to establish the world's largest group of early stage and symptomless SCA1 and SCA3 individuals.



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Ann Arbor, MI

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Minneapolis, MN

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Rochester, NY

Univ. of South Florida
Tampa, FL

★ Indicates location of Clinical Trial Site

For more information on READISCA contact:
Houston Methodist Research Institute
Tetsuo Ashizawa, MD–Contact PI/PD
Phone: 346-238-5021 • Email:U01SCA1&3@houstonmethodist.org

Ataxia Tips

for Ataxians... from Ataxians

For many with Ataxia, everyday tasks can become increasingly difficult. One person's shared tip might just be the help someone else needs. See what advice Ataxians are giving to make everyday tasks easier...

Ataxia Tips must be submitted by 2/3/20 to be eligible for inclusion in the next issue of *Generations*. Submit them via email to naf@ataxia.org.

1. Install handles in all your doorways leading in/out of your house. These handles have been extremely helpful to me in stepping up/down a step or just crossing a threshold. (Submitted by Cheri Bearman)

2. Buy a trike bike. It is so much easier to ride than a bike and it keeps your muscles strong and healthy. You get to have fun while riding your bike. (Submitted by Lucrezia Viviano)

3. If you are a walking/standing Ataxian, I just found out a way to stabilize yourself when you are standing. Place your feet at a wide base but the key is to place one foot in front of the other and slightly bend your front knee. This stance will give you strength and you will wobble less and feel more grounded. (Submitted by Elissa Fisher)

4. I have a trick to help me balance when I lift each leg to put my pants on. I back into a corner to brace myself while standing on one leg. The corner gives me more stability than just leaning against one wall. (Submitted by Karen DeVito)

5. I've stopped making pasta that involves pouring hot water into a colander. I make something like penne or rotini, scoop it out of the hot water with a slotted spoon and leave the hot water to cool on the stove before I wash it. (Submitted by Julia Kay Pantoga)

