



National Ataxia Foundation

GENERATIONS

THE OFFICIAL PUBLICATION OF THE NATIONAL ATAXIA FOUNDATION

Fighting for Freedom

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Highlights **Pg. 26**

2018 Annual Ataxia Conference

Full Schedule and
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Deadline to submit materials for the Spring issue of *Generations* is Friday, February 2nd.

Please direct correspondence to:



National Ataxia Foundation

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

Generations Staff:

Joel Sutherland, Executive Director
Sue Hagen, Patient and Research Services Director
Lori Shogren, Community Program and Service
Director
Stephanie Lucas, Communications Manager
Leader Printing – Printing and Production
Jessica Johannes – Design

The National Ataxia Foundation does not endorse products, therapies, services, or manufacturers. Those that are mentioned in ***Generations*** are included only for your information. The NAF assumes no liability whatsoever for the use or contents of any product or service mentioned in the newsletter.

Happy Holidays!



All the staff at NAF wish you and your family and wonderful holiday season.

NAF Update

At the time of print, the Research Drive is still underway! 84 applications for Ataxia research grants are being reviewed and independently scored by top Ataxia researchers and clinicians around the world. Only the best research will be selected and funded - thanks to your help and support. Research grant awards will be published in the Spring edition of *Generations*.

THE DEADLINE FOR SUBMITTING MATERIALS

for the Spring issue of *Generations* is Friday, February 2nd. Please send articles, your personal story, recaps of Ataxia-related events, photos and reports to stephanie@ataxia.org. Thank you.



CHECKOUT THE NEW NAF WEBSITE! ATAXIA.ORG

YOUR DOLLARS AT WORK: A Look at NAF Funded Research

The following are lay summaries from research projects that NAF was able to fund because of generous contributions from our donors. All of these research summaries are of grants funded by NAF for fiscal year 2016. Thank you to each of you who made a donation to last year's Research Drive "Proud Past... Focused Future."

Unless you are a scientist, these research summaries can seem like "Greek" to you, however, it does demonstrate the complexity of science, particularly neuroscience. These summaries were submitted directly from the researchers. While they may be difficult to read, we at NAF think it is important to keep you up-to-date on the science that your membership and donations support.

SEED MONEY GRANT

A New Look at Ataxia7 as a Regulator of Substrate Selection by the KAT2a Acetyltransferase



Michael Downey, PhD
University of Ottawa, Ontario,
Canada

Spinocerebellar ataxia type 7 (SCA7) is a neurological disorder characterized by loss in motor coordination and vision. This results from cerebellar (brain) and photoreceptor (eye) degeneration, respectively. Prognosis is related to age of onset - with younger patients experiencing enhanced deterioration as they age. There is no cure for SCA7 and more research is necessary into the basic mechanisms underlying this devastating disease.

My lab studies the protein at the heart of SCA7 - called Ataxin7 - at the molecular level. In patients, the Ataxin7 protein has changes to the sequence of the amino acid building blocks that make up the protein. We know this is a problem, but we don't know why. We have been investigating the idea that the disease form of Ataxin7 changes the way that another protein, called KAT2, functions

in the cell. KAT2 is an enzyme that hands out instructions in the cell in the form of a small chemical modification. If the cell is a factory, then KAT2 is a foreman within the factory telling other proteins what to do. We want to know which molecules are targeted by these instructions and how the lines of communication break down in SCA7 patients. We hope this will uncover new options for therapies.

With funding from the National Ataxia Foundation we have built new molecular and cell biology tools that will enable us to look at the relationship between Ataxin7 and the KAT2 protein. Over the past year, I have recruited a highly skilled technician and a post-doctoral fellow interested in Ataxin7 function. We have optimized methods of reading the 'instructions' handed out by KAT2 using a tool called a mass spectrometer. We have also used advanced methods to generate cell lines expressing versions of Ataxin7 seen in healthy patients and versions seen in diseased patients. In the near future, we will combine these tools to learn more about Ataxin7 function.

