



National Ataxia Foundation

GENERATIONS

THE OFFICIAL PUBLICATION OF THE NATIONAL ATAXIA FOUNDATION

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Deadline for to submit materials for the Fall issue of Generations is Friday, August 4

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From the Desk of Executive Director Joel Sutherland



Hi everybody! There has been a lot going on since the last time you heard from me - in a good way! I want to start by taking the time to recognize all our fundraiser organizers and volunteers. You are the lifeblood of

the NAF and I want to make sure you know how much you are appreciated. Whether you organize a Walk n' Roll, a 60 for 60, support groups, or an individual fundraiser to support the NAF - the time and effort that you put into your events makes a difference. It shows your dedication to helping the Ataxia community. Your efforts provide the resources to our researchers that they need to look for a cure.

I want to give a special shout out to the Clementz Foundation as well - for their generous \$75,000 matching gift campaign! It inspired us and our community to come together and work towards that goal. The NAF received donations that were large, small, and everything in between - and I appreciate each and every one of them. Thanks to all who helped with the match campaign. When we reach our goal - that will be \$150,000 worth of resources the NAF will have to use in the search for a cure. All inspired by the generosity of the Clementz Foundation. Awesome!

The NAF recently hosted The Katie Campbell Clinical Trial Readiness Conference for Ataxia researchers and clinicians from across the country. It was a two-day conference and there was great energy and passion from the group. They set ambitious, but achievable goals to reach before

next year's conference. The researchers let the NAF know that they'll need our support to meet their goals and prepare their clinical trial readiness sites. It motivated me and let me know that we're headed in the right direction - building the engine of the NAF. They need us - and we need you.

How can you help? Join a local Walk n' Roll, support a 60 for 60 team or participant, start your own fundraiser, or donate. Check our website at www.ataxia.org for information about any of those things.

Thank you!



THE DEADLINE FOR SUBMITTING MATERIALS

for the Fall issue of *Generations* is Friday, August 4. Please send articles, your personal story, recaps of Ataxia-related events, photos and reports to joan@ataxia.org. Thank you.



Morgan's Wonderland

Submitted by Juliana Helmke



Group 1: L-R: Bonnie Wiley Sills - Texas, Shannon Dunphy Lazo - Illinois, Mary Liebert - Louisiana, Tanya Tunstall-Marshall - Michigan, Brian Park - England, Juliana Helmke- Illinois, Beryl Park - England



Group 2: L-R: Alan Thomas - Wales, Jeffrey Klas - California, Dawn Morgan - Wales, Alison Love - Scotland, Tanya Tunstall-Marshall - Michigan, Bonnie Sills - Texas, Mary Liebert - Louisiana and **Back:** Shannon Dunphy-Lazo - Illinois and LeeAnnMcGurk - Scotland

Morgan's Wonderland is a theme park located in San Antonio, Texas, that is the world's first fully-accessible amusement park. Alan Thomas-Wales, and Juliana Helmke-Illinois, worked together to plan this outing while in San Antonio at the 60th NAF Annual Ataxia Conference in March. They invited interested people to sign-up and attend the outing.

Juliana worked with the logistics in San Antonio. She worked with the San Antonio Paratransit Department, bus/public transportation, to have proof of disability waived and direct transportation to and from the hotel.

The rides, including a ferris wheel, were fun for adults and the speed and height of the rides allowed participation without adverse side-effects. The group had fun and were also able to share awareness about Ataxia.

Those who participated were: Bonnie Sills-(Texas), Shannon Dunphy-Lazo-(Illinois), Mary Leibert-Louisiana, Tanya Tunstall-Marshall-(Michigan), Brian & Beryl Park-(England), Juliana Helmke-(Illinois), Alan Thomas-Wales, Jeffrey Klas-California, Dawn Morgan-(Wales), Alison Love-(Scotland) and Leeann McGurk-(Scotland).

Alan and Juliana are excited and working on the next adventure while attending the 61st Annual Ataxia Conference in Pennsylvania and hope that those interested in an additional outing will contact them to get more information. If you are interested in signing up, receiving information about the next adventure, or have a suggestion please contact them at:

Alan: onamission.thomas@btinternet.com or Juliana: thatgirlmetwo@sbcglobal.net

Pearls of Wisdom

Walkers and Rollators

Submitted by Donald Overmyer

Bend the elbows, keep them close to your body. There is benefit in standing taller. I find I am much more stable than with a cane.

Moving Around in Bed

Submitted by Pete Myerhoff

This can be surprisingly difficult. If your bed is located near a wall try pushing off that wall.

Rolling is more successful than sliding.

Try pushing up on your elbows.

Experiment, experiment.

Never Spill a Drop!

Submitted by Ginny Atwell and Mike Cammer

Ginny and Mike say that the "Incredible SpillNot" is a must have! They say that it allows them to carry their coffee/tea without spilling. It keeps your drink from spilling, no matter how unsteady you are when carrying it.

<https://spillnot.myshopify.com/>

International Ataxia Awareness Day September 25, 2017

International Ataxia Awareness Day (IAAD) is on Monday, September 25, 2017. It is a coordinated effort from individuals and Ataxia organizations around the world to help shed light to this rare disease. What better way to get involved in the fight against Ataxia than IAAD? The NAF is committed to leading the way on this outreach effort - but we need your help! We encourage individuals, disease, and Ataxia advocacy organizations to join us by planning events and/or awareness campaigns for IAAD. The NAF will release an official campaign kit for 2017 in the coming month that will provide ideas for key messages to use at your events or in your campaigns. This kit can be used as a guide or just for ideas to get you started in planning your own messages. Please watch for more info on our website and in our monthly e-newsletter! Not subscribed to that? Sign up at <http://bit.ly/NAFemail>. Report your IAAD events to the NAF to get them listed on our events calendar.

Get Involved in IAAD - Make a Difference

Organize or Join an Activity

Planning an event or activity is a great way to raise awareness and get others involved in taking-action. Organizing your awareness activity on or around September 25, will help build strength of the awareness effort and draw media attention. Activities can be small or large, social or educational, informational or fundraiser - the possibilities are endless!

Post on Social Media

An easy and free way to help with Ataxia awareness is social media. You can post a personal story, facts, or information about Ataxia to help with the awareness efforts. The NAF's IAAD campaign kit will offer social media post ideas and images. You can follow the NAF on Facebook, Twitter, and LinkedIn to share our IAAD messages as well. Use #IAAD17 for your

social media posts to help them be found/seen by others.

Use the NAF's Campaign Materials

Looking for some handouts about Ataxia for your event? Or flyers to post at local venues? Shareable images for social media? The NAF will supply printable and downloadable materials that you can use - free of charge!

The 2017 IAAD Campaign Kit will also provide facts about Ataxia and suggestions for awareness topics. You can use the pieces of the kit that you find helpful and ignore the pieces that you don't need. It



will be provided as a tool to help you generate ideas for your events and awareness campaigns. Want to be notified when the kit is available? Email the request to naf@ataxia.org.



The Ultimate Finish Line....a Cure for Ataxia

What is Walk n' Roll to Cure Ataxia?

The Walk n' Roll to cure Ataxia program is the National Ataxia Foundation's largest national grassroots fundraising event held in recognition of International Ataxia Awareness Day (IAAD).

Walk n' Roll, which began in 2007, is held in cities across the U.S. Walk n' Roll to Cure Ataxia has raised more than \$2,258,000 thanks to the support and tireless commitment from walkers, rollers, runners, volunteers, donors, and sponsors.

Why Walk n' Roll?

Thousands of families, friends, co-workers, neighbors, and communities come together each year to support the 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 Lori Shogren, NAF Community Program and Service Director at **(763) 231-2743** or lori@ataxia.org.

2017 Walk n' Roll Events:

Tri-State Walk n' Roll • Jersey City, NJ - August 26

Contact: Kathy Gingerelli kgingerelli@msn.com
www.ataxia.org/walk/tristate

Northeast Ohio Walk n' Roll • Cleveland, OH - August 27

Contact: Julie Clarich julieplus3@gmail.com
www.ataxia.org/walk/NEOWalk

Minnesota Walk n' Roll • St. Louis Park, MN - September 9

Contact: Carla and Wendy Sweeney
wendysweeney1@comcast.net
www.ataxia.org/walk/minnesota

Walk for Dave • Ithaca, NY - September 9

Contact: Marc Alessi mja244@cornell.edu
www.ataxia.org/walk/walk4dave

Denver Run, Walk n' Roll • Denver, CO - September 10

Contact: Charlotte DePew cldepew77@comcast.net
www.ataxia.org/walk/denver

OC Walk n' Roll • Orange County, CA - September 16

Contact: Cindy De Mint cindyocataxia@gmail.com
www.ataxia.org/walk/oc

Atlanta Walk n' Roll • Duluth, GA - September 23

Contact: Greg Rooks atlantaataxia@gmail.com
www.ataxia.org/walk/atlanta

Utah Walk n' Roll • Salt Lake City, UT - September 23

Contact: Lisa Ord, PhD, LCSW lisa.ord@hsc.utah.edu
www.ataxia.org/walk/utah

Western PA Walk, Run n' Roll • South Park, PA - September 23

Contact: Madalyn Gottschalk samgotts32@gmail.com
www.ataxia.org/walk/wpa

New England Walk n' Roll • Bristol, RI - September 30

Contact: Jeannette Viveiros jeannette@ataxia.org
www.ataxia.org/walk/newengland

New Hampshire Walk n' Roll • Londonderry, NH - October 7

Contact: John Mauro john@ataxia.org
or Jill Porter jilleporter@comcast.net
www.ataxia.org/walk/newhampshire

Oklahoma Walk n' Roll • Coalgate, OK - October 7

Contact: Tori Wood torifaye289@gmail.com
www.ataxia.org/walk/oklahoma

For the most current information on Walk n' Roll for Ataxia events please visit:

http://www.ataxia.org/events/walk_n_roll.aspx.



Hope for the Ataxian: Technology, Community, and Therapeutic Advances

Submitted by Dana Creighton

Identifying markers of rare genetic disorders could be as simple as sending a blood sample to a lab, thanks to new technology. It was not always so. Recently technological advances were discussed, in exciting detail, as the University of Rochester hosted a day-long meeting, “Technology and Rare Neurological Diseases Symposium” (TRNDS) on May 12.

I learned about this symposium on a National Ataxia Foundation Facebook post. As I looked at the posts, I recalled my mother’s struggling to find a diagnosis for her condition from the early 1970’s until she got confirmation of SCA2 in 1980, based on symptoms and family history. It was much more efficient for me and my two brothers to determine our status during the first decade of 2000. For us, dealing with the positive or negative outcome associated with Ataxia was not as simple.

And the two keynote addresses illustrated exactly what we were feeling.

There were two thirty-minute keynote addresses in addition to four one-hour panel discussions. Each keynote speaker brought a unique and specific perspective. My eyes opened widely when the director of innovation at Pfizer, Craig Lipset presented “Research as a Care Option” and stated that within research trials, patient input during study design and the obligation of the researcher to provide patient feedback of study findings are integral to move innovations forward at a faster pace. The founder of Global Genes, Wendy White, stressed the importance of needing to coordinate the care of the health provider

and patient so that each can benefit from the interaction maximally.

I was increasingly attentive as sixteen representatives, all from different biotech or pharma companies, spoke specifically about how what they do aligns with accelerating novel therapeutic interventions for rare neurological diseases. Each of the four sessions included a moderator who was an expert in the field of

neurology and led a discussion guided by questions specific to a presenter or questions from the audience. Komathi Stem of monARCH Bionetworks described the patient as being the “gateway” which can then drive the research as opposed to riding as a passenger in the process. Jennifer Farmer, Executive Director of FARA, suggested that we need to leverage current technologies to develop and grow patient registries.



Dana Creighton

Community, I know, is essential to my resilience. As a follow-up after this meeting I will be helping Sue Hagen, at NAF, directly ask each representative who participated in this meeting how patients with Ataxia can step up and get involved. As I am learning, there are likely many ways a patient can contribute. In my case, I am currently raising awareness and money through the 60 for 60 to Cure Ataxia campaign through the NAF. As I reach out to present and past personal connections in my life, individuals have stepped up and contributed directly in varying amounts. Others have shared my story and fundraising page with their friends with whom I would otherwise have had no direct connection. My hope for my fellow Ataxians and myself is sustained by

several things, the fact that there was an idea to host this meeting at the University of Rochester, by co-chairs Erika Augustine and Ray Dorsey, in itself is very hopeful. Augustine does research focused on advancing therapeutic development for rare pediatric neurologic disorders and is incredibly optimistic. Dorsey, with his colleagues, seeks, to enable anyone, anywhere, to receive care, participate in research, and benefit from therapeutic advances. In addition, almost two dozen leaders from medicine, pharmacology, government, law, and ethics participated and spoke throughout the day repeating over and over that they have the tools, technology and desire to help.

A call for action: We need to continue the direct line of communication from these organizations to the NAF so that as patients with Ataxia, we can all join this crusade to participate in helping make a discovery that will lead to a viable treatment.

Participants in symposium:

- Univ of Rochester Medical Center & Ataxia Clinic
- Pfizer
- Global Genes
- Blackfynn
- MC10
- National Organization for Rare Disorders
- FARA-Friedreich's Ataxia Research Alliance
- Harvard Law School
- Think Genetic
- Evidation Health
- AMC Health
- FDA, Food and Drug Administration
- TRND Community
- Biogen
- FasterCures
- Georgetown University
- Seeker Health
- monARC Bionetworks, Inc.

Approved January 31, 2017



JOHNS HOPKINS
M E D I C I N E

ATAXIA RESEARCH STUDY

Patients diagnosed with cerebellar Ataxia, age 18-75, are needed for a study of short-term memory.

Participation involves 1 visit lasting 1-4 hours. Tests include computerized games and eye tracking.

Receive \$20/hour for your time.

Call (410) 502-4664 to learn more and see if you qualify.
Confidential.