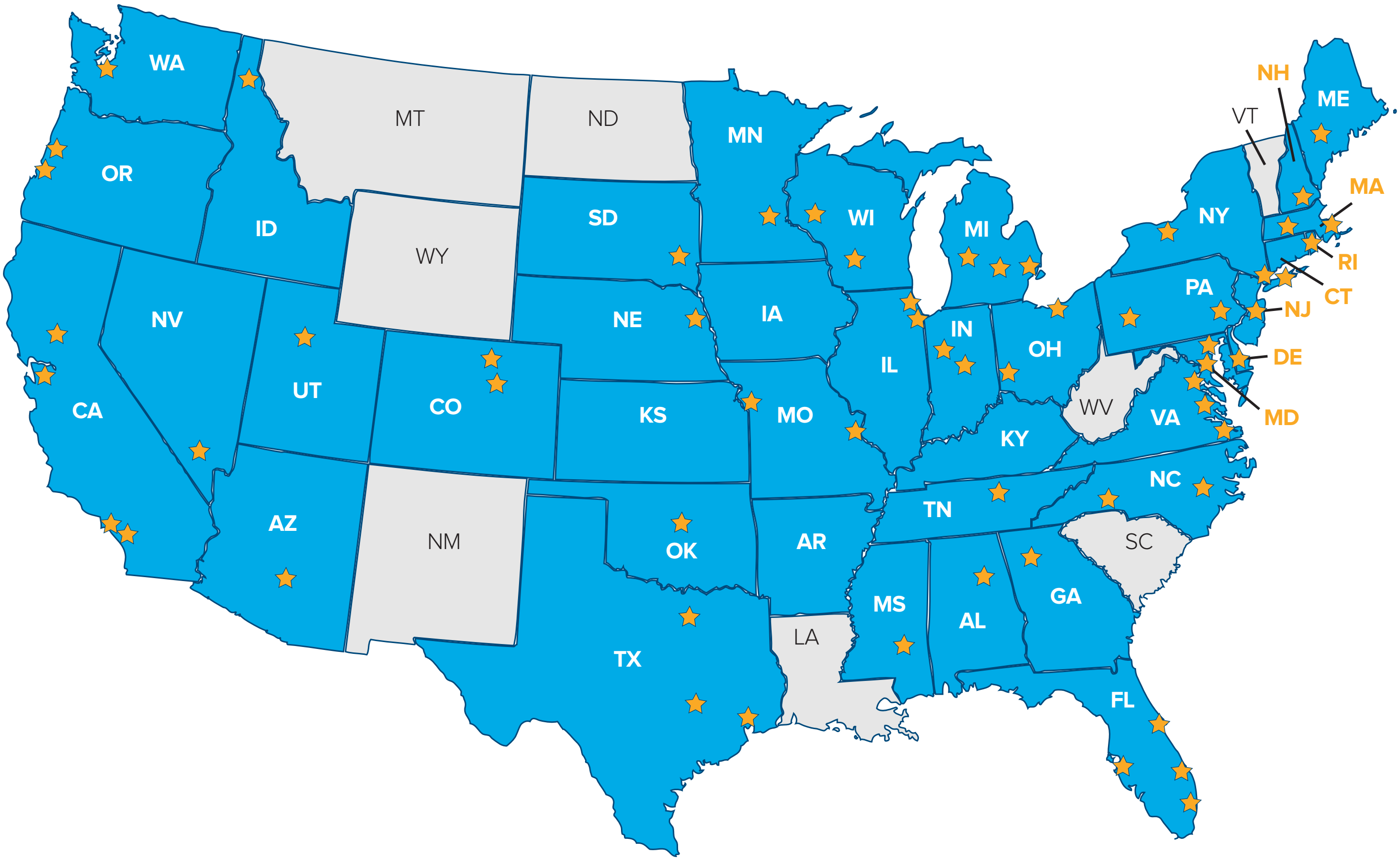
Support Groups & Events

The most current support group and event information is available on the NAF website, www.ataxia.org.

Support groups can remind us that we are not alone. Each person experiences Ataxia in a different way, but we still have many things in common. A benefit of attending a support group is having the chance to talk with others and learn how different people deal with the same disease.

If you or a loved one has been newly diagnosed with Ataxia, please contact the support group leader nearest you. If there is not a group in your area, we encourage you to visit our online social networks. You may also consider starting a support group in your area or becoming an NAF ambassador. If you are interested in these volunteer positions please contact Lori Shogren of the NAF staff at lori@ataxia.org or (763) 231-2743.

Come. Learn. Share. But most of all, know that you are NOT alone.



Join one of our Facebook Support Groups!

NAF Support Group	*www.facebook.com/groups/NAFmail*
Under 30 with Ataxia	*www.facebook.com/groups/under30withataxia*
Parents of Ataxia	*www.facebook.com/groups/ParentsOfKidsWithAtaxia*

Support Group News and Community Events

Welcome new support group leaders and ambassadors

Please join us in welcoming our new support group leaders. We have 5 new leaders who are volunteering their time to plan meetings and be there for you when you need to talk to others dealing with Ataxia

Idaho: Sarah Stuker, 907-947-1011, sarahestuker@gmail.com – SG Leader

Nevada: Libby and rich Hoops, 775-223-2809, hoops.e.a.hoops@gmail.com – SG Leader

Michigan: Shenlei Winkler, 517-993-7655, shenlei.winkler@aol.com – SG Leader

Virginia: Karen Russell, 804-543-8707, klruss@comcast.net – Richmond SG Leader

Illinois: Julia Pantogo, 414-899-5195, sharpturninstitute@gmail.com – Chicago SG Leader

Community Fundraiser Events

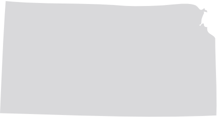
We had another successful year with the National Ataxia Foundations 2019 event season. Thank you to the nearly 2,500 people who contributed over $330,000 to the Walk n' Rolls across the country. The International Ataxia Awareness Day (IAAD) theme this year was United Against Ataxia and support came in from all over the world. Some of NAF's staff were in Washington DC working on getting a proclamation signed to make September 25th National Ataxia Day here in the United States. Here is a sampling of some of the Walk n' Roll and IAAD events that took place across the country. These events were not only raising funds for NAF but bringing Ataxia awareness to their communities.

Fort Wayne Walk n' Roll, Fort Wayne, IN – October 5, 2019

Submitted by: Cheri Bearman

The Fort Wayne Walk n' Roll brings the Ataxia community together even from other states. Amy Hamrick has SCA1 and resides in Georgia. Members of her family, staunch supporters of Amy and the Ataxia cause, live in Indy and drove up to FW to represent Amy at our Walk!! They also did a fair amount of fundraising for our event!! This was the first time I had met them and affectionately called them the "Purple People"!! They added an element of color, fun, and excitement to our event!! Amy Hamrick is the Leader of "Amy's Army". She is not pictured as she was not at the walk.

Brian and Alyssa Donnelly, Curtis and Stefanie Dyer with their boys Will and Blake



Kansas City Area Walk n' Roll – September 14, 2019

Submitted by: Laurie Colby

We had our Walk n' Roll on Sept 14th. It was such a beautiful day. Was held at Macken Park in NKC. It has a perfect trail for the event. The NKC Fire Department came to start the race. We raised more than $5,000 for NAF!

