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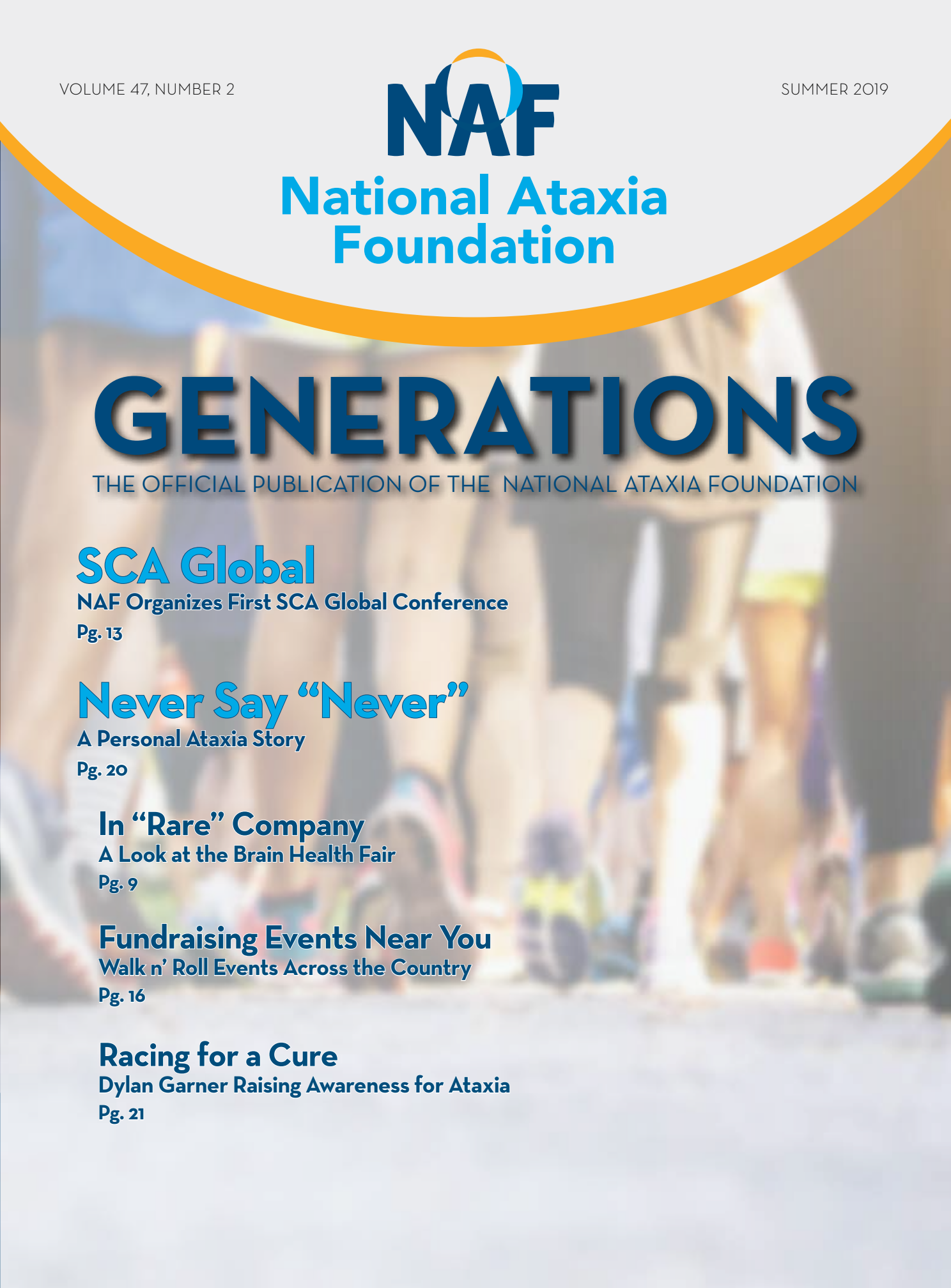
SUMMER 2019

National Ataxia Foundation

GENERATIONS

THE OFFICIAL PUBLICATION OF THE NATIONAL ATAXIA FOUNDATION



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Deadline to submit materials for the Fall issue of *Generations* is August 5, 2019

Please direct correspondence to:

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

National Ataxia Foundation
600 Hwy 169 S., Ste. 1725
Minneapolis, MN 55426
Phone: (763) 553-0020
Fax: (763) 553-0167
Website: *www.ataxia.org*
E-mail: *naf@ataxia.org*
CFC #10752

Generations Staff:

Andrew Rosen, Executive Director
Joel Sutherland, Development Director
Sue Hagen, Patient and Research Services Director
Stephanie Lucas, Communications Manager
Lori Shogren, Community Program and Services Director
Mollie Utting, Communications Coordinator
Nick Gullickson, Finance Associate
Jon Wegman, Development Associate
Leader Printing – Printing and Production
Jessica Johannes – Design

Generations Schedule:

Issue	Spring	Summer	Fall	Winter
Mail Date	April	July	October	January

NAF Update:
Letter from the Executive Director

Andrew Rosen,
Executive Director

Hello Everyone!

There's a widely known management principal centered around what a new leader can hope to accomplish in his or her first 90 days on the job. Well, I've been with NAF for about 90 days now, and I'd like to share a few areas of focus and some initial impressions of the Ataxia community that I'm honored to have started to get to know.

First, I've spent the majority of my time these first weeks getting to know our staff here in Minneapolis, our national Board of Directors, and our amazing volunteers and donors around the country. What I can say unequivocally is how committed these groups are in working toward NAF's mission: improving the lives of persons affected by Ataxia through support, education, and research. I had the privilege of meeting our board members and many in our Ataxia community at our annual conference in Las Vegas. Here at the office, we've realigned our staff a bit to fill some functional gaps and dedicate resources to critical areas. We're looking at revenue growth areas such as institutional support by applying for more philanthropic grants for NAF, and corporate support from our partners in the pharmaceutical community. Lastly, building awareness of Ataxia continues to be a driving force in our day to day work.

My previous nonprofit experience was at an agency focused on providing support for people with cancer. While cancer is a terrible disease, it is largely random in who it chooses to affect. What I didn't fully grasp until starting at NAF is the emotional complexity that is present due to the genetic component of many forms of Ataxia. I've heard numerous personal family stories from NAF board members, donors, and members that have brought me to tears and made me aware of how issues like family planning, genetic testing, and when, or even if, to learn one's diagnosis are a huge part of living with Ataxia. These stories motivate me to work even harder in support of NAF's mission. My admiration and respect for this community, for you all, has been the true highlight of my first 90 days.

Thanks for all you do in support of NAF.

Until next time,

Andrew

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.

Ataxia Webinars

NAF will be hosting a series of educational webinars this year. The first one, **"Dietary Considerations in Ataxia"**, was offered in May. NAF members will receive early access to register, which is a big deal since spots are limited.

Membership is free. Become a member today so that you don't miss out on future webinars!

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. NAF has a goal to have 2,019 people enrolled in the Ataxia registry by 2019. 1,869 participants are currently enrolled.

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.

CoRDS

SANFORD RESEARCH

Enroll at www.sanfordresearch.org/SpecialPrograms/cords

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

BECOME A MEMBER OF NAF TODAY!

By now, many of you have seen the announcements about NAF moving to free membership.

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

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
- Patients 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 another by using chemicals, such as glutamate.

- 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.*
- 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, but also includes SCA3, SCA6, SCA7, SCA8 and SCA10
- 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, SCA2, SCA3, SCA6, SCA7, SCA8 and SCA10
- ☑ 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.clinicaltrials.gov, identifier: NCT03701399.**

The study is sponsored by Biohaven Pharmaceuticals.

NAF Attends the BioMarin North American Patient Advocacy Forum

NAF's Patient and Research Services Director, Sue Hagen, attended BioMarin's North American Patient Advocacy Forum. BioMarin is a pharmaceutical company with a focus on developing therapeutics for patients who live with serious rare genetic diseases. Their mission is to bring new treatments to market that will make a big impact on small patient populations. In their pipeline is a candidate in pre-clinical testing for Friedreich's Ataxia.