FA Patient Focused Drug Development Meeting

Submitted by Michael Cammer, NAF Board of Directors Member

On June 2, I attended the externally led FA Patient Focused Drug Development Meeting along with Sue Hagen in College Park, MD. The meeting was part of an initiative by the Food and Drug Administration (FDA) to expand on the way it looks at patient therapies, specifically seeking input from patients and patient disease groups. The FDA wants a platform to hear directly from patients regarding their experience living with specific diseases, the impact of potential treatments and the benefit/risk analysis of new targeted medications. In addition to the patients and the FDA, there were representatives from academic institutions and pharmaceutical companies to hear directly from patients and caregivers the impact that Friedreich Ataxia has on their lives.

The meeting began with a welcoming introduction by Jen Farmer the Executive Director of FARA, a moving story by Ron Bartek, Founder of FARA, about his personal involvement to FA and remarks from Dr. Bryan of the Rare Diseases Program at the FDA. The session continued with the moderator, James Valentine. He started the discussion by polling the audience for demographics of patients or caregivers. The polling was done electronically either online or by text. After the demographics polling, James introduced the first of two panels of patients and caregivers. They each presented their stories from having a healthy lifestyle to the challenges of living with a progressive degenerative disease like Friedreich's Ataxia. The floor was then opened to additional input which will all be

transcribed into a "Patient Voice" report that will be sent to the FDA for input and collaboration with Pharma into the needs and future drug development of FA patients. The morning session was closed by remarks from Dr. Goldsmith of the FDA and Jen Farmer.

The afternoon was filled with discussions and updates on FA research, clinical programs and trial summaries, but the topic of most interest was wearable technology for continuous activity monitoring by Dr. Amir Lahav from Pfizer. Most appointments with your health professional are just a "snapshot of time" in your life. The value of the wearable devices is that with the continuous data from a wearable device, your physician can receive measured data over an extended period to get a true picture of your overall health. The devices can also provide an objective tool in a clinical trial for measuring movements. It is a very exciting development not only for FA, but all Ataxias and movement disorders!

Of all the forums and conferences, I've attended, this has to be one of the most moving forums I've attended. The stories of everyday life that FA patients and caregivers face were genuinely shared and this put a reality to the challenges they face daily. Probably the most emotional moment for me was when a caregiver from the second panel said, One of her saddest days was when she realized her home would no longer be embraced by the comforting sound of footsteps from her children.

Kathy and Judy Gingerelli



Dana Creighton and Mike Cammer



Nygel Lenz and Sue Hagen



Research Study Going Virtual Reality!

Submitted by Mike Cammer

I recently got to be the first participant in a research study using an Oculus Rift virtual reality headset at the Kennedy-Krieger Center for Movement Studies in Baltimore. It was my first experience with the virtual reality technology and I must say it was a pretty cool experience! They are studying whether virtual reality training may be useful for improving the intention tremor and dysmetria that affect reaching movements in patients with Ataxia. The task uses motion capture to record the movements of the arm in real-time and feeds that information into a fully immersive virtual environment. Your movements are electronically measured with markers on your index finger, wrist, elbow and shoulder to a digital readout for the researchers. With virtual reality, they are now taking the next step to see if the technology we “play with” can improve outcomes by studying a more natural 3-dimensional movement of the arm as opposed to the more conventional 2-dimensional reaching movement studies.



24th and we got to meet with state legislators and Health Committee members at the state capital for a couple of hours followed by a press conference and lunch. In researching it more, I found my local and neighboring representatives are both on the Health Committee! We had for some good Ataxia Awareness!!!

On April 6 and 7, Mike Leader and I attended and set up an exhibitor table for the 24th Annual Neuroscience Conference in Hershey, PA. We got the opportunity to speak to nurses, occupational therapists and physical therapists who are in direct contact with patients who have Ataxia. I still find it perplexing today how little Spinocerebellar



Mike Cammer at Annual Neuroscience conference exhibitor table

Ataxia is known within the neuroscience community! Many are familiar with Ataxia as a symptom of stroke, Parkinson's, ALS, etc..., but you mention the SCA's and it's like teaching a 101-intro class to freshman in college. We were also able to attend sessions throughout the conference and a couple of the presenters referenced the National Ataxia Foundation and our Central PA Support Group in their talks, so even if attendees didn't come to our table, they were exposed to Ataxia. I also met Sandi Brettler from the Penn State Hershey Medical Center and am coordinating a relationship with our support group.

Annual Neuroscience Conference and Rare Disease Day Event

Submitted by Mike Cammer

On March 14, a Rare Disease Day Event in conjunction with NORD was supposed to take place at the state capital. We have had a very mild winter and wouldn't you know the only snow storm we get would be that day! The event was rescheduled for May

BRAIN TISSUE DONATION PROGRAM

Ataxia researchers have made many discoveries because of donations of brain tissue from those affected with Ataxia. One researcher said the following about brain donation, “This tissue is very precious.” The National Ataxia Foundation'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 Sue Hagen, NAF Patient and Research Services Director, at susan@ataxia.org or (763) 231-2742.

Social Security's New Security Enhancement to Protect Your Privacy

On June 10, 2017, Social Security is adding enhanced security to protect your privacy as **my Social Security** users. This is in addition to the first layer of security, a username and password. Adding security measures to safeguard your information – but making them easy to use – is a vital part of keeping you safe and secure.

When you sign in to your personal **my Social Security** account at www.socialsecurity.gov/myaccount with your username and password, they will ask you to add your email address or a text-enabled cell phone number. Using two ways to identify you when you log on will help better protect your account from unauthorized use and potential identity fraud.

Then, each time you sign in to your account, you will complete two steps:

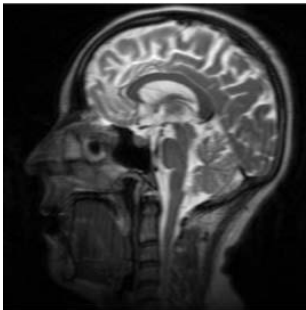
Step 1: Enter your username and password.

Step 2: Enter the security code they send by text message or email, depending on your choice (cell phone provider text message and data rates may apply).

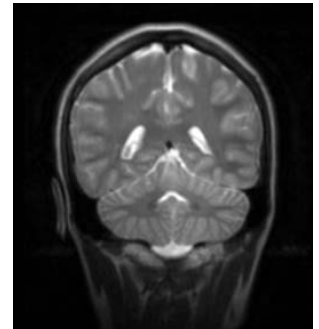
Since an email address is already required to use **my Social Security**, everyone can continue to benefit from the features **my Social Security** provides. If you plan to select email as your second method, you can ensure that the one-time security code email does not go into your spam or junk folder by adding NO-REPLY@ssa.gov to your contact list.

In addition to these security enhancements, they are also upgrading the look and feel of **my Social Security** to create an enhanced customer experience. The my Social Security portal will automatically adjust to the size of the screen and kind of device you are using – such as a tablet, smart phone, or computer. No matter what type of device you choose, you can have full, easy-to-use access to your personal **my Social Security** account.

[Sign in or Create an Account](#)



PATIENTS with SCA2, SCA3 and MSA-C needed for an MRI study



at the University of Minnesota, Minneapolis

Travel expenses reimbursed.

Contact: Diane Hutter
(612) 625-2350 • hutte019@umn.edu

Glut1 Deficiency Syndrome - a Treatable Cause of Ataxia in Children

by Toni Pearson, MD, Associate Professor of Neurology, Washington University in St. Louis

Ataxia in childhood has many potential underlying causes. When evaluating a child with Ataxia, pediatric neurologists take special care to test for conditions that have a specific treatment. One such condition is Glut1 deficiency syndrome (Glut1 DS), a genetic disorder in which glucose transport into the brain from the bloodstream is impaired due to defective function of the glucose transporter, Glut1. Glut1 DS was first described by Dr. Darryl De Vivo and colleagues at Columbia University in 1991. Several hundred patients with the disorder have since been diagnosed worldwide.

Patients with Glut1 DS typically have a variety of neurological symptoms. About 70% have Ataxia, which may cause an unsteady, clumsy gait, coordination problems, and difficulties with speech articulation in the young child. Ataxia often occurs together with other movement symptoms, including spasticity (stiffness, usually most prominent in the legs) and dystonia (abnormal postures of the limbs, trunk, or neck). Given this constellation of symptoms, it is not uncommon for patients with Glut1 deficiency to be labelled as having “ataxic cerebral palsy” before their specific underlying diagnosis is identified.

An important characteristic of the movement symptoms in Glut1 DS is their tendency to fluctuate in severity, becoming more noticeable in the setting of fasting, illness, or sustained physical activity. For example, parents may observe that their child's walking is most unsteady when they first wake up in the morning, or right before mealtimes, when they have not eaten for several hours. These periods of symptom worsening presumably occur when the mismatch between the brain's demand for glucose and the available supply is most pronounced.

Another core feature of Glut1 DS is the occurrence of episodic neurological symptoms. The most common of these is epileptic seizures. In the most severe cases, seizures begin in early infancy and are very difficult to treat with anti-seizure medications. Some patients have much milder forms of epilepsy, with occasional seizures that respond readily to standard treatments.

In addition to seizures, young infants with Glut1 DS

may experience characteristic brief episodes of darting eye and head movements as one of their first symptoms. Children, adolescents, and young adults with Glut1 DS commonly experience episodes of involuntary movements that are triggered by exercise, called “PED” (paroxysmal exertional dyskinesia). Movements in PED may consist of stiffening of the legs, or writhing and flailing movements of the body. Other examples of episodic symptoms include

migraine headaches (sometimes associated with vomiting), weakness on one or both sides of the body, lethargy or confusion, and episodic Ataxia. Episodes may last from minutes to hours.

In addition to seizures and movement disorders, patients with Glut1 deficiency often experience attention and learning difficulties which may range from mild to severe. The combined occurrence of the symptoms described above is the clinical clue to the correct diagnosis, although not every patient necessarily experiences every symptom.

Glut1 DS is an autosomal dominant genetic disorder. This means that it is caused by a mutation in one of the body's two copies of the gene for Glut1. In the majority of known cases, patients are the first person in their family to have the disorder - that is, the genetic change occurred



Toni Pearson, M.D.

'out of the blue', rather than having been inherited from either parent. It is also possible for the gene to be passed from parent to child.

If a neurologist suspects a possible diagnosis of Glut1 deficiency, the single most informative test to perform is a spinal tap: the laboratory hallmark of the disorder is the finding of an abnormally low glucose level in spinal fluid, together with a normal glucose level in the blood. Analysis of the SLC2A1 gene identifies the underlying genetic abnormality in 90-95% of patients with typical symptoms and a low CSF glucose level. From a practical standpoint, it is important to remember that if genetic testing is performed first and yields negative or inconclusive results, a spinal tap should be performed to definitively rule in or rule

out the diagnosis.

Glut1 DS is a treatable condition. The current standard treatment is for patients to be placed on a ketogenic diet, to provide an alternative source of fuel to the brain other than glucose. The ketogenic diet often dramatically improves symptoms, particularly seizures and other episodic symptoms, and may also improve the long-term outcome. Because of this, it is vital to make the diagnosis as early as possible.

For more information regarding genetic testing or a Phase 3 clinical trial (<https://clinicaltrials.gov/ct2/show/NCT02960217>), please contact Ultragenyx Pharmaceutical at (415) 483-8800.

New York Metro Abilities Expo

Submitted by Kathy Gingerelli

Imagine everything you need, under one roof! For nearly 40 years, the Abilities Expo has been the go-to-source for people with disabilities, their families and healthcare professionals. On May 5-7, the NAF, for the third year, had a booth at the event held at the New Jersey Convention and Expo Center in Edison, New Jersey. Facilitated by the Tri-State Ataxia Support Group members for the 3-days of exhibits, workshops and events for every one of all ages and disability. Members spoke with many people about Ataxia, covering everything the National Ataxia Foundation does and passing on information about the Tri-State Ataxia Support Group meetings to locals.

With more than 150 exhibitors there was a lot to see but the daily events, workshops and activities made the total Abilities Expo experience. Each daily schedule included all day activities, fun events and free workshops for all attendees

including a Service Dog demonstration, Acupressure for stress Relief, Living Well with Chronic Pain, Putting Insomnia to Sleep, Dance for Everyone, and an adapted wheelchair basketball game.



Kathy Gingerelli hosts the NAF Ataxia Awareness booth

On Saturday we listened to, and met, ABC's *Speechless* star Micah Fowler, a 19-year old American actor with Cerebral Palsy born in New Jersey. Over at booth #734, the NAF booth, we had our own celebrity sighting!! Tri-State group member, Ian Bouras, showed up and entertained by demonstrating "live looping" on his guitar. Ian is in the process of preparing his next CD, *Absence*. For more information about his new CD, you'll find an article in the Spring issue of *Generations* on page 25 or visit <http://www.sdmprecords.com/sdmphome.html>. Overall, the Expo was a success with many contacts made for future events and we look forward to being back there again for 2018.

Our Family Planning Story: Let's Make a Baby... or Two!

By: Jessica Pape

My grandmother died at the age of 60 of a degenerative muscular disease that I didn't know much about. I went on living my life as a teenager and a short time later found out that my mother had inherited the disease that took my grandmother's life. I was in denial for a while and didn't like to talk about it. As I grew older, I began to do my own research and went to a neurologist appointment with my mother, to get more information. I spoke about my experience losing my grandmother and finding out that my mother had the same disease, SCA3, in front of a lecture hall of students in my final semester of college.

Our Story

Cole and I met at a bar ... it seemed too good to be true. We dated long distance for a couple of years while I went to grad school. During that time, we traveled and enjoyed each other's company on the weekends. I moved in when I was done with grad school and were engaged in July 2011, on one of our many trips to Las Vegas. We got married in May 2012 at Caesar's Palace in Las Vegas with 50 of our closest friends and family members. I wore five inch heels for the first and most likely, the last time!

Our first year of marriage flew by and we started talking about having children. There was one barrier that stood in our way...I wondered if I had the same hereditary disease? I had to find out if I had inherited SCA3. I suffered from anxiety every time I would go to a new doctor and dreaded having to tell my story to another new person who may have never even heard of the disease.

Step 1: Discuss Family Planning

I did get comfortable with my OB/GYN who discussed family planning with me and gave



Jessica, Cole and Penelope Pape

me a referral to the genetic testing/neurology department at the same place that my mother was tested.