Kansas City Area WNR

Pittsburg Walk n' Roll – September 8, 2020

Madalyn Gottschalk who runs the Pittsburg Walk n' Roll in the fall also hosts a golf tournament in the spring. These events combined raised $34,657 for the National Ataxia Foundation and awareness of Ataxia in the Pittsburg area. Madalyn and her family consistently create incredible events that raise awareness in the community and exceed their fundraising goals.

Arizona Walk n' Roll

Submitted by: Mary Fuchs

The Arizona Ataxia Support Group hosted their annual IAAD event on Saturday, October 5th. The "Eat for a Cure" event was held at the Old Spaghetti Factory in Chandler, Arizona. 52 guests enjoyed a sit-down dinner and won raffle prizes such as a stay at a luxury resort and Arizona Diamondback baseball game tickets, among many other exciting prizes.

NFocus Entertainment graciously donated their time and talents to provide excellent entertainment including a motivational speaker and live singing and music. The entertainment company also donated their supplies and decorating expertise to transform the venue into a beautiful space to celebrate ataxia. Mike Wolfson, an Arizona group member, described how ataxia has affected the lives of his daughters and their family. Dancing ensued with all the fun music and a great time was had by all.

Support group members worked hard to sell dinner tickets, raise money, and sell raffle tickets. We were able to raise $4,600 towards finding a cure for Ataxia. Special thanks to all who attended, fund raised, and to our sponsors who donated raffle prizes and NFocus for wonderful entertainment.

Arizona IAAD Eat for a Cure event

Delaware Ataxia Fundraiser

Submitted by: Cathy DeCrescenzo

Dee and Ronnie Anderson, and Cathy and Joe DeCrescenzo hosted "A Festival of International Flavor…An Ataxia Fundraiser" on Sept. 21, 2019. Approximately 200 attendees participated in the event, which included free admission, free food, free beer and wine, raffles and live music for dancing. Overall, the event exceeded our goal of $15,000! The attendees enjoyed over 58 various raffle prizes and made good use of the "photo op" set-up. LA Productions provided the live music.

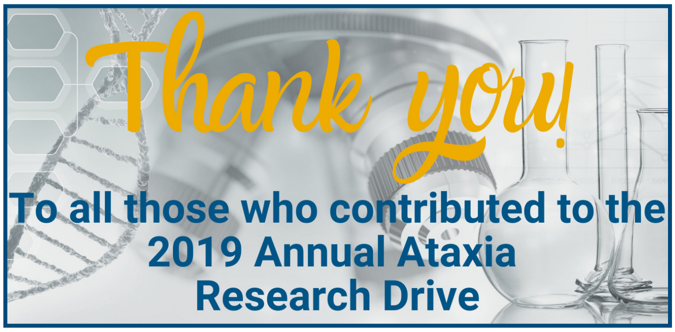
Delaware IAAD event

Missouri Ataxia Support Group Gets Local Press Coverage for IAAD

Submitted by: Shannon Dunphy

The St Louis Ataxia Support Group and CBS Channel 4 celebrated International Ataxia Awareness Day for the entire month of September 2019! Our group and logo were profiled each weekday night on a segment during the weather, called the 4 Degree Guarantee. What is the 4 Degree Guarantee? If the actual temperature is within 4 degrees of the weather prediction, Channel 4 and Cardinals Care donate to that month's charity. As of September 27, we had raised $1050 for the National Ataxia Foundation!

Delaware IAAD event



TO SEE THE LATEST SUPPORT GROUP NEWS AND UPDATES VISIT:

ataxia.org/blog

REMEMBERING NAF IN YOUR WILL

Throughout the years, individuals have named the National Ataxia Foundation as a beneficiary in their wills. Their thoughtfulness and foresight has enabled NAF to provide more research studies, more services to patients and families and more education and Ataxia awareness to the public. We are grateful for the impact that has been made by these compassionate acts. If this is something you would like to consider, please contact Joel Sutherland at ***joel@ataxia.org*** or call (763) 231-2748.

#IAAD19

INTERNATIONAL
ATAXIA
AWARENESS DAY
SEPTEMBER 25

2019 International Ataxia Awareness Day (IAAD) was September 25.

United Against Ataxia

Memorials and In Your Honor

NAF is grateful to those who have made contributions in memory of or in honor of their friends and families whose names are listed below. This list reflects contributions made in September 2019 - November 2019.