The Forum brought together representatives from patient advocacy groups whose organizations provide research and support for patients with diseases for which BioMarin has approved or candidate treatments. During the Forum, participants heard from expert speakers on non-profit governance, organizational leadership and best practices for patient advocacy, as well as opportunities to network with other attendees. One highlight of the Forum was meeting at the BioMarin campus with the scientists who are working on the Friedreich's Ataxia program.

Jean-Jacques Bienaime', Chairmain and CEO of BioMarin, says, "We have the fortitude to embrace risk, pursue bold science and defy conventional wisdom to change the world for patients with rare genetic diseases."

Attendees of the 2019 BioMarin North American Patient Advocacy Forum

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.**

JOHNS HOPKINS MEDICINE

Kennedy Krieger Institute

Individuals with SCA6 and SCA8 are Needed to Participate in Research Studying Ataxic Movements at the Kennedy Krieger Institute

Participation will involve 2-4 hours of behavioral testing and a neurological exam, with multiple visits to our lab possible.

Behavioral testing may involve having small sticky markers placed on your arms and legs so that a computer can detect your movement as you stand, balance or walk on a treadmill.
It may also involve reaching with your arms while sitting at our KinArm robot.
We may also ask you to do non-invasive, very low intensity brain stimulation.

Through our studies we hope to gain a better understanding of why cerebellar disease makes movements ataxic and whether different behavioral therapies can help rehabilitate ataxia symptoms.

There are no significant risks associated with our studies.
Participants will be paid $20 per hour of study time and lunch will be provided.

Contact **The Center for Movement Studies**
by email at **ataxiastudies@kennedykrieger.org**
for more information.

Principle Investigator: Amy J. Bastian, PhD
Kennedy Krieger Institute
Funded by the National Institutes of Health
JHM IRB Application #: NA_00043851

Watch our videos on the NAF Facebook page!
www.facebook.com/Ataxiafoundation.

In "Rare" Company at the Brain Health Fair

Michael Cammer

I recently attended the Brain Health Fair at the Philadelphia Convention Center with Sue Hagen of NAF, and Rich Pardys from our Central PA support group. We also had a visit from Dr. Pedro Gonzales, the local Ataxia doctor from Penn Medicine. The event was held in conjunction with the American Academy of Neurology (AAN) conference, which brings together approximately 14,000 neurologists from across the globe! The day was filled with lectures, events and displays that featured the brain. There were many organizations present that I have never heard of just like many have not heard of Ataxia. We were definitely in "Rare" company! Many attendees stopped at the NAF table where we distributed crayons and coloring sheets of the brain with the cerebellum clearly marked. Both children and adults enjoyed grabbing NAF branded bags, lip balm and candy, while Sue, Rich and I told them about Ataxia, support groups and the work of the National Ataxia Foundation. It was a great Ataxia awareness raising event.

Among the displays was the BrainDome, a larger than life state-of-the-art audio-visual show exploring the inner workings of the brain. The Capital Health Stroke Mobile with an on-board CAT scan that can link up with a neurologist. The vehicle is one of only 20 worldwide to provide this lifesaving technology! There was a wheelchair obstacle course to show the challenges faced everyday by those who are disabled. Service dogs from Canine Partners for Life (CPL) were there to show how service dogs can bring more independence to individuals. And always a crowd favorite and friend of mine with his brain collection is Dr. Russ Buono (A.K.A. Brain Dude). Brain Dude takes his display of human and animal brains to the Brain Health Fair every year. His collection has brains as small as a mouse and as large as a dolphin. What makes his display most fascinating to people is he not only explains the anatomy of the brain to you; he allows you to hold it while he explains it! If you visited three or more of these displays and got your passport stamped, you could get a free bike helmet to protect your brain.

There were many lectures throughout the day including keynote presentations from the AAN "The Future of Neurology is Now" and from Robin Williams' wife, Susan, presenting "Life Found Through Art". A lecture by the University of Pennsylvania Parkinson's Center spoke about movement disorders and Cerebellar Ataxia. There was a popular section for "Ask the Neurologist" that always seemed to have a never-ending line!

If the Brain Health Fair is ever in your area, I highly recommend a visit. It makes a great field trip for kids too! In 2020 the Brain Health Fair and AAN conference is in Toronto, Canada.

Michael Cammer is the Central PA Ataxia Support Group Leader, NAF Board Member, US Navy Veteran and retired federal employee Mike was diagnosed with Sporadic Ataxia in 2004 and lives in Downingtown PA with his wife, Larissa, and twins, Nicholas and Sidney. Mike and Larissa share their anniversary with IAAD on September 25th!

Stay up-to-date — Get on our email list

NAF sends emails to keep our members up to date about Ataxia research, events, and other news.

Please email your contact information to *naf@ataxia.org* so you don't miss out.

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

MICHIGAN MEDICINE
UNIVERSITY OF MICHIGAN

EYE STUDY OF PATIENTS WITH SPINAL CEREBELLAR ATAXIA (SCA)

Dr. Vinod Mootha, M.D. is an ophthalmologist trying to learn more about how SCA can affect the eye. The purpose of the research study is to learn more about how SCA can affect the cornea, or the front "window" of the eye.

What is Fuchs' dystrophy?

Fuchs' dystrophy is an aging disease that involves the endothelium or the innermost layer of the cornea. These aging changes start to appear in affected patients of age 40 and over and can result in swelling of the cornea.

How are SCA and Fuchs' dystrophy related?

We want to learn if patients with SCA develop Fuchs' dystrophy. It has been determined that both diseases are genetically passed down through families in a similar way and, thus, learning more about one disorder can help us learn more about the genetics of the other and vice versa.

What all is involved in Dr. Mootha's genetics research study?

The study recruitment process is a one-time study visit to Dr. Mootha's eye clinic in the Aston building at UT Southwestern Medical Center of Dallas. The visit involves the following:

- Eye exam of the front and back of the eye with dilation drops
- Photo imaging of the front of the eyes
- One-time blood draw to study DNA

Why contribute to studying these diseases?

While there is no reimbursement for your participation, we will share your eye exam findings with you. Your help is greatly appreciated and know that your time and effort put forth into this study visit are going toward helping future generations with these disorders.

How can you participate?

Please call Department of Ophthalmology's Research Study Coordinator Aimee Fuerte at: 214-645-2012 or email her at aimee.fuerte@utsouthwestern.edu to set up an appointment.

UT Southwestern
Medical Center

NAF Funded Research
(Grant Dates June 1, 2019 – May 31, 2020)

SCA3 SPECIAL PROJECTS RESEARCH AWARD

Hayley McLoughlin, Ph.D. | University of Michigan | Ann Arbor, MI
Biomarker Discovery for SCA3 disease