I was unsure of the whole process but, coincidentally, I had a younger sister who was going through the same thing, at about the same time. After meeting with the neurologist

in April 2013, I waited for several months for the doctor to order my test. The waiting was so frustrating! I finally received the orders in the mail and took them to a lab to have my blood drawn. It took about three weeks before I got the results.

Step 2: Research and initial appointment

After getting my positive test results, we did not hesitate to do some research as to what our options were for having a baby. We decided to pursue in vitro fertilization with pre-implantation genetic diagnosis. We checked with our insurance and found that they didn't cover any fertility treatment of IVF.

At our first appointment, we met with the financial department and got estimates for the IVF. We had been saving for the last few years in case this would happen so we were somewhat prepared for the cost. We then sat down with the doctor who explained the whole IVF process and a nurse who went over the planning and preparation tasks for us to do.

Step 3: Waiting and more waiting

We had an appointment in September and they told me what to do in the next few months and I would be reassessed in December. In December, I had my baseline ultrasound. I didn't even meet with the doctor that day. The nurse told me to go ahead and wait until January and we could start my cycle.

In January, I called my clinic and was very excited to start my cycle. I was disappointed when they told me they would have to check if my PGD was ready. Later that day I got a call back that my PGD was not expected to be ready until March. It was almost a full year since I started this whole process. It was initially estimated that it would take 16-20 weeks to complete when everything got turned in... and they were right on.

My younger sister found out she was negative...

and was pregnant. I was very happy for her but just a bit jealous at times that I had to spend so much time waiting and planning.

Step 4: Injection training

In April, I would get another ultrasound and begin the injection training. I spent about two weeks researching pharmacies to use that offer a discounted price for the medications I would need to purchase since we were paying out of pocket. I didn't really know what to expect.

For the first few days I would start off with one shot, for three days I would have two shots, and for the remainder of my cycle I would be giving myself three shots a day. The rest was kind of "tentative." I knew that around cycle day 8-10, I would have an ultrasound and sometime close to then I would have a pre-op appointment where we would talk with the doctor about retrieval. I found out that after the pre-op appointment there would be one big shot called "the trigger," followed by one day with no shots, and then the retrieval two days after the trigger.

Step 5: Stimulation and Retrieval

I had been getting injections starting with 1 a day, then 2 a day, then 3 a day. We had our pre-op appointment where I got an ultrasound and learned more about the trigger shot and retrieval day. We signed some consent forms with the doctor and got the news we would be giving the trigger shot. That meant no more 3 a day injections, and the needle was pretty big and looked like it could be painful.

The retrieval day had finally arrived. We met with the nurse first who took gave me a brief description of what to expect.

Step 6: Transfer

About a week following retrieval we found out we had 3 healthy, unaffected embryos! They recommended starting with one embryo since I had no known fertility problems so we requested

to begin by thawing our strongest one and to leave the other two frozen for later use.

Next was to prepare for our first frozen transfer. A lot goes into creating the perfect environment. The doctor said our transfer was textbook. It was amazing! I couldn't stop smiling and almost cried. We knew everything would be well worth it in the end. Now I could go to sleep happy and we would wait until June 19 when I would have a pregnancy test!!

Step 7: Results

We welcomed our daughter into the world on February 19, 2015. Knowing that we went through all of that work to produce an Ataxia free child was well worth the wait!!



Rosalie Pape

During the summer of 2016 we decided to try for baby number two. The process was much simpler. We started with a frozen transfer requiring no preparation except tracking, preparing my body, and then after transfer, injections. Piece of cake! I have been reassured to hear a heartbeat at every appointment and am happy to be in my third trimester with my second daughter!

May 2017 our second daughter Rosalie, was born, and she is doing great!

If you would like more information or to contact Jessica please email her at: jessicaleeper@gmail.com

Check out these recently held 60 for 60 Events!



Nebraska Ataxia 60 for 60 to Cure Ataxia

The Nebraska Ataxia team held their first 60 for 60 to Cure Ataxia event on May 19. Team Captain Mark Sidwell, Cheri Albin and Paul Sidwell walked 20 miles each day, for three days, from Omaha to Nebraska City, Nebraska. You can see their route here: <https://goo.gl/maps/wGaj2XTWeBF2>. You can still donate and support their efforts in meeting their fundraising goals by following this link: <https://ataxia.donorpages.com/201760For60/NebraskaAtaxia/>



Nebraska 60 for 60 to Cure Ataxia

Treasure Coast 60 for 60 to Cure Ataxia

The Treasure Coast Team held their 60 for 60 to cure Ataxia Walk n' Roll event at Jaycee Park in Fort Pierce on June 24, where approximately 20 people walked about 3 miles. Team captain Lisa Cole and team members Dan & Sue Freedland, Frances Diedling, and Hank



Treasure Coast 60 for 60 to Cure Ataxia

Westerfield met at the Jaycee Park and headed to Jetty Park. You can still donate and support their efforts in meeting their fundraising goals by following this link: <https://ataxia.donorpages.com/201760For60/TreasureCoastAtaxiaSupportGroup/>

60 for 60 to Cure Ataxia - Possum Pedal Bike Ride Submitted by David Henry, Jr.

On Saturday, June 3, in Graham, Texas, David Henry, Jr. rode 67 miles for his 60 for 60. Beginning at 7:30 a.m. he participated along-side other bikers in the Possum Pedal Bike Ride, traveling through rolling hills, smooth roads, and some beautiful areas in Texas. There were rest stops available and activities at the Start and Finish line that included the Third Annual Food Truck Championship of Texas, live music, and a concert at the arena. If you would like to support David's ride please visit his website here: <https://ataxia.donorpages.com/201760For60/DavidWHenryJr/>



Possum Pedal Bike Ride

What I Find Helpful

Submitted by Linda Snider

Fun-loving, vibrant, loves to laugh, dance and enjoys the outdoors. That was me at 21 when I was first diagnosed with Ataxia, and it is still me at 45. I am a fighter and I don't know the word quit. Because of my positive outlook on life and will to stay as healthy and functional as possible, I do everything I can to slow the progression of this disease.

I recently attended the National Ataxia Conference in San Antonio, Texas. I was approached by many people – neurologists, researchers and Ataxians – all wondering what I was doing to stay healthy and keep my disease progression as slow as possible. Although Ataxia has no cure and no known medical treatment, here are the things that I find most helpful:

MOVEMENT: You need to move as much as you can. Staying active and strong are beneficial to anyone, but they're especially important to someone with Ataxia. Strengthening your legs and core muscles helps balance. Do something fun for exercise. There are recumbent trikes for the disabled. I also do yoga, which is proven to help balance. I need to use a wall or chair for assistance, but if you talk to the group instructor ahead of time, they can help modify the moves and supply props. Private yoga sessions are also available.



Mark Sidwell and Linda Snider

BALANCING: Actually - practice balancing. Do anything that makes you work harder to balance. The more you practice anything, the better you get, and it's no different for Ataxians. Our practice may involve walking, standing on one foot, or getting up out of a chair. If in a wheelchair, you can practice sitting upright without the backrest as a support. There are yoga moves designed for

sitting or those in a wheelchair. Standing on uneven surfaces is an excellent opportunity for increasing difficulty. I stand on a foam pad every day. Foam from a physical therapy office is great, but an egg crate will work too. Stand on it with two feet. Try to stand on one

BALANCE VEST:

I wear a BalanceWear vest from Motion Therapeutics (<http://www.motiontherapeutics.com/>).

It has helped me immensely, and I swear by it. It allows me to work less to balance and helps decrease fatigue. I work out in it because I can push myself farther. The vest also helps with speech, writing, hand movements, tremor and vision. You must go to someone certified to fit it, and the weights change with you over time so it needs adjusting.

STRETCHING: Mobility in the joints is needed for balance, especially in the hips, knees and ankles. Using a yoga strap or a simple belt can help you stretch. This online article demonstrates

poses you can do with the strap: www.doyouyoga.com/10-ways-to-use-the-yoga-strap-with-photos-55570/. Always do these stretches carefully and with assistance if needed. Some of the poses are not possible but many are and can be done while sitting or lying down.

TESTOSTERONE: A testosterone pellet injected every three to four months helps keep muscle fibers strong. Your primary care physician, a urologist, or another health care professional must insert the pellet.

DIET: Diet is more important than you realize. Most Ataxians would agree that when you feel run down or have an illness or fever, your Ataxia symptoms are worse. Inflammation in our bodies from what we eat and process internally will affect our health and our Ataxia symptoms. Toxic chemicals in the products we use and in the food we eat make it harder for our bodies to function at their best. Eat as many clean, nutritious foods as possible. Gluten and dairy are known to cause the most inflammation in our bodies even if you aren't allergic. There is an informative book called "The Wahls Protocol," or watch the Ted Talks by Terry Wahls, MD online for a complete explanation of why this type of diet helps. In addition, using MCT oil in coffee with a tablespoon of melted ghee or butter is also known as "bulletproof brain." The fats in the MCT oil are helpful to the brain.

SUPPLEMENTS: I take supplements with the guidance of a nutritionist. I also do alternative therapies through a doctor, including IV glutathione and low-dose naltrexone, which a physician must prescribe and administer.

You may want to consider taking Biofilm Defense for six months to help clean the lining of your bowels to help supplements absorb better. Antioxidants, particularly Protandium, have been proven to improve health. Atrantil helps

decrease inflammation in the gastrointestinal tract. Furthermore, increased levels of vitamin D have been shown to protect the brain. DHEA is a known neuro regenerator. Magnesium is a crucial mineral that is essential for over 300 different biochemical reactions and functions throughout the body. Magnesium plays an important role in neurological function and the health of the central nervous system in addition to increasing energy, relieving muscle aches and spasms, and calming nerves and anxiety. Prior to taking any supplement regimen, you will need to consult with your physician to make sure it will not interfere with other medicines you may be taking.

Supplements are not created equally. The FDA doesn't monitor the manufacturing etc so the quality differs. I use and recommend the Designs for Health brand.

MOTOR SKILLS: To help with my fine motor skills and keep my hands active, I do an adult coloring book.

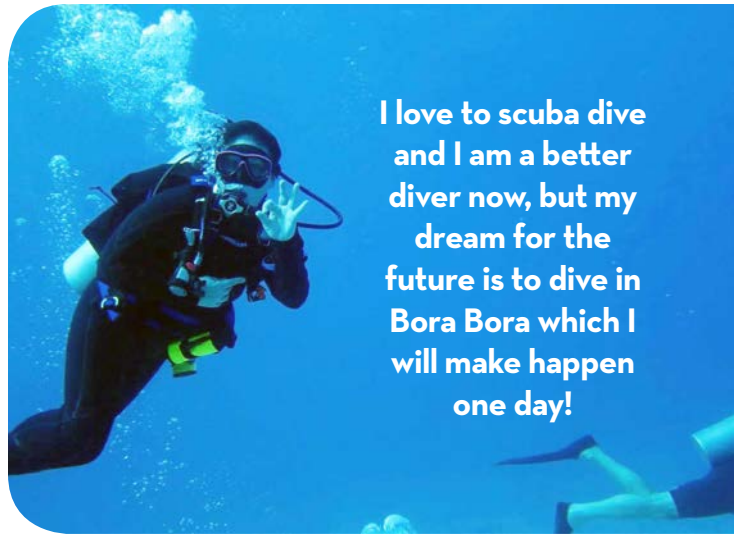
SPEECH: To improve my speech clarity and speed, I see a speech pathologist and there are handouts for tongue and cheek exercises. Also playing games like Taboo or Catch Phrase will help you practice your speech in a fun way.

HOLISTIC APPROACH: You should see a functional medicine doctor in addition to or in place of a traditional doctor. Find a physician that will treat you as an entire person and not focus on one part of your health. Functional medicine physicians tend to be more familiar with supplements and nutrition. Assistance in finding a functional medicine physician can be found at www.functionalmedicine.org.

That's a lot of information. Incorporate things one at a time so it isn't overwhelming. Start slowly and see how you feel. What works for one person may not work for someone else. I am only trying

to communicate what I find helpful. This regimen has taken me over a year to implement.

A positive outlook on life will help any situation. Talk about your struggles and your triumphs. Ask for assistance, and don't be afraid to be different. Ataxians are able to stay active and be vibrant members of society. We may need to modify how we do things, but there should be no shame or embarrassment with that. Look to the future and know that research is coming along, but in the mean-time, take control of what you can and forge ahead, fighting for every step.



I love to scuba dive and I am a better diver now, but my dream for the future is to dive in Bora Bora which I will make happen one day!

Friedreich's Ataxia Clinical Trial at Mayo Clinic with Medication Epicatechin

Study # NCT02660112

Study # NCT02660112

Dr. Gavrilova and team at Mayo Clinic Rochester Minnesota are recruiting individuals with Friedreich's Ataxia to participate in a drug clinical trial. This clinical trial is designed to determine if the study medication Epicatechin will improve the neurological or heart functions of patients with Friedreich's Ataxia. Epicatechin is an organic based medication with a good safety record. We are recruiting children and adults (age 10-50 years) with a confirmed diagnosis of Friedreich's Ataxia and neurological and heart related symptoms. The participants' disease duration should be of 7 years or less.

In this clinical trial, you will be evaluated at Mayo Clinic Rochester during three separate visits over a 6 month period. After the first visit, if you qualify for participation and if you are willing to take part in the study, you will be asked to take an oral

medication three times per day for six months. At each visit you will be evaluated by neurology, cardiology, endocrinology, genetic and physical medicine specialists. You will also have an MRI and an echocardiogram. Blood and urine samples will be obtained at each visit to the clinic.

More detailed information about this clinical trial is available in the consent form and on the website clinicaltrials.gov, Mayo, NAF and FARA websites.