Brent Masserant
Alan Boyce
Alice Tapper
Amy and Corby Legault
Amy Lynn Bac
Annabel and George Guffin
Anxi Xu
Billy Gaul
Bob Bittick, Sr
Bob Keiter
Brett Masserant
Brian Bredberg
Cameryn Cobb
Carla Moellendorf
Carol Medvac
Carolyn and Giovanni Bertussi
Cecil Bergman
Cheri Bearman
Chris Cozmanoff
Chris Richardson
Christina Cozmanoff
Cletus Brunnert
CMDR William Leet
Daniel Nugent
Darlene Schomber
David Chernoff
David Hunt
David Renz
Debra Hazlin
Den Antonellis
Denise Mindle
Denise van Voorhis
Dick Brown
Donald, Jan, Donnie Matias
Doris Rhoden
Doris Schaal
Doug Brunnert
Dr. Sow-Hsin Chen
Ed Schwartz
Eleanore Mantovani
Ella Barbara Sisk Edwards
Floree Gee
Garfield Cammon
Gary Lunzer
Gary Zweig
Georgia Martin
Gordon Hoffmann
Gregory Bittick
Gregory Griffin
Gruenfelder Family
Handoyo Triputra
Hannah Xu
Heather Kurpiewski
Henry Schut
Jack Macdonald
Jacqueline Guercio
Janae Broyles
Jane G. Shaw
Janet Bair
Janet Coyne
Janet Hannaford
Janet Houghton
Jeannette Martinho
Jeff Mossburger
Jeffrey B. Gibson
Jenny Law
Joe Decrescenzo
Joe Rhoden
John "Sonny" Blake
John F. Crubaugh
John T. Norton
Johna Leidholt
Jonathan Zilles
Joseph Papa
Josephine Fisher
Joyce Kennedy
Judith Ann Irons
Judy King
Kathryn D. Smithers
Ken Porter
Kenneth Clark
Keri Naccarato
Krista Humes
Kyle Swier
Larry & Loretta Schut
Lauri Siebenthall
Leah Minkin
Linda Mierer
Lisa Jaffe
Lorraine Kasprzak
Lorraine Lerner
Louis "Butch" Howe
Lucille E. Becker
Marc and Ginny Gokenbach
Margaret Morris
Mariola Chyla
Mark Minkin
Mark Peterson
Martin Gorovsky
Mary Beth Farley
Mary Fuchs
Mary Gorovsky
Mary Schlickbernd
Matt Stabenow
Michael Yuan
Michelle Baumgart
Mike Derosa
Mortensen Family
Nan Vail
Nathan Lanz
Nathan Redman
Norman Lapin
Pat and Jim Lee
Pat Messigian
Patricia Schimke
Patty Lehman
Paul Aust
Peggy Marquis
Peggy Taylor
Penni Sutherland
Raylan Hardigree
Raymond Roderick
Refiye Miller
Renuka Kalaria
Richard Curran
Richard Keith Brown
Rick Roemke
Rita Dunbar
Rita Garcia
Robert D. Davis
Robert Schriefer Jr
Rocio Wu
Rodney Harner
Roger Cooley
Ron Anderson
Ryker
Santa Croce Family
Sarah McNaughton
Shirley B Wagner
Stacy Coyne Leger
Stephanie Peterman
Stephanie Swier
Stephany Torres
Stryker Quellhorst
Tom Swenson
Walter Herbert Jones
Wayne Walters

NAF Staff Directory and Social Networks

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Social Networks:

NAF Facebook Page	*www.facebook.com/ataxiafoundation/*
NAF YouTube Channel	*www.youtube.com/user/NatlAtaxiaFound*
NAF Twitter	*www.twitter.com/NAF_Ataxia*
NAF LinkedIn	*www.linkedin.com/company/nationalataxiafoundation*

THE ATAXIA COMMUNITY IS INTERESTED IN YOUR GREAT IDEAS.

If you have Ataxia Tips or a personal story you would like to share in a future issue of *Generations*, please submit it to ***naf@ataxia.org***. Those submitting a personal story are asked to please include a photo or two and a brief author bio (1-2 sentences).

THE DEADLINE FOR SUBMITTING MATERIALS

for the Spring issue of *Generations* is February 3, 2020. Please send articles, your personal story, recaps of Ataxia-related events, photos and reports to ***naf@ataxia.org***. Thank you.

BECOME A MEMBER OF NAF TODAY!

Now it's time for action – especially for our current members!

Our new membership enrollment form has new types of membership.
Once you enroll with the new form, your membership will not expire.
We are working to get everyone converted to the new membership enrollment form.
The sooner – the better!

As a member, you will receive:

- News and research opportunities about your specific type of Ataxia as they become avilable
- Early access to free webinars
- eNewsletter and *Generations* publications
- Personalized communication interests

Enroll at www.ataxia.org/JoinNAF

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New year, new gift!

Consider making your 2020 contributions a recurring gift. When you make a donation just select recurring and you are all set. **Plus**, this helps us plan more efficiently for the year. Win-win!

Donate at www.ataxia.org/donate

Questions about recurring gifts,
contact Jon Wegman, jon@ataxia.org

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