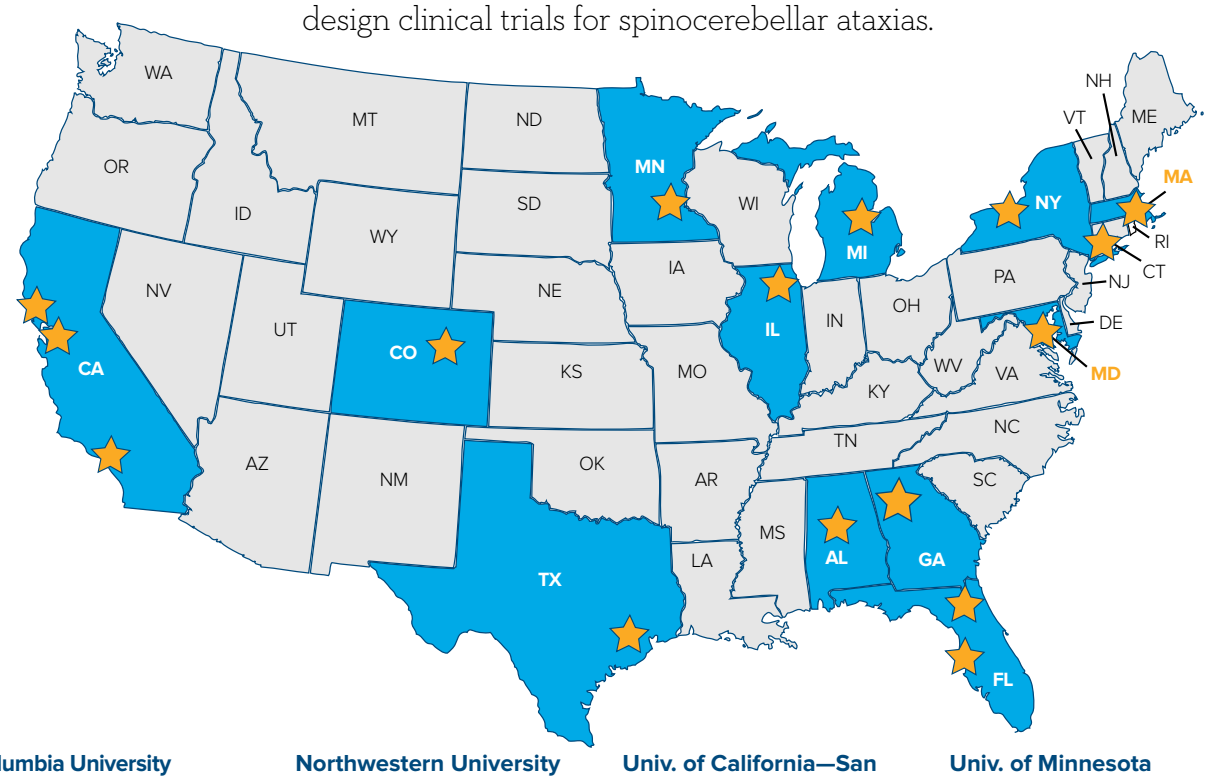
The rapid and remarkable success of ASOs in reducing disease features in SCA3 mice has led us to a stark realization: a major barrier to carrying out effective clinical trials for such therapies is the current absence of robust, readily measured biomarkers of disease. Dr. McLoughlin will lead a team that will perform studies that seek to identify necessary biomarkers to move ASO's or other disease-modifying therapies for SCA3 into the clinic. Leveraging our existing mouse models of SCA3, our experience with potent anti-SCA3 ASOs, and our collection of cerebrospinal fluid (CSF) and plasma from individuals with SCA3 at all levels of severity, we will a) measure specific candidate biomarkers and b) perform unbiased proteomics screens to define novel biomarkers that will reflect disease state as well as, hopefully, response to therapy. Biomarkers will also be measured in the blood and CSF of individuals harboring the SCA3 mutation, as well as in sex and age-matched individuals who do not have the SCA3 mutation. In parallel, complementary candidate biomarker studies will be carried out in a validated mouse model of the human disease. Biomarkers will be measured in the CSF and blood of SCA3 mouse models spanning the full range of disease course. Because we are carrying out therapeutic ASO trials in these same mice, we will be able to correlate any change in identified biomarkers with response to ASO therapy. These results will provide a powerful predictor of whether we are likely to observe similar changes in humans who receive ASO therapy.

Carmo Costa, Ph.D. | University of Michigan | Ann Arbor, MI
Identification of novel genes that modulate ATXN3 abundance

Reducing levels of mutant SCA3 disease gene (ATXN3) products pharmacologically or using nucleic acids has been reported by others and us as an encouraging therapeutic strategy for SCA3 patients. While antisense oligonucleotides targeting ATXN3 transcripts seem to be a promising therapy and are rapidly advancing toward clinical trials in SCA3 patients, alternative, less invasive, and cost-effective approaches, such as the use of small-molecules, are still in demand for SCA3 and other polyQ diseases. Identifying novel small-molecules that decrease mutant ATXN3 protein abundance in the mammalian brain and/or manipulating specific pathways that cells use to control mutant ATXN3 production, stability, or clearance is therefore an unmet need for SCA3. By performing a siRNA screen of the human "druggable" genome we identified several promising genes that regulate levels of mutant ATXN3 protein in mammalian cells. One kinase gene is particularly promising because it can be targeted pharmacologically. This proposal, led by Dr. Maria do Carmo Costa, will seek to confirm the importance of this kinase as a therapeutic target in cell and animal models of SCA3. We will study in more detail the molecular mechanism through which this kinase modulates ATXN3 levels using human embryonic stem cell (hESC)-derived neuronal and glial cells harboring the SCA3 mutation. By deciphering this mechanism, we anticipate identifying novel target genes involved in reducing ATXN3 abundance that could be as, or perhaps even more, pharmacologically targetable as this kinase. We will assess in vivo whether SCA3 disease features shown by a well-characterized SCA3 mouse model will be slowed or minimized by the absence of this kinase gene by crossing SCA3 mice to mice genetically engineered to lack the kinase gene. If this genetic test is successful, we will have strong justification to follow up this result with studies to test whether compounds that pharmacologically inhibit this kinase have a similar beneficial effect in the mouse model. Positive outcomes would strongly support efforts to develop inhibitors of this kinase as therapy for persons with SCA3.

READISCA Observational Study for SCA 1 & 3

This is a major initiative that will provide industry partners with the data they will need in the future to measure whether a treatment or drug is effective to stop or slow down the progressions of the SCAs. The main goals of this study are to establish the world's largest group of early stage and symptomless SCA1 and SCA3 individuals, to validate imaging signs in early stage and symptomless SCA1 and SCA3 individuals and to adapt recent findings to design clinical trials for spinocerebellar ataxias.



Columbia University
New York, NY

Emory University
Atlanta, GA

Houston Methodist Hospital
Houston, TX

Johns Hopkins University
Baltimore, MD

Mass General Hospital (Harvard)
Boston, MA

Northwestern University
Chicago, IL

Stanford University
Palo Alto, CA

Univ. of Alabama—Birmingham
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Univ. of California—Los Angeles
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San Francisco, CA

Univ. of Chicago
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Univ. of Colorado—Denver
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Univ. of Florida
Gainesville, FL

Univ. of Michigan
Ann Arbor, MI

Univ. of Minnesota
Minneapolis, MN

Univ. of Rochester
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

NAF Organizes the First SCA Global Conference

Sue Hagen, SCA Global Steering Committee member

Under the direction of Dr. Thomas Klockgether and Dr. Tetsuo Ashizawa, NAF coordinated the first-ever SCA Global Conference in conjunction with the Annual Ataxia Conference in March 2019 in Las Vegas, Nevada. The SCA Global Conference brought together more than 100 Ataxia researchers and clinicians from around the world. Attendees came from Australia, Austria, Brazil, Canada, China, France, Germany, Hong Kong, Italy, Japan, Netherlands, Poland, Portugal, Switzerland, Taipei, and UK. There was strong presence from the pharmaceutical industry with 16 companies represented by 34 attendees who were there to learn from the leading Ataxia researchers regarding their drug development programs.

The goal of the conference was to better understand the manifestation, evolution and impact of various SCAs. In addition, the conference organizers wanted the group to define and agree on common standards for clinical assessment, brain imaging and bio sampling in order to facilitate development of robust clinical trials in SCAs. There was an emphasis on the involvement of young investigators who will be the next-generation leaders in the field.

The first morning of the conference began with a moving talk from Cameryn Cobb, a young woman who has SCA7. Cameryn shared her experience of living with Ataxia and how that affects her life. Conference attendees remarked that her speech was extremely meaningful and enhanced their motivation to return to their clinics and labs to explore treatments for those affected with Ataxia.

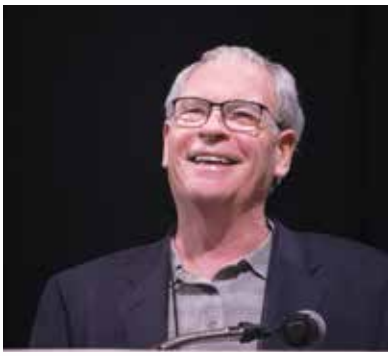
All attendees left the conference with enthusiastic evaluations of the sessions and the direction that the SCA Global initiative is moving, with the goal to serve the Ataxia patient community by moving the science to treatment development. The next SCA Global Conference will take place in April 2020 in Bonn, Germany.

Thank you to the SCA Global Steering Committee members: Dr. Thomas Klockgether and Dr. Tetsuo Ashizawa, Principal Investigators, Julie Greenfield, Ph.D., Holm Graessner, Ph.D., M.B.A., Alexandra Dürr, M.D., Ph.D., Laura Jardim, M.D., Ph.D., Bing-wen Soong, M.D., Ph.D., and David Szmulewicz, M.D., Ph.D.