If you would like further information or are interested in participating, please refer to this study by its clinicaltrials.gov identifier: **NCT02660112**

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Principal Investigator: Ralitza H. Gavrilova, MD



Edward E. Noel - by Mrs. Rosemary Noel

My husband, Edward E. Noel, was diagnosed with Ataxia in his mid-thirties. Later, Cerebellar Spinal Degeneration was added to his diagnosis. His main issues, at first, were balance and double vision. He was actively employed and remained so until his early 60's. As the disease progressed he also began having tremors, speech and swallowing issues. Eventually he began using a cane due to an unsteady gate, then moved on to a walker, and the last aide being a power wheel chair ... all of which he adamantly put off using for as long as he possibly could manage. Additionally, he worked hard to keep his strength with exercises designed by a physical therapist but the disease became relentless and the exercises didn't help anymore.

In the final stages, his vocal cords would not function so he lost his ability to speak above a whisper and his ability to swallow diminished causing aspiration into the lungs. After a fall and

partial hip replacement, he was then reluctantly placed on a feeding tube which increased his problems instead of helping. Additionally, he was weakened by a severe bout with pneumonia and sepsis. He died February 7, 2017 at age 84.

His struggle was of courage and determination throughout his long journey. He never once said why did this happen to me or feel sorry for himself. His biggest concern and regret was not for himself but that he had unknowingly passed his disease on to two of his offspring; our daughter and son ages 63 and 58, respectively. The onset of their disease also came in their thirties. Thankfully, it appears their two siblings have been spared the disease. I pray that none of our grandchildren will be affected.

It is my hope that the memorial submitted to the National Ataxia Foundation in my husband's name will not only benefit our family but others with this relentless neurological disorder.



Thank You

By Allida

Morning light beams through a
Wide, jagged crack in the wall,
And brings an interest to my eye,
My silent yawn mimics my silent room,
as I heavily sigh,
my blurry thoughts are brought into focus,
and as I push the white fabric aside,
such are quickly floating away,
As my altered brain begins the ride,
"Fear not," sings the bird,
"this morning is a gift, and you shall celebrate."
"Breathe with gratitude, that you can still do
what you are able to do, today..."
"and though each ability is fading fast...
don't ever be afraid it won't last."

Dr. Ajay Sanghi

Submitted by Sunanda Sanghi

My husband, Ajay Sanghi, PhD, is 70 years old and has SCA12. He was diagnosed in 2010 by Dr. S.H. Subramony at the University of Florida, in Gainesville, Florida. The clinic sent his blood work to Boston University, School of Medicine. The test came back positive.

Ajay worked at the Department of Energy for New York State. He was a director who specialized in Global warming. The first sign, in 1997, was a tremor in his right hand that made him realize that something was wrong. His handwriting was becoming distorted and his signature was changing. His tremors were slowly progressing but his life style remained normal. He continued to do boating, skiing, driving, fishing and hunting.

In 2000, at 53, he was advised to consult the Department of Neurology at the Albany Medical Center. He was diagnosed with essential tremors and although I was concerned about possible early signs of Parkinson, that was ruled out at Columbia University in NYC.

In 2002, he had no head, voice, chin, or tongue tremors. At that time, the doctor at the Albany Medical Center, did not see any signs of Cerebellar Ataxia. He was using a cup with a lid to reduce spilling, had normal dexterity and could stand up from a chair easily. He tried various medicines, none of them were effective. An MRI was performed but nothing was found.

In 2004, he started to have difficulty buttoning his shirt, working on his computer, eating became difficult. He also had developed some balance trouble. His mind was sharp and fully functional and he took early retirement in 2005.

In 2007, we move to Ormond Beach, Florida. We started taking him to the Shands Clinic in Gainesville. Now, he had difficulty with his gait and sometimes lost his balance. When he was fatigued, he tended to tilt backwards and had some difficulty remembering names. Deep brain stimulation was discussed, Dr. Okun and his team, thought that he is the best candidate for it. However, we decided against it.



In 2013, I took him to Mayo Clinic in Jacksonville to Dr. Wszolek who sees Ataxia patients in the hope for any new treatment. His condition was progressing and he had to use a walker. He was driving to the YMCA and walking on the beach.

In 2015, he lost all ability to walk and now used a wheelchair. I continued to have him do different types of physical exercise like biking at home, and using range of motion, etc. I started accepting the reality. I still questioned why there was no cure for it. He had now lost interest in verbalizing, conversation, and there was no communication, and no relationship. It hurts to see him as he is, the man whom I loved and travelled the world with.

Ajay is confined from his bed, to a wheelchair and then to his recliner. Nurses do everything for him. I miss terribly his company. I am all alone. We have two lovely sons. One has an IT consulting firm the other one is a radiologist. They are both married. It is my hope and wish, that researchers who are studying SCA12, can find some answers for my sons. My mind is in peace after writing this article.

If you would like to contact Sunada (Sue), you can email her here: Sanghi@gmail.com



60 for 60: The Personal Journey to Help Cure Ataxia

The NAF is proud to announce that the first few “60 for 60 to Cure Ataxia” fundraisers of the season are completed or in progress!

We're still looking for more people to sign up. 60 for 60 to Cure Ataxia is an easy way to help support the NAF's mission to find a cure. Folks across the nation are committing to complete 60 miles to help Cure Ataxia. The journey is tough, but rewarding. The awareness and support that it brings make the effort worth it. One person or small group of people can make the commitment and plan their journey on their own time. Its flexibility creates possibilities that are proving to make for interesting journey stories. A 60 for 60 to Cure Ataxia event allows you to choose your own date(s) and method for travel - with some walking, some running, and some bike riding - to support the NAF. To sign up, visit www.ataxia.org or contact Julie at julie@ataxia.org.

A special thank you to those who have planned a 60 for 60 to Cure Ataxia this year!

Openly Disabled • Falls of Neuse Greenway, Wake Forest, NC - September
Team Captain: Dana Creighton
Team Members: Elizabeth Chevres, Julie Hughes, Liza Arnold, Ruth Tesfalidet, Tricia Dasilva
60-mile bike Journey
<https://ataxia.donorpages.com/201760For60/OpenlyDisabled/>



Dana Creighton

Team Ruehl • Biking 60-miles along the Erie Canal Sunday, July 23
Team Captain: Susan Ruehl
Team Members: Charlie Ruehl, Mary Beth Yale and Mary Ruehl
<https://ataxia.donorpages.com/201760For60/TeamRuehl/>

Mind over Miles • Superior Hiking Trail - September 3-7
Team Captain: Gülin Öz
Team Members: Bartholomew Longworth, David Okar, Larry Schut, Marija Cvetanovic, Michael Kerr Gülin, David and Bart -Sep-

tember, Michael will hike on his own
<https://ataxia.donorpages.com/201760For60/MindoverMiles/>

Spinner's 60b for the 60th at NAF
Team Captain: David Henry, Jr.
<https://ataxia.donorpages.com/201760For60/Spinners60b-forthe60THatNAF/>

Ontario 60 for 60 Walk and Ride to Cure Ataxia
Springbank Park, London Ontario, Canada - 10 a.m.
Team Captain: Greg Ostrom
For more information contact Greg Ostrom at (519) 639-0630 or fregs@live.ca
<https://ataxia.donorpages.com/201760For60/RideforAtaxia/>

10K Days for the Rare Steve Bratt
Team Captain: Amber Bratt
For Steve's 50th birthday, 10,000 steps a day for 50 days
<https://ataxia.donorpages.com/201760For60/10KDaysfortheRareSteveBratt/>

Glow in the Park
Hap McLean Park - September 16, 6:30 - 9 p.m.
Team Captain: Jalean Retzlaff
<https://ataxia.donorpages.com/201760For60/GlowinthePark/>

Storm Warriors
Team Captain: Jacquelynn Knoll
<https://ataxia.donorpages.com/201760For60/Stormwarriors/>

Jason Wolfer
Began in June, with a goal to walk several miles each morning for exercise, Jason will walk 60 miles to honor the anniversary of the National Ataxia Foundation.



<https://ataxia.donorpages.com/201760For60/JasonWolfer/>

TN 60 for 60 Walk and Run to Cure Ataxia
Saturday, August 5 - 8 a.m.
Team Captain: Karla McMurtry
Moss-Wright Park, 745 Caldwell Dr., Goodlettsville, TN 37072
<https://ataxia.donorpages.com/201760For60/TeamMcMurtry/>

Steven Ofenstein
Began July 1st to walk 60 miles.
<https://ataxiadonorpages.com/201760for60/stevenofenstein>

Announcing the
61st NAF Annual Ataxia Conference
April 5-6, 2018 at the
Marriott Philadelphia Downtown Philadelphia, PA

Hotel Reservations and Conference Registration open on
Wednesday, November 29, 2017



Join us in Philadelphia!
www.discoverphl.com

For the latest information on conference registration, program schedule,
and area information keep checking NAF's website – www.ataxia.org

National Ataxia Foundation's 60th Annual Ataxia Conference March 10-11, 2017 • San Antonio, Texas "Proud Past...Focused Future"

The 2017 Annual Ataxia Conference (AAC) was hosted by the NAF's Southcentral Region. The National Ataxia Foundation would like to congratulate the Southcentral Region on hosting such a successful meeting! More than 400 attendees came for the two-day event. Attendees came from 38 US states and from two international countries, Canada, and the United Kingdom.

The National Ataxia Foundation would like to extend a special thank you to all the attendees, speakers, facilitators, exhibitors and the outstanding volunteers of the 2017 60th Anniversary NAF Annual Ataxia Conference held in San Antonio, TX. The NAF recognizes the resources, sacrifices, and challenges that many attendees face to attend an AAC. Your attendance is abundantly appreciated. This conference would not have been possible without the time, contributions, and efforts given by so many. Thank you very much for the wealth of information and knowledge that was brought to the conference by all the speakers, facilitators and exhibitors. The information and skills taken away from this conference by the attendees is invaluable and worth more than any words can say. It was so wonderful working with the Southcentral Region Leadership. Their commitment and dedication toward the successful execution of this conference was truly exceptional. Thank you to Dianne Williamson for volunteering as our on-site nurse at the conference. We would also like to thank Cindy De Mint for taking such memorable pictures of this year's event.

This year's AAC program was very exciting and well received! The format of the program was structured so that the General Sessions were scheduled in the mornings and Birds of a Feather Sessions were divided and offered either Friday or Saturday afternoon. This provided many attendees with an afternoon free to visit the exhibitor booths, check out the Activity Room, visit local attractions, visit with other attendees or attend the small group sessions. The conference concluded with a banquet on Saturday evening in recognition of the NAF's 60th Anniversary. All General Session presentation slides are available on the NAF's website www.ataxia.org. A portion of the 2017 AAC Presentations will be transcribed in a future issue of "Generations" and released on the NAF's YouTube Channel

I am the Strength Behind the National Ataxia Foundation Award Recipients



The Sweeney Family



The Schut Family



Marc Alessi

Kathy Gingerelli

throughout the year. Currently, you can find some presentations from the 2017 conference general sessions on the NAF's YouTube Channel <https://www.youtube.com/user/NatlAtaxiaFound>.

At this year's AAC the National Ataxia Foundation recognized the numerous fundraising events that were conducted in 2016. "I am the Strength Behind the National Ataxia Foundation" awards were presented to Marc Alessi, Kathleen Gingerelli, the Sweeney Family, and the Schut Family.

**Exceptional
Service Award**



Dr. Henry Paulson

**Distigished
Achievement Award**



Dr. Huda Zoghbi

Dr. Huda Zoghbi received a Distinguished Achievement award and Dr. Henry Paulson received an Exceptional Service award for their significant research accomplishments.

Considerable appreciation and gratitude goes out to this year's sponsors Biohaven Pharmaceuticals, Reata Pharmaceuticals, MassMutual Special Care, Invitae, and OraLabs. Thank you to the San Antonio Convention and Visitors Bureau for the local information provided for this year's conference. Thank you to the Grand Hyatt for their service and hospitality throughout this event.



INVITAE



REATA
PHARMACEUTICALS



SpecialCare
a special needs program developed by MassMutual



**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.

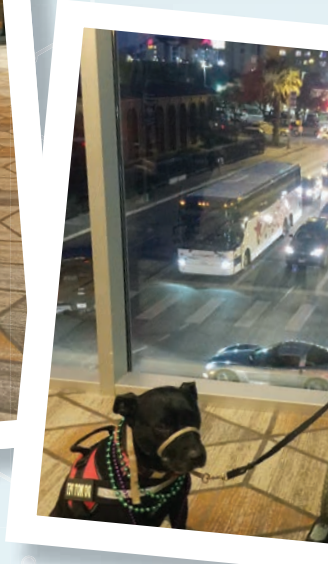
Principle Investigator: Amy J. Bastian, PhD
Kennedy Krieger Institute
Funded by the National Institutes of Health
JHM IRB Application #: NA_00043851



Linda Snider

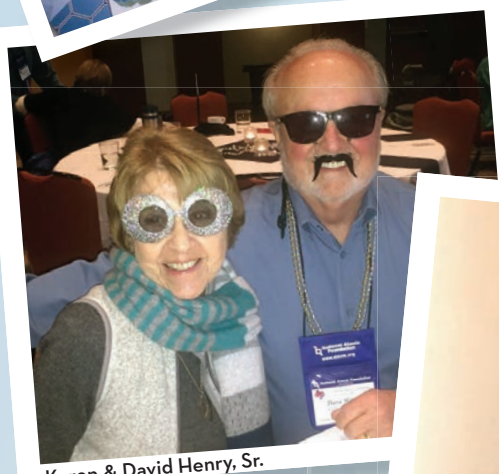


Christina & Christy Hernandez



“Proud Past..Fo 60 Snap

The National Ataxia Foundation • 60th
San Antonio, TX



Karen & David Henry, Sr.



Lee O'Banion & Mike Anderson



Cindy a



Alan Thomas and Friends



Bonnie Sills

ocused Future” shots

60

Anniversary Annual Ataxia Conference
• March 10-11, 2017



Daniel Navar



The Leonard and Kapuscinski Family



The Mariachi Band



Nothing but Smiles!



Nachos Bar



and Gerry De Mint



Joan & Diane O'Connell, Angela Fleischman



JoAnn and Paloma Gomez

Fundraisers and Awareness Events

Running for Sophie

Stephanie Yi ran the Hollywood Half Marathon on April 8, in honor of her daughter, Sophie, who has Ataxia. She raised funds for the NAF at the event - surpassing her goal. To date, she has raised \$563.50.