2019 Annual Ataxia Conference

ATAXIA: A Treatable Disease

Las Vegas, Nevada



The 62nd Annual Ataxia Conference took place March 29-30 at the Flamingo Hotel in Las Vegas, NV. Dr. Susan Perlman from the David Geffen School of Medicine at UCLA was the keynote speaker. Her talk, "Ataxia: A Treatable Disease," reviewed the history of the disease, her role in research, and her belief that there will be at least 1 approved disease-modifying drug within the next 5 years. It was a great way to kick off the 2-day conference which was packed with information on Ataxia. The conference was wrapped up with a banquet on the second night where attendees made new connections and met up with old friends.

NAF would like to extend a special thank you to all the attendees, speakers, facilitators, exhibitors and volunteers of the 2019 AAC. This conference would not be possible without the time, contributions and efforts given by so many. We understand the resources, sacrifices and challenges that many attendees face to attend AAC. Your attendance is greatly appreciated.

AAC STATS:

683 Attendees

47% First time attendees

47 States
13 Countries

22 Sponsors

2019 AWARD RECIPIENTS

Outstanding Achievement Award – Dick Manley
Pictured with Joel Sutherland

Dr. John W. Schut Research Achievement Award – Dr. Tetsuo Ashizawa
Pictured with Sue Hagen

Arnie Gruetzmacher Lifetime Achievement Award – Jonas Cepkauskas
Pictured with Dana Mauro

WALK N' ROLL TO CURE ATAXIA

National Ataxia Foundation

What is Walk N' Roll?

It is NAF's largest grassroots fundraising event! Walk N' Roll to Cure Ataxia currently takes place in cities across the U.S. Since its inception in 2007, Walk N' Roll has raised over $3,000,000 thanks to support and tireless commitment from walkers, rollers, runners, volunteers, donors, and sponsors.

Why Walk N' Roll?

Thousands of families, friends, coworkers, neighbors, and communities come together each year to support NAF's fight to improve the lives of people affected by Ataxia and their families.

How Can I Participate?

For more information, or to start a Walk N' Roll in your community, please contact Jon Wegman, Development Associate at **763-231-2747** or **jon@ataxia.org**.

For more info and to find Ataxia events visit **ataxia.org/events**

Upcoming Locations

Tri-State NY
Northeast Ohio
New England
Denver
Orange County
Atlanta
North Kansas City
Central PA
Pittsburgh
Utah
New Hampshire
Fort Wayne
Minnesota
South Dakota

happy 20TH anniversary IAAD

International Ataxia Awareness Day (IAAD) – September 25

Join the IAAD movement to raise awareness and efforts against Ataxia! We welcome you to participate in this year's 4-week United Against Ataxia series in recognition of IAAD. Visit the IAAD webpage, **https://ataxia.org/international-ataxia-awareness-day/**, for this year's campaign kit and other information about how to get involved. Every action and story matters. Together we are United Against Ataxia! #IAAD19

Let us know how you took action for IAAD.
Email us at naf@ataxia.org

INTERNATIONAL
ATAXIA
AWARENESS DAY
SEPTEMBER 25

Go the EXTRA MILE with NAF...TODAY!

EASY. FUN. IMPACTFUL.

Three words to describe NAF's "Go the Extra Mile" campaign

Easy? That's right! No need to organize volunteers for check-in. No need to get items for a silent auction. No need to hang multiple banners, no need to design and distribute T-Shirts. Our office will even help create your fundraising page for you!

Fun? You bet! Imagine getting friends together on a sunny day to celebrate everyone's effort in this Go the Extra Mile. Bring some beverages, snacks, maybe some music and of course, a camera to capture the joy of your success!

Impactful? Undoubtedly! Raising funds, building awareness and energizing our Ataxia community are three pillars of a great event. This Go the Extra Mile program does all three. You are making a tremendous impact on our entire Ataxia community by leading the way.

Make an impact for all those living with Ataxia today.

GO THE EXTRA MILE 2 Cure Ataxia

Contact Joel Sutherland at joel@ataxia.org or Jon Wegman at jon@ataxia. org to get started.

We look forward to hearing from you!!!

The Michael and Patricia Clementz Family Fund, along with their sons Steve and Eric Peterson, have agreed to match all funds contributed to NAF, up to $100,000, during the Summer Match Challenge. That means more support for persons affected by Ataxia, more education, and more research!

We're up for the challenge, are you? The Summer Match Challenge will last until July 15th. You can participate in a few ways:

- **We encourage you to create your own fundraising page on Facebook.** To start one, click "Fundraisers" in the left menu of your news feed. Click "Raise Money." Select "Nonprofit/Charity." Then start typing "National Ataxia Foundation" to select us as your charity. Choose a cover photo, fill in your fundraiser details, and click "Create."

- **Contribute to the Summer Match Challenge and your gift will be doubled.** Your donation will go to fulfilling NAF's mission to improve the lives of persons affected by Ataxia.

- **Spread the word about the Summer Match Challenge** by forwarding the emails you receive, sharing our social media posts, and telling your family/friends/coworkers.

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_peterson@ataxia.org*** or **763-231-2750**.

Tissue donations for research in Friedreich Ataxia

If you have been diagnosed with Friedreich Ataxia and wish to contribute to its eradication by helping research, please consider donating your tissues after death. To do so, contact Dr. Arnulf H. Koeppen for detailed information. Tissues affected by Friedreich Ataxia are brain, eyes, spinal cord, dorsal root ganglia, sensory peripheral nerves, heart, and the insulin-producing beta-cells of the pancreas.

Arnulf H. Koeppen, MD
Professor of Neurology and Pathology Research Service (151)
VA Medical Center | 113 Holland Ave, Albany, NY 12208
Tel. 518-626-6377 • FAX 518-626-5628
E-mail: arnulf.koeppen@va.gov or koeppea@amc.edu

Never Say "Never"

Catherine DeCrescenzo

Our Ataxia journey began 15 years ago when my husband was diagnosed with SCA2. He has been progressing steadily over the years. He is now on a rollator continually. When we travel, he uses his trusty motorized scooter. Approximately two years following Joe's diagnosis, our youngest daughter tested positive as well.

Over the years, I have written articles and even a couple poems for *Generations*. My writing is a coping mechanism helping me comprehend, accept, and deal with what our family is going through. Trust me, find what works for you as a caregiver and pursue it...you need an outlet.

There is one article which stands out vividly; though this particular article was not published in *Generations*. In March of 2016, I was contacted by Stanford University School of Medicine, who partners with "Inspire", a company that builds and manages online support communities for patients and caregivers, to launch a patient-focused series on "Scope", which is the Stanford School of Medicine Blog. Once a month, patients and caregivers/advocates share their unique stories. I was extremely humbled they contacted me and chose to publish our story. Two weeks later, I was contacted by *Neurology Now* and I was interviewed for their magazine. It was such a whirlwind few weeks. I felt I was doing my part in raising awareness and it was truly rewarding.

"Never say "Never" because you truly do not know what the future holds."

In the article/blog for Stanford, I stated we would NEVER leave our neurologist, Joseph Savitt, M.D., PhD, whom we first met at Johns Hopkins and who is now practicing at the University of Maryland. At the time, we truly believed that we would be with him for the duration, especially after our intense and prolonged search for the perfect Ataxia neurologist. This man has been there for us for many years and we worship the ground he walks on...we are so grateful. We are privileged to call him not only our neurologist, but our friend. Unfortunately, due to Joe's progression, after our last visit to Baltimore in August of 2018, it became apparent that this was no longer going to work for us. The commute was stressful, crossing the major street from the parking garage, along with entering the building was extremely difficult. About a year or so ago, we heard of a new local neurologist with one of his specialties being Ataxia. His office is only 10 minutes from our home, and he is affiliated with our local hospital. We contacted him and invited him to speak at our Delaware Support Group, which he accepted. We felt an instant connection with him, and the wheels started turning. Upon listening to him speak, he reminded us so much of Dr. Savitt, which was so refreshing. His name is Justin Martello, M.D., and come to find out, he studied under Dr. Savitt.

Getting back to our August of 2018 visit with Dr. Savitt in Baltimore...before we could mention our thoughts about possibly transferring and that Dr. Martello spoke at our support group a few months prior, he graciously suggested we consider Dr. Martello and relayed how he knew him and that he recommended him highly. Dr. Savitt said he would miss us but would keep in touch. We will definitely miss him, but it was a mutual decision to do what is best for Joe. We left Dr. Savitt's office emotionally saddened, but also with a positive attitude knowing we will be in good hands as we continue our Ataxia journey with Dr. Martello.

So, the point is, NEVER say "NEVER", because you truly do not know what the future holds. Ataxia is a sneaky disorder which forces you, when you least expect it, to learn to go with the flow, change paths along the way, take it day by day, and, even sometimes, minute by minute.

Thank you, Dr. Savitt, from the bottom of our hearts for being there for us all these years and for giving us hope. We have been through so much together and sometimes all it took was a phone call and hearing your voice. We appreciate all you've done for us, we will miss you, and we will never forget you!

To everyone out there with Ataxia as well as the caregivers, take care of yourselves, keep a positive attitude, raise awareness, and stay strong as we await a treatment and/or cure!

Cathy DeCrescenzo is co-founder of the Delaware Ataxia Support Group along with her husband Joe, who has SCA2. They have been blessed with 42 years of marriage, 2 daughters/sons-in-law, and 3 granddaughters. Cathy is an Administrative Assistant at their local church.

Racing for a Cure

Submitted by Cindy DeMint on behalf of Dylan Garner Racing, LLC

Giving back comes second nature to 20-year-old, Dylan Garner, from Yorba Linda, CA. You see, not only is Dylan a NASCAR race car driver, he is also an Eagle Scout.

When he heard that his neighbors, just a few blocks away, were suffering from a rare form of Ataxia, Oculomotor Apraxia Type 2 (AOA2), he was moved by their story and wanted to help. Since his passion is NASCAR oval track racing, and race fans are passionate people, he decided to take his quest, of raising awareness for this debilitating disease, to the track.

"He decided to take his quest, of raising awareness for this debilitating disease, to the track."

The decision was made to treat the family of Cindy and Gerry DeMint, to a VIP race night at Irwindale Speedway in California. Special arrangements were made, months in advance, and the track officials went above and beyond to accommodate the needs of the family. They had a chance to visit the pit area, and then meet some of the race teams and drivers out on the track before the race for a special photo and autograph session. The family was also treated to a private suite that enabled them to watch the race in comfort. The track officials enriched the experience by offering to take family members up to the starter stand, to help wave the flags during the race.

Dylan and his family team continue to help raise awareness at the track each race weekend by displaying the National Ataxia Foundation logo on their race car and by handing out wrist bands, ribbons of hope and vital information to the fans regarding the disease and how to donate.

At a recent annual "Walk N Roll" event, Dylan signed autographs and donated the hood of his race car that had been raced for most of the season that displays a full-scale photo of the DeMint brothers. The hood was auctioned off and all the funds were donated to NAF.

Dylan attends as many cars shows and events as possible away from the track to continue his mission to help raise awareness for Ataxia, taking every opportunity to educate fans about this devastating disease.

Dylan is a co-owner and operator of a family owned NASCAR Whelen All-American Late Model race car and team. Not only does he drive the race car, he does all his own fabrication, assembly, chassis setup, and maintenance out of his garage at home. He is currently competing for a 2019 California State and dual track Championship.

Dylan is in the early stages of his career and racing at the grassroots level of the sport. With drive and determination, it is his hope to compete at the premier level of the sport and raise awareness for Ataxia, all along the way.

You can follow Dylan on his journey on Instagram and Twitter @dylang_racing, as well as Facebook /DylanGRacing

Taking Notes

Jason Armstong

In a world with Nicholas Sparks it's hard to write something original about love.

Love is a well-traveled topic. One, I'm sure, you've taken plenty of notes on.

Love is patient. Love is kind. Love is engraved in your heart and scrolled among the stars. Love is in air. Love is an open door. And, if you find the right station, love is a battlefield.

Anytime you write about love you ink a fine line between cliché and Nicholas Sparks. So, in my attempt to avoid such fate, the only thing I can offer is a secret love story about love. So secret that when my wife reads this, she will read it for the first time.

I've written about my health issues and personal shame and failure but writing about love is something I've avoided. For me, writing about love is a little embarrassing. A little too revealing. And plus, how do I write about love in such an authentic yet impenetrable way that it's not the subject of dissection, comparison and judgment?

Truth is—you can't.

It's simple emotional physics: To love is to want. And to want is to have weakness. Therefore, you can't open yourself to love without subjecting yourself to dissection, comparison and judgment.

I fell in love with a girl when I was 16.

The first time I saw her standing in the blue painted threshold of the doorway to her biology class I just knew, with an absolute bone-certainty that I would marry her one day.

And 10 years later I did.

Even though that story is absolutely true, I understand your skepticism. And I don't blame you. It seems too easy and yet, at the same time, too impossible. Too Nicholas Sparks.

So, I'll tell you another story that's more believable. Yet, in some ways, just as fantastical. Cindy and I are sitting at large round table, the kind guests sit around at weddings. We're in the back of a Las Vegas hotel ballroom, the kind couples rent for weddings.

Except instead of a DJ, there's a UCLA professor at the far end of the ballroom. He's standing on a stage, behind a podium. To his right is a movie screen holding an MRI of a human brain. A brain whose cerebellum is damaged. A cerebellum that looks a lot like mine.

"After all the romance and celestial promises of the initial courtship, love becomes a lifetime of small moments that add up to make something enormous."

The room is filled with people of all ages. Some people in wheelchairs. Some people clutching canes and walking sticks. The same haunted glow in everyone's eyes.

We're in Las Vegas attending the 2014 National Ataxia Foundation's Annual Ataxia Conference for patients with neurological diseases because seven months earlier, I was diagnosed with cerebellar atrophy.

Cindy and I are surrounded by people of all ages stricken with rare neurological diseases. ALS. MS. Huntington's Disease. Brain tumors.

Some people sit with their spouse. Some sit with their parents. Some sit alone.

The UCLA professor is discussing advancements in stem cell research as a way of improving and repairing brain growth.

Cindy is beside me taking notes.

Her hand moves in small yet amazing ways. She is writing down what the professor is saying as fast as he is saying it.

Her penmanship is catholic school perfect. Her notes are well-spaced and organized and her margins are aligned.

It was a secret moment in my history. One I've never told Cindy about.

A moment of enormous fear, yet as my eyes trace the ink-curls of her words, a small moment of enormous comfort and safety. A moment where love was learned. A moment when I finally realized I was lucky enough to find a woman who cared more for me than I could possibly care for myself.

A moment that gifted me the eventual courage to roll my shoulders and write these sentences—*Let my cerebellum soften to oatmeal. Let my brain cells explode. Let my eyes go blind. Because there's a girl with green eyes standing in the blue doorway and she's not moving. And she never will.*

And that is what love becomes. After all the romance and celestial promises of the initial courtship, love becomes a lifetime of small moments that add up to make something enormous. But even that seems Sparksian.

A chronically sick man whose hands are shaking, whose body aches, whose teetering on the edge of self-destruction is sitting beside his wife in a Las Vegas ballroom. They're high school sweethearts. They have three children together. But seven months ago, things suddenly got harder.

And yet she still takes notes.

As the professor speaks and the damaged brain that holds the screen looms like a thundercloud over the room with her free hand, she reaches across the table to hold his hand, to ease him, to feel his pain.

Jay Armstrong is a writer, Ataxian, and motivational patient advocate. Jay uses the power of writing, speaking, and storytelling to motivate and inspire others. See what Jay is up to and read more of his writings at writeonfighton.org. You can contact Jay at writeonfighton@gmail.com.

Supporting Independent Living

Hannah Xu

I am Hannah Xu, a member of NAF. I live in California with my husband and my 6 year old son. I was diagnosed with SCA1 a few years ago, which I inherited from my father.

I went through phases of anger and denial, then...

Then, I decided to join the local support group as well as NAF. I came across so many fantastic people in the group who are affected by Ataxia, who never stop fighting and always support each other.

These actions plus my profession of many years in import/export, inspired me to create a company to sell "daily living aids" to assist anyone who has my condition.

My goal is to support people being independent. Every item was tested either by me or by my father.