Running for Sophie

Tampa Works to Strikeout Ataxia

Submitted by Neddroy "DJ HeadBussa" Bent

The Sixth Annual Strikeout Ataxia Bowling and Health Expo event was held on Sunday, April 30th. Raising Ataxia awareness and supporting the NAF mission were the main goals of the event. Thanks to all involved in coordinating this fun activity for a good cause!



Strikeout Ataxia

Chuck n' Duck Tournament for the NAF

Submitted by Andrew Haluska (ahaluska@bhbl.org)

Fifth grade teacher Andrew Haluska coordinated the Eighth Annual Chuck n' Duck Dodgeball Tournament at Charleton Heights Elementary School in Ballston Lake, New York. The tournament was held on Friday, May 5



Chuck n' Duck

where students participated in a dodgeball tournament for Ataxia. They had a blast and are looking forward to the tournament next year! This year's event raised \$5367 in honor of Jacob Van Buren, a past Charlton Heights student who has Friedreich Ataxia.

Ataxia Night Guest Bartender

Ellie Reuefle spent her Cinco de Mayo teaming up with The Boulevard Restaurant in Pittsburgh, Pennsylvania to help cure Ataxia. She was the guest bartender on May 5th, donating all the proceeds from the evening to support the NAF's mission.



Blvd Bar Event

Katie Campbell Clinical Trial Readiness Conference

Katie, who lost her battle with Ataxia in January 2017, is being memorialized through a fundraising effort, coordinated by her friends and family, to provide funding for the Annual Clinical Trial Readiness Conference in Minneapolis. This Conference, which has now been named in her honor, will be for Principal Investigators to meet face-to-face and collaborate in the implementation of clinical trials for Ataxia.



Katie Campbell

Kettle Moraine Lutheran High School

Submitted by Brian Hoerchner

The Kettle Moraine Lutheran High School Girls' Soccer team held a fund raiser on May 19 as part of their home soccer match in memory of long-time supporter of the KML soccer program and an assistant varsity boys and girls coach for ten years, Barry Washburn. Barry passed away this past fall and will surely continue to watch over the KML soccer team.

Manny, Mike and Mary Ride to Cure Ataxia

Submitted by Mike Cammer

Manny Wittels, Mike Cammer, and Mary Deitimam enjoyed a Six-mile Fun Ride event that was



Manny, Mike and Mary

followed by a picnic at the Lyon's Pavilion at Kerr Park, Downingtown, Pennsylvania. Many of the support group came to cheer them on and to enjoy the picnic. The event has raised more than \$2344 in support of the NAF.

The Chicago Abilities Expo

The Chicago Abilities Expo was held on June 23-25 at the Renaissance Schaumburg Convention Center in Schaumburg, Illinois. The Chicago Ataxia Friendship Group represented the NAF at the event. They had quite a bit of traffic and the pens and chapstick went like crazy. There were not too many pamphlets left either.



Tapas for Ataxia

Submitted by Sue Freedland

Tapas for Ataxia was held on Friday, June 16 from 6-9 p.m. The event was hosted by Howard Freedland, Dan Freedland's son. We had more than 40 people attend the evening of good food, wine, a discussion of the challenges of individuals with Ataxia and also the function of the NAF. Both Howard and Dan help those attending understand and become more aware of Ataxia and its affect and progression on those diagnosed with it. Howard also offered suggestions how to become involved in the NAF and how to contribute to the research that is so vital to all those with Ataxia.



L-R: Dan and Sue Freedland, Lisa Cole, Tracey, Howard and Bennet Freedland

It was an enjoyable and informative evening and a good time was had by all. The event raised more than \$1000 for the benefit of the NAF.

We want to hear about your fundraising success stories –
send them to joan@ataxia.org

University Hospitals Health and Safety Day

Submitted by Julie Clarich

Cleveland Area Ataxia Support Group members, Julie Clarich and Ginger Pieragastini represented the NAF with an Ataxia information table at the University Hospitals Health and Safety day on Saturday, June 17 in Beachwood, Ohio. There were various organizations and businesses there to inform families and individuals about a variety of health-



Julie Clarich and Ginger Pieragastini

related programs and opportunities. Ginger and I helped inform people about Ataxia is and we spread the word about the Northeast Ohio Walk n' Roll to Cure Ataxia. The day also included entertainment, food and a chance to learn about the University Hospital centers and a wide range of programs offered throughout the community.

Support Group News

A Great Link for Why Support Groups are so Important

The following is the title from an article from Neurology Now: December/January 2016- Volume 12-Issue 6-p 26-31.

Life Lines: Support groups offer information, advice, encouragement, and community. Use these tips to find the right one for you or to start your own.

There are several topics that it covers that may be beneficial. Life Savers, Keep it Positive, Pick Your Preference, Understand the Limits, and Assign a Leader are just a few. Here is the link to the article for more information: <http://bit.ly/2iPi1yy>



Tampa Bay Ataxia Support Group •

Submitted by Linda Farrow

On Saturday, April 15, the Tampa Bay Ataxia Support

Group had their annual picnic at shelter #7, Seminole Park in Seminole, Florida. We had 25 people attend and food and beverages were plentiful with delicious b-b-q chicken wings/legs taking center stage. A great time was had eating, socializing and playing games that our support group leader, Darlene Harris, supplied along with prizes for the winners. The picnic was a success and those that attended had a blast!

Pictures of the recent Annual Ataxia Conference (AAC), San Antonio, Texas, held in March were shared. Several of our group attended the ACC and donated silent auction items.

Treasure Coast Ataxia Support Group (TCASG)

Submitted by Lisa Cole & Sue Freedland

The Treasure Coast Ataxia Support Group met on April 29 at 1 p.m. at the Port St Lucie Community Center. There were 24 people who attended the meeting which included some with Ataxia and some significant others. Name tags were provided, which made it nice and easy to speak to each other more directly. There was a table with literature, available to everyone attending. Folders were provided, on the seats, with some additional info already in them.

Our guest speaker was Dr. S.H. Subramony, Co-Director of the Ataxia Clinic in the Movement Disorder Center, as well as Chief of the Neuromuscular Division, within the Department of Neurology at the University of Florida. Dr. Subramony is considered one of the world leading experts on Ataxia. After a brief introduction, he opened the floor to everyone to ask questions with hopes he would be able to answer them all. Almost every member attending had a question and he was very informative when giving his answers.

Some items promoting awareness of SCA were handed out and then we spent about 30 minutes to socialize before ending the meeting.



Treasure Coast Ataxia Support Group

Submitted by Lisa Cole & Sue Freedland

The Treasure Coast Ataxia Support Group met at on Saturday, June 3 at 11:30 a.m. at the Buffalo Chophouse in Port St. Lucie, FL. This was the first lunch meeting at a restaurant and there were eight people that attended.

We discussed the 60 for 60 to Cure Ataxia

Fundraiser and looked to see how our team was doing. We have three members on our team and are hoping that more members will join. Hank Westerfield brought his computer and showed the registration page and helped those with questions through the process. We also looked at how the individual page can be customized based on each person's preferences.

We had a speaker at our meeting; Mark Bozzo, a massage therapist, that specializes in "medical massages" by working on specific areas, muscle stretching and making sure the body remains flexible and strong.



Treasure Coast Ataxia Support Group at Buffalo Chophouse



Central PA Ataxia Support Group •

Submitted by Mike Cammer

The Central PA Ataxia Support Group had Gail Metzger from Good Shephard Rehab do an occupational therapy presentation on March 18, with a lower than normal turnout, of seven. We still had a wonderful meeting and walked away with numerous helpful tips and information about "Improvement Standard" for skilled care for treatment. Many of us are told therapy discontinues because there is no improvement, but in the case of "Jimmo vs. Sebelius" it states: "...does not turn on the presence or absence of a beneficiary's potential for improvement, but rather on the beneficiary's need for skilled care." Please consult with your insurance or healthcare provider for further clarification.

We had an informal "Birds of a Feather" type meeting on April 15th at Mercy Suburban Hospital, a new location for us, but meetings

used to be held there by another past support group. Only four of us were there, but hopefully with a positive outlook, we can get the group going again and offer support closer to the southeastern PA Ataxians and caregivers who would like to meet and chat.



Central PA Ataxia Support Group



Alabama Ataxia Support Group

Submitted by Becky Donnelly

The Alabama Ataxia Support Group had its April meeting at Covenant Presbyterian Church in Homewood, with 24 members present. We welcomed two new families, Kerra and Jonathan Payne and their 3-year old son Abraham, and David and Brenda Vines.

Bill Smith, Wealth Management, LLC, gave financial guidance to the members; there was much interest shown. After Cell Group reports and a short business meeting, a delicious lunch was enjoyed. Cudos to Sandee Mackinaw and Stephanie Culbreth! The members then divided into Break-out Sessions, a favorite activity. Juanita Dorroh, Inspirational Leader, closed the meeting with thought-provoking questions, leading to laughter and smiles as members departed.



Alabama Ataxia Support Group at the Birmingham Zoo

The May social was held at the Birmingham Zoo on a beautiful Saturday. Denise and John Higdon were leaders for this activity and did a fabulous job of getting good entrance and lunch prices for the group. It seems the favorite site visited was the pen of the giraffes and seeing them hand-fed. After tired feet, we all met back together and enjoyed lunch and fellowship.

Tri-State Ataxia Support Group

Submitted by Kathleen Gingerelli

The Tri-State Ataxia group held their meeting on May 11 and had a great night welcoming a large group of more than 25 people. I started off with the information I brought back from the NAF Annual Ataxia Conference that was held in San Antonio, Texas, in March. I was able to show (on the big screen) a video of me receiving the "Strength Behind Ataxia Award" highlighting our group's first Walk n' Roll Event and my NY football Giants! We spoke about next year's conference, in Philadelphia, and how many members of our group may be able to attend because of the location.



Tri-State Ataxia Support Group

We reviewed the Abilities Expo that was held in Edison, New Jersey on May 5-7 and then talked about up-coming events. We are excited to participate in the Third Annual New York Disability Pride Parade held on July 9. The parade celebrates the ADA's 27th Anniversary by spreading Inclusion - Awareness - Visibility. We planned on gathering in Union Square Park to march, roll or ride down Fifth Avenue to Washington Square Park where there was a Disability Rights Festival with music, dancing, comedy and speakers. For more information about the parade please check out their website www.disabilitypridenyc.org.

We continue to plan for our Second Walk n' Roll to Cure Ataxia event to be held at Liberty State Park in Jersey City, NJ on August 26. After a phenomenal inaugural walk, I have challenged every member to make this year bigger and better than last year. www.ataxia.org/walk/tristate

Our speaker for the night was Mr. David Berger, a licensed physical therapist. David had an informative discussion with the group that included topics on

- Balance & Coordination and exercises to maintain & improve each
- Demonstration of exercises (with our happy volunteer Frank)
- Power of a positive attitude

After speaking, David answered questions from the group which proved both challenging & informative.

Greater Atlanta Ataxia Support Group

The Greater Atlanta Ataxia Support Group had their picnic on Saturday, June 3 at the shelter at Lake Lanier. Hot dogs and burgers were provided and it was a great day with a great turnout of over 45 people attending!



Greater Atlanta Support Group at Lake Lanier

NCASG - N. California Ataxia Support Group - Lafayette

Submitted by Shirley Hanks

The NCASG held their meeting on Saturday, April 8 and had Dr. Laurice Yang, Stanford, speak. Dr. Yang spoke about the science behind the beneficial effects of



exercise, the risk factors for falls, and physical therapy vs. occupational therapy.



Dr. Yang

Dr. Yang also spoke about the hurdles that her research team is working on in Gene Splicing, Protein Tagging and Medication developments. She also shared that it is a 5 - 10-year process to get the FDA to approve medications.

NCASG - April BORP Outing

Submitted by Tomoko Jennings

On Saturday, April 22. Alan Acacia, a regular rider at Aquatic Park in Berkeley, was our liaison along with the Bay Area Outreach and Recreation Program (BORP). In all, 20 participants had signed up for the ride. The ride day was perfect. As people arrived, forms were submitted, trikes were selected to meet each person's needs, and necessary adjustments were made. Most were foot-pedaled recumbent trikes, but there were also tandems, a hand-cranked recumbent, and a side-by-side four-wheeled bike. Preparations took about 30 minutes and then they were ready to start the ride.

After a group photo in front of BORP, they began the 2-mile ride around a beautiful lagoon. They



Bay Area Outreach and Recreational Program Outing

stopped a few times to regroup and take photos. Near the end of the course they parked at the picnic area and had a relaxed lunch. Everyone seemed to enjoy the ride. It was great to see everyone helping one another.

Delaware Ataxia Support Group Submitted

by Joe DeCrescenzo

The Delaware Support Group held a meeting on Saturday, June 24 at Christina Hospital.



Their guest speaker was Dr. Martello, a Movement Disorder Neurologist at the hospital. He answered questions and explained the hospital's vision of expanding the neurological department to include an Ataxia Specialist.

We also discussed our upcoming fundraiser, Little Bit Country, Little Bit Rock 'n Roll, to be held Sunday September 24. After light refreshments, we held a session on the importance of membership to the NAF.



FLORIDA COMEDIANS

Florida Comedians, Casey n' Spaz will promote IAAD at some upcoming shows.

For more information <https://www.facebook.com/caseyn.spazcomedy>



NAF Staff Directory, Directory of Chapters, Support Groups, Social Networks and Ambassadors

The National Ataxia Foundation has a large network of volunteers who serve as support group leaders, chapter presidents, and ambassadors for our organization. These volunteers help identify important local resources and professional care for people with Ataxia and their families.

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 a NAF ambassador. If you are interested in these volunteer positions please contact Lori Shogren of the NAF staff at:

lori@ataxia.org or (763) 553-0020.

The use of these names and contact information for any purpose other than requesting information regarding the NAF, joining a chapter or support group without the NAF's written permission is strictly prohibited.