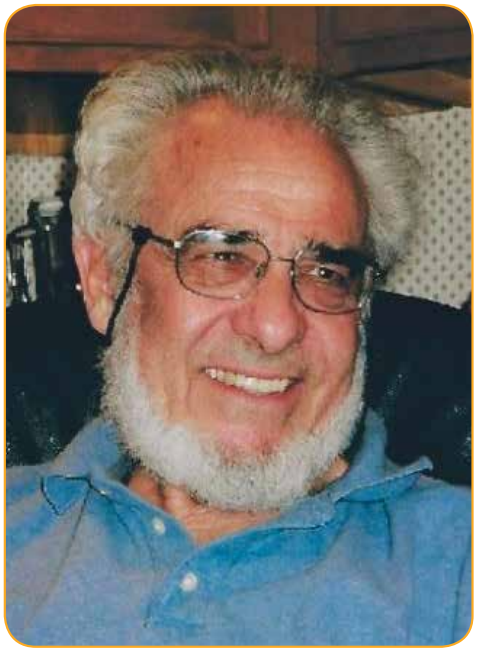
I also wanted to pursue this because I didn't think there was a shop people could go to and find items like these all in one spot. They are small things, but they will create convenience in our daily living. You can visit my store here: www.ebay.com/str/aagear

It feels good to find a means to support my community. Please contact me at hannah.aagear@gmail.com if you need something which you do not see in my store.

In Memory of William Alden Lee *Carolyn Davis*

The National Ataxia Foundation and Chesapeake Chapter lost a staunch supporter this year. William Alden Lee passed away on March 28, 2019, at the age of 85. Bill lived a full life, both before and after being diagnosed with Ataxia.

Bill started exhibiting symptoms of Ataxia around age 40, the third generation of his family to be affected by this disease. By that time, he had a bachelor's degree from Eastman School of Music at the University of Rochester and an MBA from Northwestern University. He was a gifted musician, playing in several US Army bands and singing with professional choirs. He also served 22 years as a reserve intelligence officer in the US Navy, retiring as a Commander in 1988. He started his own tax and financial services firm and later in life spent time editing novels and short stories by his friend and well-known author, Theodore Jerome Cohen.



Bill was actively involved in several community organizations during his lifetime and left his mark on each one. The National Ataxia Foundation had existed just five years when three people in Maryland decided to apply for a chapter charter. In an article written by Bill on the 30th Anniversary of the chapter's formation, he indicated it was a "dim picture for persons with Ataxia in 1982." Bill had SCA6; Dallas Pearson had a family member with Ataxia; and Ray Madison, in whose home they met, had Sporadic Ataxia.

The Chesapeake Chapter saw steady growth under Bill's leadership as the first president of the Chapter. Regular social and informational gatherings were held, including an annual medical meeting. Bill was always anxious to inform others about Ataxia and kept a supply on hand of the Chapter's "Yellow Book" which included an exhaustive list of the known types of Ataxia at the time it was written and revised. He also solicited contributions to help fund Ataxia research.

Bill was especially gratified when the Chapter was able to help support the creation of the Ataxia Center at Johns Hopkins. We had been looking for a worthwhile project for the "nest egg" the Chapter had accumulated. Although our sum was small in comparison to what was needed and so willingly provided by the Macklin Foundation, we were grateful for the opportunity to add our support.

The Chesapeake Chapter initially included Maryland, Virginia, Delaware, and the District of Columbia and then added members from parts of Pennsylvania, West Virginia, and North Carolina. Support groups have now been organized in several of those areas. Bill was always encouraging support groups to be organized in order to serve the needs of those in their local area. It was even one of his focuses in 2005 when he spent time in Spokane, Washington, where he tracked down and married his college sweetheart. He was also tracking down those with Ataxia while he was there.

When Bill was named an Ambassador by the National Ataxia Foundation, he considered that position to be an opportunity to reach out to the whole community, not just those affected by Ataxia. His passion to inform others led to proclamations recognizing International Ataxia Awareness Day. These were issued by the Mayor of Frederick, Maryland, and the Commissioners of Frederick County, as well as the Pennsylvania General Assembly.

Even with his activities being limited because of the effects of Ataxia taking their toll, Bill remained positive and upbeat. A few years ago, he wrote, "One thing is for sure: the best is yet to come." I think he certainly would agree – the best is yet to come as we continue to spread awareness of Ataxia, offer support to those affected by it, and fund the research which brings us closer to treatments and cures. We have, indeed, lost a champion for the cause of Ataxia awareness, support, and research. And those who knew Bill Lee have lost a friend.

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 08/05/19 to be eligible for inclusion in the next issue of *Generations*. Submit them via email to naf@ataxia.org.

1 Do you do this? I plan out any errands I need to make. I plan my route, including where and which entrance. I figure out the easiest route, not necessarily the fastest or most direct. I'm sure others think I'm nuts, but I want flat. No steps or stairs and ramps and easy access are good. (Submitted by Stephanie Hales)

2 I still do the laundry. I put the dirty laundry in a trash bag and throw it downstairs. After washing and drying, I fold the clothes, place them in the bag, and take the finished laundry back upstairs. It's not that easy but it helps you stay in shape and challenges you. Some ask me how this is done. One of the many things I use are double handrails in stairways. If you don't have them, call a carpenter! Also, the bag of clean laundry is stowed on my back freeing my hands to use those handrails. Get moving! You can do it! (Submitted by Stephen Trusedell)

3 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)

4 My Mom suffers from Ataxia and has a difficult time picking things up from the floor/ground after she's dropped them. I purchased a "light weight grabber" which allows her to pick items up she has dropped without having to bend over which causes her to fall forward. I have purchased a few of these "grabbers" and put them in several rooms so there is always one ready when she needs it. (Submitted by Brenda Sommers)

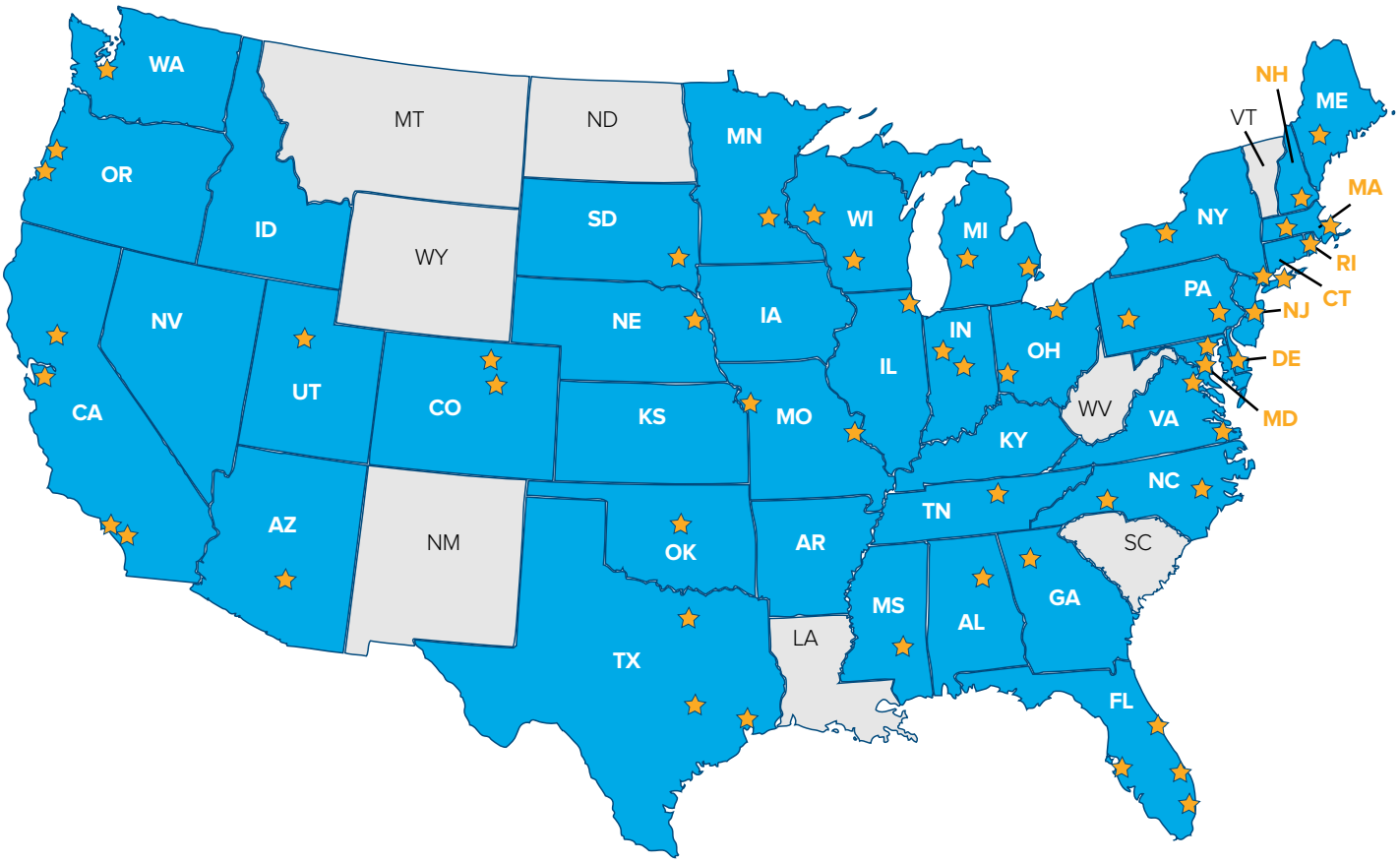
Support Groups & Events

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 NAF 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

Alabama Ataxia Support Group

Submitted by: Becky Donnelly

The Alabama Ataxia Support Group met on March 30th in Homewood, AL, with 24 members present. The meeting began with coffee, cupcakes and fellowship. Cell Group leaders gave reports on members in their group and then we discussed the 2019 Rare Disease Day to be held in Birmingham on May 4th with the purpose to educate the next generation of rare disease advocates. Two Members from our support group plan to attend, and others were encouraged to do so.

The group enjoyed a delicious brunch planned and prepared by Sandee, and then enjoyed fellowship while awaiting our speaker, Dr. Marissa Dean, Dept. of Neurology, UAB Hospital. Dr. Dean, who had just returned from the 62nd Annual Ataxia Conference, gave an overview of her first visit to this meeting. She expressed amazement at the number of people present from many parts of the world. She then spoke of the SCA Global Conference and shared how trials are conducted and the need for people to be involved.

Dr. Dean asked members to share their Ataxia story, giving her and support group members insight into the struggles that families face while dealing with Ataxia. Dr. Dean expressed that this helped her more fully understand about living with Ataxia, whether as one affected or as a caregiver. She spent a lengthy time answering questions from members and discussed topics relevant to the group.

Before leaving, the group expressed that there be a way to acknowledge members' birthdays. We had two members volunteer and will undertake this responsibility. A summer social was discussed, future plans are in the works and members will be notified. The meeting ended with more time for fellowship, an element that truly helps to bind us together as a cohesive group.

Arizona Ataxia Support Group

Submitted by: Mary Fuchs

The Arizona Ataxia Support Group met on Saturday, May 4th in Phoenix. Mary Fuchs opened the meeting and we were VERY excited to welcome 6 new members! We talked about the recent conference in Vegas. Joanne gave a great "Take Away" presentation. We also discussed ideas for our IAAD event and fundraiser. Joanne introduced our speaker, Dr. Jefferson Holm, a board-certified Neuro-clinical specialist from Advanced Neurologic Rehabilitation. He talked about the importance of exercise & neuro physical therapy, no matter what stage of Ataxia you are in. We look forward to our next meeting on Saturday, August 3rd in Phoenix and will welcome a guess speaker who will discuss accessible travel.

Denver Ataxia Support Group Annual Picnic

Submitted by: Charlotte DePew

We had a wonderful gathering of new and "seasoned" members at our April 20 quarterly meeting. After our potluck lunch and fun socializing, we had our invited guest, Emily Todd, MS, CGC, University of Colorado Med. Cen. speak on genetic testing. After familiarizing us with some basics of genetics, as dominant vs recessive, she then discussed the proverbial issues of why to get tested and cost. When cost is considered, it may range from a few hundred to thousands of dollars depending on

the physician's order, insurance, and the laboratory doing the test.

If the physician writes for a specific narrow DNA area, such as SCA..., then the cost may be a few hundred. The greater the search, the more it costs. Medicare does not cover this testing. Some insurances do cover testing, some do not. In addition, if you are working with a neurologist and geneticist, you can work with the genetic laboratory in negotiating a lower price. The final message I have is, pursue testing for yourself and offspring, negotiate the price for what insurance does not pay, and then decide.

Our next meeting is July 20 and I asked one of the CU Ataxia Clinic neurologists to give an update on the recent good news in Ataxia research toward cures and symptom improvement. On August 10, both the Denver group and the Northern Colorado Ataxia Group plan a picnic near Longmont. More details to come.

Denver Support Group

Tampa Bay Ataxia Support Group Annual Picnic

Submitted by: Jan Colon

On April 20, 2019 we had our Annual Ataxia Picnic at Rowlett Park Tampa, Fl. It was a beautiful breezy day. We decorated Easter Egg Ataxia Rocks, played board games & fellowshipped with each other! We had new members attend the picnic thanks to NAF posting our event on the Support Group events calendar. We had hamburgers, hot dogs, baked beans, yellow rice, potato salad & a host of desserts. Thanks to everyone that participated in the Rowlett Park Picnic. We had a great time!

Tampa Bay Support group

Treasure Coast Walk n' Roll

Submitted by: Lisa Cole

First of all, thank you to all volunteers! I am so grateful to have so many people help with what I care about doing.

Our 2nd Annual Walk n' Roll to Cure Ataxia was another huge success. In addition to the actual walk, several radio stations and local newspapers added our event flyer to their calendar of events and we even had a couple of local newspapers do a short story on the event. Awareness helps and thank you to all that helped share this great event for a wonderful cause.

This was also our first time to have so many vendors with a total of 7 and each vendor shared our event with others which brings more awareness.

We had over 120 people in attendance and I have been told that I have to do it again next year, I say, bring it on, we can do it.

Thank you to all our sponsors; Smallcakes A Cupcakery, Florida Movement Therapy Centers, Eyeglass World in Port St. Lucia, and A+ Quality Property Maintenance LLC., and to Adam's Artwork's for creating our Walk n' Roll to Cure Ataxia t-shirts and The Sign it! print shop for creating our board and signs for the event. Once again, all the materials needed were provided by

NAF which helps spread the word, thank you! Finally, a BIG thank you to Ronnie O for helping create a beautiful event.

Treasure Coast Walk n' Roll

Greater Atlanta Ataxia Support Group Meeting

Submitted by: Greg Rooks

The Greater Atlanta Ataxia Support Group held a meeting on April 13th at the Emory Brain Health Center at 1:00 pm. The meeting was well attended with 27 individuals. The meeting started with welcomes and introductions by everyone in attendance.

Our guest speaker was David Keane, Business Development and Genetic Diagnostic Specialist with GeneDX. GeneDx was founded in 2000 by two scientists from the National Institutes of Health (NIH) to diagnose patients with rare disorders and assist the clinicians responsible for treating these patients. Led by its world-renowned clinical genomics program, GeneDx has cutting edge diagnostic testing for most inherited genetic disorders. David has over 20 years' experience in genetic testing first with Athena Diagnostics and with GeneDX since 2011.

His presentation covered the genetics of Ataxia, tests available, insurance coverage and billing for patients, genetic counseling options, and other patient resources. The group found the presentation was very interesting and informative.

After the meeting adjourned everyone enjoyed refreshments and social time.

Greater Atlanta Support Group

Tri-State Ataxia Support Group Meeting

Submitted by: Kathleen Gingerelli

The Tri State Ataxia Support Group meeting was held on Thursday, May 9 at the Mt Sinai Downtown Center 10 Union Square East NYC, NY in the 2nd floor conference room from 6:30p-8:30p. After brief introductions for our 1st timers we got the meeting started. Members who attended the 2019 AAC in Las Vegas were asked to speak about their favorite parts. Everyone was very encouraged and happy to talk about the progress being made in research.

We also spoke about the Abilities Expo which was held May 3-5 at the Convention Center in Edison, NJ. Volunteers from the group worked a booth for NAF to educate and spread awareness while also having the time to walk around and check out other exhibitors and workshops being held throughout the weekend.

As always, the importance of exercise was stressed to all with each member talking about what they do to keep moving. Each member was advised to become a NAF member and to also sign up for CoRDS. We talked about getting ready for our Walk n' Roll event being held on August 24, 2019 at Liberty State Park in Jersey City, NJ.