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Moderator - Atilla and Bear
www.ataxia.org/forum/toast.asp



NAF Facebook Group

www.facebook.com/groups/NAFmail

NAF Facebook Page

<http://bit.ly/2sj5fC3>



NAF YouTube Channel

www.youtube.com/user/NatlAtaxiaFound?feature=mhum



NAF Twitter

https://twitter.com/NAF_Ataxia



NAF LinkedIn

www.linkedin.com/company/nationalataxiafoundation



NAF Chatroom

www.ataxia.org/connect/chat-rooms.aspx

Matching Gifts

Please ask your employer if there is a Matching Gift Program. If so, you and your co-workers donations may be doubled to support the work of the NAF.

Thank you.

Chapters, Support Groups and Ambassadors

Please note: Hometown of each Support Group Leader or Ambassador is noted below. For group meeting locations please refer to the Calendar of Events & Support Group Meetings

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Tarheel Support Group Leaders

Ron and Donna Smith- Garner, NC

(919) 779-0414

E-mail: rsmith@sacherokee.com

E-mail: dsmith@sa-pr.com

www.ataxia.org/chapters/Tarheel/default.aspx

Ambassador

Jodie Kawa - Brevard, NC

(828) 384-8414

E-mail: jodiekawa@citcom.net

Ohio

Ambassador

Julia Soriano-Cincinnati, OH

(513) 899-1195

E-mail: julia@epivision.com

Group Blog: ataxiafoundationcleveland.blogspot.com/

www.ataxia.org/chapters/Cincinnati/default.aspx

Cleveland Area Support Group Leader

Carmen Pieragastini-Willowick, OH

(216) 272-5588

E-mail: willowpier@roadrunner.com

www.ataxia.org/chapters/Cleveland/default.aspx

Oklahoma

Central Oklahoma Ataxia Support Group

Christopher DeHaven - Blanchard, OK
(405) 387-9227
E-mail: photoman94@gmail.com
Facebook Group: <https://www.facebook.com/groups/421890291503549/permalink/428669084159003>

Oregon

Willamette Valley Support Group Leader

Jason Wolfer - Gervais, OR
(503) 502-2633
E-mail: wolferjason@gmail.com
Facebook Group:
www.facebook.com/groups/388993597939205/
www.ataxia.org/chapters/Willamette/default.aspx

Pennsylvania

Central PA Support Group Leader

Michael Cammer- Downingtown, PA
(610) 873-1852
E-mail: michael.cammer62@hotmail.com
Facebook Group: www.facebook.com/groups/1475283086068548/
www.ataxia.org/chapters/CentralPA/default.aspx

Western PA Support Group Leader

Ed Schwartz- McMurray, PA
(724) 941-2210
E-mail: eds@ataxia.org
Facebook Group: www.facebook.com/wpaataxiainafwesternpasupportchapter.weebly.com/
www.ataxia.org/chapters/SouthPark/default.aspx

Donna Eiben - South Park, PA
(412) 655-4091
E-mail: dawn.eiben@verizon.net

Rhode Island

Rhode Island Support Group Leader

Anabela Azevedo - Bristol, RI
(401) 297-8627
E-mail: azevedo70anabela@gmail.com
www.ataxia.org/chapters/RhodeIsland/default.aspx

South Carolina

Ambassador

Brad Forth - Greenville, SC
(864) 415-8147
E-mail: bradf@photoforth.com
www.ataxia.org/chapters/Greenville/default.aspx

Tennessee

Middle TN Area Support Group Leader

Alex Cohn - Nashville, TN
(256) 504-0240
E-mail: alex.j.cohn@us.pwc.com
www.ataxia.org/chapters/TN/default.aspx

Texas

Greater Houston Area Support Group Leader

Dolly Richards-Houston, TX
(979) 900-6660
E-mail: Lumoos@hotmail.com
Facebook Group:
www.facebook.com/groups/ataxia.houston/
www.ataxia.org/chapters/Houston/default.aspx

North Texas Area Support Group Leader

David Henry Jr. - Trophy Club, TX
(817) 739-2886 (contact by email preferred)
E-mail: chevelle@sbcglobal.net
Facebook Group: www.facebook.com/Ataxiasupport
www.ataxia.org/chapters/NorthTexas/default.aspx

Ambassadors

Dana LeBlanc - Orange, TX
(409) 883-5570
E-mail: tilessal@yahoo.com
www.ataxia.org/chapters/GoldenTriangle/default.aspx

Debra Whitcomb - El Paso, TX

(915) 329-0721
E-mail: debrawhitcomb@hotmail.com
www.ataxia.org/chapters/Whitcomb/default.aspx

Utah

Utah Support Group Leader

Grant Beutler - Salt Lake City, UT
E-mail: grant.beutler@gmail.com

Jenny Durrant - North Ogden, UT

E-mail: jenny@utahataxia.org

Dr. Lisa Ord, PhD, LCSW - Salt Lake City, UT

(801) 585-6635
E-mail: lisa.ord@hsc.utah.edu
Facebook Page: www.Facebook.com/utahataxia
SG Website: www.utahataxia.org
www.ataxia.org/chapters/Utah/default.aspx

Virginia

Chesapeake Chapter President

Carolyn Davis - Vienna, VA

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Disability Resources

<https://www.dol.gov/odep/topics/disability.htm>

(703) 759-2008

E-mail: ccnafpres@gmail.com

www.ataxia.org/chapters/Chesapeake/default.aspx

Washington

Western Washington Support Group Leader

Sherry McLaughlin

(360) 344-2445

E-mail: ccherilynmc@yahoo.com

www.ataxia.org/chapters/Olympic/default.aspx

Ambassador

Linda Jacoy - Spokane, WA

(509) 482-8501

E-mail: linda4727@hotmail.com

www.ataxia.org/chapters/Spokane/default.aspx

Wisconsin

Wisconsin Support Group Leader

Kory Macy - Madison, WI

(608) 628-2700

E-mail: kstab77@yahoo.com

www.ataxia.org/chapters/Wisconsin/default.aspx

INTERNATIONAL SUPPORT GROUPS AND AMBASSADORS

Canada

Ottawa Support Group Leader

Prentis Clairmont - Ottawa, Ontario

(613) 864-8545

E-mail: prentis.clairmont@gmail.com

Facebook Group:

www.facebook.com/groups/1468963499991380/

www.ataxia.org/chapters/Ottawa/default.aspx

India Support Group Leader (Samag)

“Seek a Miracle Ataxia Group”

Chandu Prasad George

Hyderabad, Secunderabad, India

Mobile: 0091-9989899919, 0091-9885199918

E-mail: sam_ataxiaindia@yahoo.com

Facebook Group: www.facebook.com/ataxiain

www.ataxia.org/chapters/Chandu/default.aspx

SG Website: www.ataxia.in

SG E-mail: india.ataxiagroup@gmail.com

Pakistan

Ambassador

Sajjad Haider - Karachi, Pakistan

0092-(300) 828-1784

E-mail: sajjadhaiderb@hotmail.com

2017

Ataxia Calendar of Events

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

Why Attend an Ataxia Support/Social Group?

Many of you may ask, "Why should I attend a support group meeting?"

Support groups can remind us that we are not alone and that while each individual may experience Ataxia in a different way, together we have many things in common. A benefit of attending a support group is simply to have a chance to talk with others and learn how different people deal with the same disease.

Attending a support group meeting may give you a glimpse into the many different stages and types of the disease. This can help by using some of the strategies that have been beneficial to others in order to avoid and/or plan for some of the same challenges that others have faced in the progression of their Ataxia.

Hopefully attending a support group meeting will leave you with a sense of hope and inspiration, knowing that if others can cope, so can you.

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

SUPPORT GROUP MEETINGS

Thursday, July 13, 2017

Tri-State Ataxia Support Group Meeting

Time: 6:30-8:30 p.m.

Location: Mt. Sinai Beth Israel Downtown at Union Square, Phillips Ambulatory Care Center (PACC), Second Floor Conference Room, 10 Union Square East, New York, NY 10003

Details: For more information contact Kathy Gingerelli at kgingerelli@msn.com

Saturday, July 15, 2017

Denver Area Ataxia Support Group Meeting

Time: 1-4 p.m.

Location: Accessible Systems, 3025 W. Jefferson Ave., Englewood, CO 80110

Details: For more information contact Charlotte DePew at (720) 379-6887 or cldepew77@comcast.net

Greater Atlanta Ataxia Support Group Meeting

Time: 1-3 p.m.

Location: Emory Rehabilitation Hospital, 1441 Clifton Road, NE Rm 101, Atlanta, GA 30322

Details: For more information contact (404) 822-7451 or atlantaataxia@gmail.com

NCASG -Sacramento Area Ataxia Support Group Meeting

Time: The group meets on the third Saturday of

each month at 1 - 4 p.m.

Location: Sutter Roseville Medical Center, 1 Medical Plaza Dr., Meeting Rm. 8, Roseville, CA 95661

Details: For more information contact Teresa Bredberg at (916) 215-2686 or tbredberg@sbcglobal.net.

Nebraska Ataxia Support Group - Grill Out

Time: 11 a.m. - 2 p.m.

Location: Lake Zorinsky, Omaha, NE

Details: Burgers and hot dogs provided. For additional information contact Linda Snider at (402) 212-3060 or lindasnider@cox.net.

Twin Cities Ataxia Social Group Meeting

Time: 10 a.m. on the third Saturday of every month (approximately two hours)

Location: Langton Place in Roseville at 1910 W. County Rd. D, Roseville, MN 55112

Details: For additional information contact Lenore Healey Schultz at (612) 724-3784 or schultz.lenore@yahoo.com

Saturday, July 22, 2017

New Hampshire Ataxia Support Group Meeting

Time: 10 a.m. - 12 p.m.

Location: Villa Crest Nursing and Retirement Home, 1276 Hanover St., Manchester, NH.

Details: For more information contact Jill Porter at (603) 626-0129 or jilleporter@comcast.net

Wisconsin Ataxia Support Group Meeting

Time: 12 - 2 p.m.

Location: Sequoya Library, 4340 Tokay Blvd., Madison, WI.

Details: For additional information contact Kory Tabor at (608) 237-6090 or kstab77@yahoo.com

Saturday, July 29, 2017

Central Pennsylvania Ataxia Support Group Meeting

Time: 11 a.m. - 1 p.m.

Location: Hershey Medical Center's Hope Drive facility, 30 Hope Dr.,

Details: Guest speaker, Jennifer Millar, PT from Johns Hopkins Ataxia Center. Potluck picnic at the Leader Farm after the meeting. For additional information contact Mike Cammer at (610) 996-5814 or michael.cammer62@hotmail.com

Tampa Bay Ataxia Support Group Outing

Time: 1-5 p.m.

Location: Jimmie B. Keel Library, 2902 W. Bearss Ave., Tampa, FL 33618

Details: National Dance Day Celebration. For additional information contact Darlene Harris at (813) 431-2859 or msdee004@yahoo.com or Linda Farrow at Indfrrw2@gmail.com.

Wednesday, August 2, 2017

Western PA Ataxia Support Group Meeting

Time: 7 p.m.

Location: Bethel Park Community Center, 5151 Park Ave., Pittsburg, PA

Details: For more information contact Ed Schwartz at (724) 941-2210 or eds@ataxia.org

Saturday, August 5, 2017

Arizona Ataxia Support Group Meeting

Time: 1 p.m.

Location: Ability 360, 5025 E Washington St., Phoenix, AZ 85034.

Details: For more information contact Mary Fuchs at (480) 212-6425 or mary11115@msn.com.

Oklahoma Ataxia Support Group Meeting

Time: 2-4 p.m.

Location: Mustang Conference Center, 1201 N. Mustang Rd., Rm. E, Oklahoma City, OK

Details: For more information contact Carrie Stanley at (405) 735-0037 or cdstanley1977@gmail.com or Christopher DeHaven at (405) 387-9227 or

photoman94@gmail.com.

Rhode Island Ataxia Support Group Meeting

Time: 11 a.m. - 2 p.m.

Location: Bristol Community Center, 101 Asylum Blvd., Bristol, RI.

Details: For more information contact Anabella Azevedo (401) 297-8627 or azevedo70anabela@gmail.com

Treasure Coast Ataxia Support Group Meeting

Time: 1 - 4 p.m.

Location: Port St. Lucie Community Center, 2195 SE Airoso Blvd., Port St. Lucie, FL 39484

Details: For more information contact Lisa Cole at (772) 370-3041 or lcole2234@gmail.com.

Wednesday, August 9, 2017

Willamette Valley Ataxia Support Group Meeting - Albany Location

Time: 11:30 a.m. - 1 p.m.

Location: Albany Hospital, 4th Floor Conference Rm., 1046 6th Ave., SW, Albany, OR 97321.

Details: For more information contact Jason Wolfer at (503) 502-2633 or wolferjason@gramil.com

Saturday, August 12, 2017

Central Minnesota Ataxia Support Group Meeting

Time: 10 a.m. - 12 p.m.

Location: 1038 Sunset Ridge Rd., St. Cloud, MN 56303

Details: For additional information contact Marsha Binnebose at (320) 248-9851 or mbinnebose@hotmail.com

Kansas City Ataxia Support Group Meeting

Time: 2 - 4 p.m.

Location: Northeast Library, 6000 Wilson Rd., Kansas City, MO 64123.

Details: For more information contact Stephanie Wilkins at (816) 623-3318 or sfwilkins@yahoo.com

North Texas Ataxia Support Group Meeting

Time: 10 a.m. - 12 p.m.

Location: Ben Washington Baptist Church, Rev. Jr. Shepard Educational Center, 615 Davis St., Irving, TX 75061

Details: The meeting room is in a separate bldg. from the church. For more information contact David Henry at chevelle@sbcglobal.net

Saturday, August 19, 2017

NCASG -Sacramento Area Ataxia Support Group Meeting

Time: The group meets on the third Saturday of each month at 1 - 4 p.m.

Location: Sutter Roseville Medical Center, 1 Medical Plaza Dr., Meeting Rm. 8, Roseville, CA 95661

Details: For more information contact Teresa Bredberg at (916) 215-2686 or tbredberg@sbcglobal.net.

Nebraska Ataxia Support Group Meeting

Time: 11 a.m. - 1 p.m.

Location: Creighton Prep High School, 7400 Western Ave., Omaha, NE

Details: For more information contact Linda Snider at (402) 212-3060 or lindasnider@cox.net.

Orange County Ataxia Support Group Meeting

Time: 2 - 4 p.m.

Location: Orange Coast Memorial Medical Center Hospital, Breast Cancer Center Conference Pacific Coast Rm., 9900 Talbert Ave., Fountain Valley, CA 92708

Details: For more information contact Cindy DeMint at cindyocataxia@gmail.com.
<http://orangecountyataxia.org/>

Tampa Bay Ataxia Support Group Meeting

Time: 12:30 - 3 p.m.

Location: University of South Florida, Morsani Center, 13330 Laurel Dr. #1013, Tampa, FL 33612

Details: Guest speaker: Dr. Stephenson (weighted vest). For additional information contact Darlene Harris at (813) 431-2859 or msdee004@yahoo.com or Linda Farrow at Indfrrw2@gmail.com.

Twin Cities Ataxia Social Group Meeting

Time: 10 a.m. on the third Saturday of every month (approximately two hours)

Location: Langton Place in Roseville at 1910 W. County Rd. D, Roseville, MN 55112

Details: For additional information contact Lenore Healey Schultz at (612) 724-3784 or schultz.lenore@yahoo.com

Saturday, August 26, 2017

New Hampshire Ataxia Support Group Meeting

Time: 10 a.m. - 12 p.m.

Location: Villa Crest Nursing and Retirement Home, 1276 Hanover St., Manchester, NH.

Details: For more information contact Jill Porter at (603) 626-0129 or jilleporter@comcast.net

Wednesday, September 6, 2017

Western PA Ataxia Support Group Meeting

Time: 7 p.m.

Location: Bethel Park Community Center, 5151 Park Ave., Pittsburg, PA

Details: For more information contact Ed Schwartz at (724) 941-2210 or eds@ataxia.org

Saturday, September 9, 2017

Central Minnesota Ataxia Support Group Meeting

Time: 10 a.m. - 12 p.m.

Location: 1038 Sunset Ridge Rd., St. Cloud, MN 56303

Details: For additional information contact Marsha Binnebose at (320) 248-9851 or mbinnebose@hotmail.com

Central Pennsylvania Ataxia Support Group Baseball Game Outing

Time: 6:30 p.m.

Location: Clipper Magazine Stadium, 650 Prince St., Lancaster, PA 17603

Details: Lancaster Barnstormers vs. Southern Maryland Blue Crabs. Game followed by fireworks. We will also have an Ataxia Awareness table. Tickets are \$8, RSVP required by August 30. To RSVP or for additional information contact Mike Cammer at (610) 996-5814 or michael.cammer62@hotmail.com

North Texas Ataxia Support Group Meeting

Time: 10 a.m. - 12 p.m.

Location: Ben Washington Baptist Church, Rev. Jr. Shepard Educational Center, 615 Davis St., Irving, TX 75061

Details: The meeting room is in a separate bldg. from the church. For more information contact David Henry at chevelle@sbcglobal.net

Treasure Coast Ataxia & Tampa Bay joint Ataxia Support Group Meeting

Time: 2-4:30 p.m.

Location: SW Library-Community Rm., 7255 Della Dr., Orlando, FL 32819

Details: For more information contact Lisa Cole at (772) 370-3041 or lcole2234@gmail.com, Darlene Harris at (813) 431-2859 or msdee004@yahoo.com or Linda Farrow at Indfrrw2@gmail.com.

Wednesday, September 13, 2017

Willamette Valley Ataxia Support Group Meeting - Albany Location

Time: 11:30 a.m. - 1 p.m.

Location: Albany Hospital, 4th Floor Conference Rm., 1046 6th Ave., SW, Albany, OR 97321.

Details: For more information contact Jason Wolfer at (503) 502-2633 or wolferjason@gramil.com

Thursday, September 14, 2017

Tri-State Ataxia Support Group Meeting

Time: 6:30-8:30 p.m.

Location: Mt. Sinai Beth Israel Downtown at Union Square, Phillips Ambulatory Care Center (PACC), Second Floor Conference Room, 10 Union Square East, New York, NY 10003

Details: For more information contact Kathy Gingerelli at kgingerelli@msn.com

Saturday, September 16, 2017

NCASG - Sacramento Area Ataxia Support Group Meeting

Time: The group meets on the third Saturday of each month at 1 - 4 p.m.

Location: Sutter Roseville Medical Center, 1 Medical Plaza Dr., Roseville, CA 95661

Details: For more information contact Teresa Bredberg at (916) 215-2686 or tbredberg@sbcglobal.net.

Saturday, September 23, 2017

New Hampshire Ataxia Support Group Meeting

Time: 10 a.m. - 12 p.m.

Location: Villa Crest Nursing and Retirement Home, 1276 Hanover St., Manchester, NH.

Details: For more information contact Jill Porter at (603) 626-0129 or jilleporter@comcast.net

Wednesday, October 4, 2017

Western PA Ataxia Support Group Meeting

Time: 7 p.m.

Location: Bethel Park Community Center, 5151 Park Ave., Pittsburg, PA

Details: For more information contact Ed Schwartz at (724) 941-2210 or eds@ataxia.org.

Saturday, October 7, 2017

Treasure Coast Ataxia Support Group Meeting

Time: 1 - 4 p.m.

Location: Port St. Lucie Community Center, 2195 SE Airoso Blvd., Port St. Lucie, FL 39484

Details: For more information contact Lisa Cole at

(772) 370-3041 or lcole2234@gmail.com.

Wednesday, October 11, 2017

Willamette Valley Ataxia Support Group Meeting - Albany Location

Time: 11:30 a.m. - 1 p.m.

Location: Albany Hospital, 4th Floor Conference Rm., 1046 6th Ave., SW, Albany, OR 97321.

Details: For more information contact Jason Wolfer at (503) 502-2633 or wolferjason@gramil.com

Saturday, October 14, 2017

Central Minnesota Ataxia Support Group Meeting

Time: 10 a.m. - 12 p.m.

Location: 1038 Sunset Ridge Rd., St. Cloud, MN 56303

Details: For additional information contact Marsha Binnebose at (320) 248-9851 or mbinnebose@hotmail.com

Kansas City Ataxia Support Group Meeting

Time: 12 - 2 p.m.

Location: Northeast Library, 6000 Wilson Rd., Kansas City, MO 64123.

Details: For more information contact Stephanie Wilkins at (816) 623-3318 or sfwilkins@yahoo.com

North Texas Ataxia Support Group Meeting

Time: 10 a.m. - 12 p.m.

Location: Ben Washington Baptist Church, Rev. Jr. Shepard Educational Center, 615 Davis St., Irving, TX 75061

Details: The meeting room is in a separate bldg. from the church. For more information contact David Henry at cheve11e@sbcglobal.net

Northern California Ataxia Support Group Meeting

Time: 11 a.m. - 3 p.m.

Location: Our Savior's Lutheran Church, 1035 Carol Ln., Lafayette, CA 94549

Details: You can RSVP to the meeting directly from the group website and then clicking on the meetings and entering your name and the number is your party. www.norcalataxia.org

Tampa Bay Ataxia Support Group Movie Night

Time: TBD

Location: AMC-Westshore, 210 Westshore Plz., Tampa, FL 33609

Details: For additional information contact Darlene Harris at (813) 431-2859 or msdee004@yahoo.com or Linda Farrow at Indfrrw2@gmail.com.

Informational, Awareness Events and Fundraisers

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



Starting now through International Ataxia Awareness Day, Monday, September 25, 2017

Details: Be part of the 60 who will journey 60 miles to each raise \$10,000 in recognition of the NAF's 60th Anniversary and in support of the NAF's focused future goal to end Ataxia! All proceeds benefit the National Ataxia Foundation

To register or support this campaign, please visit the event website:

<https://ataxia.donorpages.com/201760For60/>

Saturday, July 15, 2017 Rare on the Road - Rare Disease Leadership Tour

Time: 8:30 a.m. - 4:40 p.m.

Location: Shriners Hospital for Children, 3101 SW Sam Jackson Park Road, Portland, OR 97239 **Details:**

RARE on the Road will bring critical education and insights to rare disease patients, advocates and caregivers, while collaborating in an interactive and engaging environment. Building on the successful 2016 EveryLife Foundation Regional Legislative Conferences, RARE on the Road will focus on an expanded agenda that includes topics from Capacity Building to the Patients Role in Drug Development, including breakout sessions and hands-on workshops. Visit the event website for more information: http://action.everylifefoundation.org/p/salsa/event/common/public/?event_KEY=8867.

60 FOR 60 Sunday, July 23, 2017 Team Ruehl 60 for 60 Ride to Cure Ataxia

Location: Riding along the Erie Canal
Details: All proceeds benefit the National Ataxia Foundation (NAF). To donate or join our team visit our team website: <https://ataxia.donorpages.com/201760For60/TeamRuehl/>.

Friday, August 4-6, 2017 Houston Abilities Expo

Time: Friday and Saturday 11a.m. - 5p.m.

Sunday 11a.m. - 4p.m.

Location: NRG Center (Formerly Reliant Center), Hall E, One NRG Park, Houston, TX 77054

Details: Admission is free www.abilitiesexpo.com/houston/.

60 FOR 60 Saturday, August 5, 2017 TN 60 for 60 Walk and Run to Cure Ataxia

Time: 8 a.m.

Location: Moss-Wright Park, 745 Caldwell Dr., Goodlettsville, TN 37072

Details: All proceeds benefit the National Ataxia Foundation (NAF). For more information please contact Karla McMurtry at (615) 390-0922 or kmq88@msn.com.

Team Captain: Karla McMurtry

<https://ataxia.donorpages.com/201760For60/TeamMcMurtry/>

HU-MANIFEST Saturday, August 12, 2017

Time: 9 a.m. - Midnight

Location: Playground Production Studios, 5529 Bonna Ave., Ste. 10, Indianapolis, IN 46219. **Details:** Hu-Manifest is a yoga music festival located in historic Irvington presenting various forms of health and wellness lifestyles, exercise, discipline, motivational speakers, health education, live music and dance performances. Hu-Manifest's mission is to raise awareness about Ataxia and celebrate the human creative spirit. All donations and a portion of event ticket sales benefit the National Ataxia Foundation For event tickets or more information please contact Playground Productions Studio at (317) 678-PLAY (7529) or info@PlaygroundProductionsStudio.com. <https://ataxia.donorpages.com/2017HuManifest/>



Saturday, August 26, 2017 Tri-State Walk n' Roll to Cure Ataxia

Time: 9 a.m. Registration
10 a.m. Walk n' Roll

Location: Liberty State Park, 1 Audrey Zapp Dr., Jersey City, NY 07305 **Details:** All proceeds benefit the National Ataxia Foundation. To Volunteer or for more information please contact Kathy Gingerelli at (201) 681-7639 or kgingerelli@msn.com **Event Website:** www.ataxia.org/walk/TriState/.



Sunday, August 27, 2017 NE Ohio Walk n' Roll to Cure Ataxia

Time: 10 a.m. Registration
11:30 a.m. Walk n' Roll

Location: Cleveland Metroparks Lakefront Reservation - Edgewater Park, Upper Edgewater West Reserved Shelter, 6500 Cleveland Memorial Shoreway, Cleveland, OH 44102 **Details:** No registration fee-Donations gladly accepted. Participation and donations for our event's silent auction are welcome and appreciated. All proceeds

benefit the National Ataxia Foundation. To Volunteer or for more information please contact Julie Clarich at (440) 666-6078 or Julieplus2@gmail.com. **Event Website:** www.ataxia.org/walk/NEOWalk

Rockin' for Ataxia - Live Music

Time: 1 - 5 p.m.

Location: CHEERS (Formerly Sullivan's Pub), 4660 147th St., Midlothian, IL 60445 **Details:** Come and have a rockin' good time raising funds to help end Ataxia! All proceeds benefit the National Ataxia Foundation. This event will include live entertainment, auction, cash bar, and pizza appetizers. Admission is \$20 in advance or \$25 at the door. **Event Website:** www.ataxia.org/fundraiser/rockinforataxia

Thursday, September 3-7, 2017

Mind over Miles 60 for 60 Hike to Cure Ataxia

Location: North Shore of Lake Superior - Superior Hiking Trail

Details: All proceeds benefit the National Ataxia Foundation. To donate or join our team visit our team website: <https://ataxia.donorpages.com/201760For60/MindoverMiles/>

Friday, September 8-10, 2017

Boston Abilities Expo

Time: Friday and Saturday 11a.m. - 5p.m.
Sunday 11a.m. - 4p.m.

Location: The Boston Convention & Exhibition Center, Hall C, 415 Summer St., Boston, MA 02210

Details: Admission is free www.abilitiesexpo.com/boston/.



Saturday, September 9, 2017

Minnesota Walk, Stroll n' Roll to Cure Ataxia

Time: 9 a.m. Registration & Social Hour
10 a.m. Walk & Program at Wolfe Park

Location: Wolfe Park, 3700 Monterey Dr., St. Louis Park., MN 55416 **Details:** No registration fee- Donations gladly accepted. All proceeds benefit the National Ataxia Foundation. To Volunteer or for more information please contact Wendy Sweeney at wendysweeney1@comcast.net. **Event Website:** www.ataxia.org/walk/Minnesota



Walk for Dave to Cure Ataxia

Time: 12 - 3 p.m.

Location: Cornell Botanic Gardens - F.R. Newman Arboretum, 1 Plantations Rd., Ithaca, NY 14850 **Details:** This walk is in memory of David Alessi. Registration is \$10 per participant. All proceeds benefit the National Ataxia Foundation. To Volunteer

or for more information please contact Mark Alessi at (315) 506-3260 or mja244@cornell.edu. **Event Website:** www.ataxia.org/walk/Walk4Dave



Sunday, September 10, 2017

Denver Walk n' Roll to Cure Ataxia

Time: 8:30 - 10:30 a.m.