NY Metro Abilities Expo

Submitted by: Kathleen Gingerelli

The 2019 NY Metro Abilities Expo was held May 3-5 at the NJ Convention & Expo Center in Edison, NJ. The Abilities Expo showcases many events & workshops to entertain & educate. Volunteers from the Tri State Support Group helped spread Ataxia awareness & inform everyone about how NAF is dedicated to helping Ataxia families through research, education & support.

There were many activities, events and workshops scheduled each day including our very own Tri State member Ian Bouros performing his music at our table on Saturday afternoon. For a list of the schedule and other states hosting Expo's, visit the website at www.abilitiesexpo.com

2019 NY Metro Abilities Expo

Sioux Empire Support Group

Sioux Empire Ataxia Support Group

The Sioux Empire Ataxia Support Group represented NAF at the Great Plains Rare Disease Summit at the Sanford Research Center in Sioux Falls, SD. The Summit began with a screening of the movie "The Ataxian" followed by a day of scientific sessions and then a community day with many inspiring and helpful sessions for families impacted by a rare disease. Group members were able to network with other families, researchers, and organizations.

Greater Houston Area Ataxia Support Group Meeting

Submitted by: Dave Cantrell

What a wonderful group of people we have in our support group! We had 10 people attend and quite possibly had one of the best support sessions yet. New member Syed attended and immediately contributed to the group. Rob, John and John talked about how they are coping with their conditions and how having a positive outlook helps them through the day, this led to a very good discussion about depression in the Ataxia community and how everyone needs to be aware and able to recognize the signs of depression. One member talked at length about how just accepting the diagnosis was a long process and took them 7 years to finally admit it and enable them to move forward. Another member discussed how it has taken them years to get back into life and to start getting out and enjoying life and the things that are important to them. Andrea shared her latest experiences with PT/OT, and we all were impressed with her progress over the past

2 months, from wheelchair to walker. Way to go Andrea, you are an inspiration. We were also able to get into the challenges of caregiving and the stress involved in caring for our loved ones. Sometimes we are guilty of "providing" too much attention and that can add to everyone's stress level. A wonderful meeting with the strongest people that I know. Thanks for attending and sharing your support for all of us.

Under 30 Virtual Ataxia Support Group Meeting

Submitted by: Lauren Sormani

The Under 30 with Ataxia support group had its first two virtual meetings in December and January! We had a great turnout–including participants from five different countries. Our first meeting focused on reasonable accommodations and types of assistive technology. We also took some time to introduce ourselves and share our journey with Ataxia. Our second meeting featured John Cernosek and his experience with Ataxia and exercise. Those who participated talked about their barriers to exercise and we discussed what they could do to ameliorate those barriers. We plan to meet virtually every month. If you are under the age of 30 and have Ataxia yourself (parents are not permitted in this group) join us on Facebook at Under 30 with Ataxia. All meeting dates/times will be voted on and posted there. Contact Lauren Sormani at lasormani@gmail.com for more information.

India Support Group – "Seek a Miracle Ataxia Group"

Submitted by: Ramaiah Muthyala

The Indian Organization for Rare Disease (IORD) and Rotary International jubilee club jointly assisted rare diseases patients. Tuesday, May 7, 2019, Rotary club jubilee hills president Dr. SV Ramprasad and IORD General Secretary Dr. M Kridhnaji Rao jointly presented wheelchairs to MD, SMA and other rare disease patients. These wheelchairs are provided to make their life a little better. On this occasion they informed us that 6 to 8% of the general population of India, equivalent to 90 million people, suffer from 7000 different rare diseases. 80% of these diseases are caused by genetic defects like the hereditary Ataxias.

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 April 2019 - May 2019.

Barry Washburn
Lisa Maypother
Bill Lee
Tom Fleury
Tim Green
Harold Schmidt
Diane Graham
Annie Young
Krista Humes
Jana Jones
Annie Goldston
Pam Bishop
Marcia Cox Vaughey
Colleen Yosick
Howard Hunnius
William Steinlage
Kay Wolma
Joan Baermann
Leroy Wernsing
Kenneth R. White
Ronald Bellinger
Robert J. Schriefer
Lisa Langmeir
Anne Teicher
Jane Tran
Michael Mitchell

GeneDx Validation for Repeat Expansion Disorders Assay

GeneDx, Inc., a CAP/CLIA-accredited genetic testing laboratory, frequently develops new testing for genes and disorders for which there are limited testing options available. Part of the assay development process relies on the evaluation of DNA samples from individuals with a known genetic disorder and/or specific type of genetic change to validate the effectiveness of the assay. GeneDx is currently developing assays for a subset of repeat expansion disorders and is looking for samples from patients with a known diagnosis and positive genetic test results for any one of the following genes/disorders:

Disorder	Gene
SCA10	*ATXN10*
SCA12	*PPP2R2B*
SCA17	*TBP*
SCA31	*BEAN*
SCA36	*NOP56*
SCA37	*DAB1*

If you choose to participate in these studies you will be financially compensated $100 for a blood sample and $25 for a buccal (cheek swab) sample. Blood samples are preferred and a home blood draw can be arranged at a time that is convenient for you. We request that you provide a copy of the original lab report confirming your diagnosis, but we can work with your physician to acquire these documents. All required paperwork for participation in the study and compensation for your time will be discussed at enrollment.

For information email:
genedx@genedx.com

GeneDx
an OPKO Health Company

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.

Columbia University
Darya Tomishon
dvt2101@cumc.columbia.edu

Emory University
Carole Seeley
carole.seeley@emory.edu

Mass General/Harvard
Jason MacMore
jmacmore@partners.org

Houston Methodist
Titilayo Olubajo
tolubajo@houstonmethodist.org

Johns Hopkins University
Ann Fishman
ann.fishman@jhu.edu

Northwestern University
ZsaZsa Brown
zsazsa.brown@northwestern.edu

University of California Los Angeles
Aaron Fisher
ADFisher@mednet.ucla.edu

University of Florida
Stephen Gullett
Stephen.Gullett@neurology.ufl.edu

University of Chicago
Hannah Casey
hannahcasey@uchicago.edu

University of Michigan
Tasha Kaiser
kaisert@med.umich.edu

University of Minnesota
Diane Hutter
hutte019@umn.edu

University of South Florida
Joshua Vega
joshuavega@health.usf.edu

University of California San Francisco
Nancy Cai
nancy.cai@ucsf.edu

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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?

There is an important step you can take so that in future studies for which you might qualify, you will be notified. And that step is to enroll in the CoRDS Ataxia Patient Registry.

If you are affected with any type of SCA or any other form 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 Staff Directory and Social Networks

NAF Staff Directory:

Andrew Rosen, Executive Director	(763) 231-2745 • *andrew@ataxia.org*
Joel Sutherland, Development Director	(763) 231-2748 • *joel@ataxia.org*
Sue Hagen, Patient and Research Services Director	(763) 231-2742 • *susan@ataxia.org*
Lori Shogren, Community Program and Services Director	(763) 231-2743 • *lori@ataxia.org*
Stephanie Lucas, Communications Manager	(763) 231-2744 • *stephanie@ataxia.org*
Mollie Utting, Communications Coordinator	(763) 231-2741 • *mollie@ataxia.org*
Nick Gullickson, Finance Associate	(763) 231-2746 • *nick@ataxia.org*
Jon Wegman, Development Associate	(763) 231-2750 • *jon@ataxia.org*
Mary Ann Peterson, Research Assistant	(763) 231-2747 • *mary_peterson@ataxia.org*
Kelsey Trace, Research Associate	*(763) 231-2742 • kelsey@ataxia.org*

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 Summer issue of *Generations* is August 5, 2019. Please send articles, your personal story, recaps of Ataxia-related events, photos and reports to ***naf@ataxia.org***. Thank you.

JOIN US IN DENVER NEXT YEAR!

63RD ANNUAL ATAXIA CONFERENCE

MARCH 6-7, 2020
SHERATON DENVER DOWNTOWN HOTEL

VISIT **WWW.ATAXIA.ORG** FOR ANNOUNCEMENTS REGARDING REGISTRATION AND HOTEL GROUP RATES.

2019 Annual Ataxia Conference

2019 Annual Ataxia Conference

National Ataxia Foundation
600 Hwy 169 s., Ste 1725
Minneapolis, MN 55426
(763) 553-0020

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