Location: Denver City Park, 2001 Colorado Blvd., Denver, CO 80205 **Details:** This year's walk is in Memory of Mike Williams. All proceeds benefit the National Ataxia Foundation (NAF). To Volunteer or for more information please contact Charlotte DePew at (253) 720-8132 or cldepew77@comcas.net. **Event Website:** www.ataxia.org/walk/denver.



Saturday, September 16, 2017

OC Walk n' Roll to Cure Ataxia

Time: 8 a.m. Registration
9 a.m. Walk n' Roll

Location: East Lake Village Community Association - Club House Parking Lot, 5325 Village Center Dr., Yorba Linda, CA 92886. **Details:** Free event t-shirt to the first 300 participants present at the event. There will be a DJ, drawings, vendor exhibits, children activities and a chance to unite with others who are affected by Ataxia. All proceeds benefit the National Ataxia Foundation. To Volunteer or for more information please contact Cindy DeMint at cindyocataxia@gmail.com. <http://orangecountyataxia.org/> **Event Website:** www.ataxia.org/walk/OC

Sunday, September 17, 2017

Go on 3! To Cure Ataxia

Details: This year, Mike Cammer will do the "Tour de Shunk" for the 4th year in a row! He has entered to ride his trike the entire 102 miles. To support his challenge to "Go on 3" To Cure Ataxia" and complete his ride in the "Tour de Shunk" please visit the event webpage: <https://ataxia.donorpages.com/2017GoOn3/>. All proceeds benefit the National Ataxia Foundation.



Saturday, September 23, 2017

Atlanta Walk n' Roll to Cure Ataxia

Time: 9:30 a.m. Registration
10 a.m. - Walk n' Roll

Location: Shorty Howell Park, 2750 Pleasant Hill Rd., Duluth, GA 30096. **Details:** No registration fee - Donations gladly accepted. The event is a 1.25 Walk n' Roll around the park, followed by refreshments, Ataxia information, and team recognitions. All proceeds benefit the National Ataxia Foundation. To Volunteer or for more information please contact the Atlanta Ataxia Support Group at (404) 822-7451 or

atlantaataxia@gmail.com. **Event Website:** www.ataxia.org/walk/Atlanta

Little Bit Country.... Little Bit Rock n' Roll

Location: St. Elizabeth Ann Seton Church Hall, 345 Bear-Christiana Rd., Bear, DE 19701

Details: Join us for a fun evening of music, food, drink, and raffles. No entry fee - Donations gladly accepted. All proceeds benefit the National Ataxia Foundation. For more information please contact Joe and Cathy DeCrescenzo at (302) 369-9287 at (404) 822-7451 or jdecr26@verizon.net.

Event Website: here: <https://ataxia.donorpages.com/2017LittleBitCountryLittleBitRocknRoll/>



Utah Walk n' Roll to Cure Ataxia

Time: 11 a.m. - 2 p.m.

Location: Layton Commons Park - Phase 1 Pavilion, 437 N. Wasatch Dr., Layton, UT 84041 **Details:** No registration fee - Donations gladly accepted. Come and learn about Ataxia while having fun raising funds for the NAF. All proceeds benefit the National Ataxia Foundation. To Volunteer or for more information please contact Lisa Ord, PhD, LCSW at (801) 585-6635 or lisa.ord@hsc.utah.edu. Jenny Durrant at jenny@utahataxia.org. **Event Website:** www.ataxia.org/walk/Utah



Western PA Walk n' Roll to Cure Ataxia

Time: 9 a.m. Registration
10 a.m. Walk n' Roll

Location: Allegheny County South Park main route Corrigan Dr., South Park Township, PA 15129 **Details:** No registration fee - Donations gladly accepted. Food, music, fun, learn, and walk. All proceeds benefit the National Ataxia Foundation. To Volunteer or for more information please contact Madalyn Gottschalk at (412) 926-8579 or samgotts32@gmail.com. **Event Website:** www.ataxia.org/walk/wpa



Sunday, September 24, 2017 Ontario 60 for 60 Walk n' Ride to Cure Ataxia

Time: 10 a.m.

Location: Springbank Park, 1085 Commissioners Rd., London, ON O6K 4Y6

Details: All proceeds benefit the National Ataxia Foundation. For more information please contact the Greg Ostrom at (519) 639-0630 or fregs@licve.ca **Event Website:** <https://ataxia.donorpages.com/201760For60/RideforAtaxia/>

Monday, September 25, 2017

International Ataxia Awareness Day (IAAD)

Details: The goal of IAAD is for every individual to participate in some activity, creating awareness about ataxia. You could share something you know about ataxia with one other person who has never heard of it, educate a group of people by speaking at a school or civic group, contact the media, or raise financial support. International Ataxia Awareness Day has grown over the years, and more ideas keep coming in. You can download the IAAD kit which contains ideas for involvement

www.ataxia.org/events/international-ataxia-awareness-day.aspx

Saturday, September 30, 2017

Nebraska Ataxia Support Group Engagement Party Fundraiser

Time: 5 p.m.

Location: Creighton Prep High School, 7400 Western Ave., Omaha, NE 68114 **Details:** This gala style fundraiser with a silent and live auction, in addition to a presentation. Dress is casual. A portion of the proceeds from this event will benefit the National Ataxia Foundation. For more information please contact Linda Snider at (402) 212-3060 or lindasnider@cox.net.



New England Walk n' Roll to Cure Ataxia

Time: 9 a.m. Registration
10 a.m. Walk n' Roll

Location: Bristol Town Beach, 50 Asylum Rd., Bristol, RI 02809.

Details: No registration fee - Donations gladly accepted. Entertainment and raffle to follow the Walk n' Roll. All proceeds benefit the National Ataxia Foundation. To Volunteer or for more information please contact Jeanette Viveiros at (508) 837-3565 or jeannette@ataxia.org or John Mauro at john@ataxia.org. **Event Website:** www.ataxia.org/walk/NewEngland

Saturday, October 7, 2017

Italian Night for a Cure

Time: 5-8 p.m.

Location: Floridino's, 590 N. Alma School Rd., Chandler, AZ 85224

Details: Registration fee is \$25. Join us for an evening of pasta, wine, and fun. This event is a dinner with a raffle and guest speaker Joel Sutherland. All proceeds from this event benefit the National Ataxia Foundation. For more information please contact Mary Fuchs at (480) 212-6425 or mary11115@msn.com. **Event Website:** www.ataxia.org/fundraiser/ItalianNightForACure



New Hampshire Walk n' Roll to Cure Ataxia

Time: 9 a.m. Registration
10 a.m. Walk n' Roll

Location: Aviation Museum of New Hampshire, 27 Navigator Rd., Londonderry, NH 03053 **Details:** No registration fee - Donations gladly accepted. Entertainment and raffle to follow the Walk n' Roll. All proceeds benefit the National Ataxia Foundation. To Volunteer or for more information please contact John Mauro at (508) 736-6084 or john@ataxia.org or Jill Porter at (603) 626-0139 or jilleporter@comcast.net. **Event Website:** www.ataxia.org/walk/NewHampshire



Oklahoma Walk n' Roll to Cure Ataxia

Time: 9 a.m. Registration
10 a.m. Walk n' Roll

Location: Coalgate City Park, Coalgate, OK 74538 **Details:** The event is a Walk n' Roll around the City Park Track. Walk n' Roll as many laps as you like, 1 lap equals 1 mile. All proceeds benefit the National Ataxia Foundation. To Volunteer or for more information please contact Tori Wood at (580) 927-6566 or torifaye289@gmail.com. <https://www.facebook.com/OklahomaWalknRoll/> **Event Website:** www.ataxia.org/walk/Oklahoma

Tea Time to Cure Ataxia

Time: Seating times: 11 a.m. to 1 p.m. or 1:30 - 3:30 p.m. **Location:** Aubrey Rose Tea Room, 8362 La Mesa Blvd., La Mesa, CA 91944 **Details:** Please help us fill the tea room at both sitting again this year! Cost is \$35 per person. All proceeds from this event benefit the National Ataxia Foundation (NAF). For more information please contact Jane Jaffee at (619) 286-9745 or sicilianmother@cox.net.

April 5-6, 2018

61th NAF Annual Ataxia Conference (AAC)

Location: Marriott Philadelphia Downtown Philadelphia, PA

Details: Registration fee required to attend. See page 25 for more information. www.ataxia.org

Tell us how you recognized International Ataxia Awareness Day (IAAD) and share a photo with us for a future issue of "Generations."

Your stories on how IAAD was recognized could live on in a future issue of Generations. Please send us your articles, photos, and proclamations so the entire NAF community can relive this historic day. Please email your story/photo to joan@ataxia.org or mail to the National Ataxia Foundation, Attn: Generations Editor, 600 Hwy. 169 S., Ste. 1725 Minneapolis, MN 55426.

REMEMBERING THE 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 the 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.

Stay up-to-date – get on our email list

Email blasts from the National Ataxia Foundation are sent out periodically on ataxia research, events and other timely issues of interest. Please email your information to stephanie@ataxia.org so you don't miss out on important information

The Ataxia Community is always looking for great ideas to share in Generations.

If you have Pearls of Wisdom or a personal story you would like to share in a future issue of Generations, please submit it to Joan at joan@ataxia.org. Please keep your "pearls" short and personal stories to 1000 words or less. Those submitting a personal story are asked to please include a photo or two.

Memorials and In Your Honor

The National Ataxia Foundation 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 February 2017 through April 2017. We are sorry that we cannot separate the memorial contributions from those made in honor of someone, as sometimes the person making the contribution does not always let us know if the contribution is a memorial or in honor of their friend or family member.

Marjorie Alexander	Elsie Harkulich	Janet Riley
Vickie Balogh	Vivian Hayden	Nancy Rogers
Cheri Bearman	Kassi Henderson	Johnny Rorrio
Jennifer Bellini	Jordan Hubbard	Marcia Saltmarsh
Bradley Blaes	Krista Humes	John Schultz
Debbie Blaes	Amber Hussain	William Segal
Xander Blaes	Edward Kelley	Derrek Semler
Edward Boyles	Martin Keniley	Charles Sink
Myrl Branscom	Denise Kipley	Jules Smilow
Sylvia Breland	Susan Knopp	Judith Smith
Tom Briggs	Robert Koetz	Kathryn Smithers
Jaime Brooks	Jamie Kosieracki	Jenny Spiller
Angela Brown	Gail Lambert	Ellen Stamelos
William Buckley	Sandra Langlais	Joseph Stamer
Katie Campbell	Barbara Latman	Jay Sternberg
Kenny Canter	Jennifer Leader	Alice Surico
Kai Chau	Sarah Lipner	Sweeney Family
Chicago Ataxia Support Group	Brad Machado	Raietta Taborosi
Eric Christian	Eva Marosi	Jean Trinka
Joe Coelho	Rachael Marshall	Robert Tucci
Lisa Cole	Diana Mauro	Phil Turnbull
Roger Cooley	Younger Meade	Marcia Vaughney
Carolyn Cox	James Mickens	Anna Vibberts
Matthew Coyne	Mitchell Family	Eleanor Vibberts
William Coyne	Joann Mocerri	Liberty Vieson
Betty Deforest	Donald Moore	James Vingo
James Ellson	Fred Mutschler	Marvin Way
Louise Estabrook	Dr & Mrs Stuart Nerzig	Leroy Wernsing
Gregson Gann	Edward Noel	David Westrick
Ginny Gokenbach	Rita Nystrom	Mary Whaley
Tanya Goldman	Dr Harry Orr	Rorie Winkelmann
Katherine Gorman	Art Pinkston	Wilbur Youngblood
David Hankins	David Price	
Janet Hannaford	Rolando Ramos	

So you have a genetically confirmed form of Spinocerebellar Ataxia?

Invitae is looking for individuals with specific genetically confirmed forms of SCA: SCA7, SCA10, SCA12 or DRPLA who are willing to provide saliva sample and a copy of their genetic test results.

Invitae is a diagnostic testing company whose mission is to make genetic testing more widely accessible and affordable, especially to individuals with a rare disease who often face difficulty obtaining a diagnosis.

Next-generation sequencing panels have benefitted many rare disease communities, but due to the inherent technical difficulties, a reliable, low-cost, comprehensive pane has yet to be developed for Spinocerebellar Ataxia.

Invitae is offering \$200 for your participation.

If you have a genetically confirmed diagnosis of one of these Ataxias and are interested in participating, please contact Invitae Genetic Counselor Hannah White at Hannah.white@invitae.com or (415) 231-5648 for more information.



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 akooppen@mail.amc.edu

Gift – Honor – Memorial

A contribution given in memory of a friend or relative is a thoughtful and lasting tribute, as are gifts to honor your friends or family. A Gift Membership is a wonderful gift to a friend or relative for special occasions like birthdays, graduations, anniversaries, and holidays. NAF will acknowledge your gift without reference to the amount. Simply fill out this form and mail with your check or credit card information to the National Ataxia Foundation. Honor/Memorial envelopes are available free of charge by writing or calling NAF.

My contribution is: In Memory In Honor Gift Membership

Name _____

Occasion _____

Send Acknowledgment Card to:

Name _____

Address _____

City/State/Zip _____

From:

Name _____

Address _____

City/State/Zip _____

Membership

Yes, I want to help fight Ataxia! Enclosed is my membership donation.

(Gifts in U.S. Dollars)

Lifetime membership - \$500

Annual Memberships:

Patron membership - \$100-\$499 Professional membership - \$65

Individual - \$40 Household - \$60 Addresses outside the U.S. please add \$15

Recurring Gift Membership Program:

If you wish to contribute monthly or quarterly, please consider the Recurring Gift Membership Program. For more information contact the NAF office or visit

www.ataxia.org/giving/default.aspx.

Name _____

Address _____

City/State/Zip _____

Phone _____

E-Mail _____

Yes, sign me up for NAF e-mails

PAYMENT INFORMATION

Gifts are tax deductible under the fullest extent of the law.

Check. Please make payable to the NAF.

Total Amount Enclosed \$ _____

Card: Visa MasterCard

Discover AMEX

Name on Card _____

Card # _____

Exp. Date _____ CVV # _____

Signature _____

Phone Number _____

NAF National Ataxia Foundation

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Details on page 22