We have also continued to explore Ataxin7 function in the budding yeast model system. Budding (or baker's) yeast cells are used to bake bread and brew beer. But, they have also been used in scientific research for a long time. This is

because they function in the same way that our cells do. Using this system, we discovered that cells making too much Ataxin7 protein are sensitive to a drug called nicotinamide. We are continuing to explore this discovery to identify cellular pathways that could serve as drug targets in translational research.

POST-DOC FELLOWSHIP AWARD

Molecular Pathogenesis of Spinocerebellar Ataxia Type 12



Pan Li, PhD
Johns Hopkins University
School of Medicine,
Baltimore, MD

Spinocerebellar Ataxia Type 12 (SCA12)

is a rare progressive autosomal dominant neurodegenerative disease. SCA12 is caused by a CAG/CTG expansion mutation in exon 7 of PPP2R2B, a gene encoding regulatory units of the protein phosphatase 2A. Normal alleles carry 4 to 31 triplets, whereas disease alleles carry 43 to 78 triplets. Clinically SCA12 is characterized by midlife-onset movement abnormalities, with prominent tremor and gait disturbance, and less consistently psychiatric and cognitive disturbances. Pathologic findings include generalized atrophy of the cerebral cortex and cerebellum, with prominent loss of Purkinje.

We have generated and characterized 8 human SCA12 induced pluripotent stem cell (iPSC) lines from three different SCA12 patient skin fibroblast cell lines, and these iPSC lines will be a powerful tool for SCA12 research. In SCA12 iPSCs, we have detected the PPP2R2B transcripts with short and long CAG repeats; however, the PPP2R2B transcript expression is not significantly different in SCA12 iPSCs, as compared with the control,

suggesting that the repeat may not influence PPP2R2B transcript expression. Further, we also found that a novel protein containing a long serine tract may be expressed in SCA12, which is toxic to cells, and may contribute to the disease pathogenesis. To sum up, these findings provide novel insights into SCA12 pathogenesis and may provide guidance to future therapeutic development to cure the disease.

YOUNG INVESTIGATOR AWARD

Reduced Expression of Mitochondrial Aldehyde Dehydrogenases Contributes to Metabolic Stress in Friedreich's Ataxia



Jill Butler Napierala, PhD
University of Alabama at
Birmingham, AL

Friedreich's ataxia (FRDA) is a severe progressive neurodegenerative disorder caused by lower

production of the frataxin protein. Its deficiency leads to complex changes in multiple organs of FRDA patients. Neurons and heart cells are the most sensitive to lower levels of frataxin. As all functions of an organism are interconnected, the deficiency of a single, critical protein has severe consequences to other genes and proteins in cells. Identifying these changes that occur in FRDA requires sensitive analyses of many samples. Uncovering the consequences of frataxin deficiency can define new therapeutic targets and help to identify new molecular hallmarks of the disease, or biomarkers. We conducted a detailed analysis of all genes active in FRDA cells and compared them to unaffected cells. For these experiments, we used a state of the art next generation RNA sequencing technique and a large number of patient and control samples that have been collected in the past four years. Our results

indicate that enzymes responsible for eliminating certain cellular toxins are decreased in FRDA cells. Some of these toxins are known to promote neurodegeneration and are damaging to cardiac cells as well. In the proposed project we will investigate the levels and activity of the identified enzymes using FRDA neuronal cell line models. We will also experimentally manipulate the levels and activity of these enzymes and assess the effects on the fitness of the FRDA cell models to determine if they are good therapeutic candidates. The primary goal of these studies is to define new treatment strategies for Friedreich's ataxia.



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

Do you have hereditary ataxia?

The Masters in Genetic Counseling Program at the University of Maryland School of Medicine is conducting a new research study to better understand how people communicate with their family members about their condition.

We need your help and want to hear your story!

Participate from the comfort of your home

The study includes just a short survey and a phone interview.

If you are interested in learning more about this study, please follow the link below:

https://umaryland.az1.qualtrics.com/jfe/form/SV_4NoQNDUdT7OqCih

You can also get information about the study by contacting:

Shannan Dixon, MS, CGC

SDelany@som.umaryland.edu • 410-706-4713 We hope to hear from you!

Are You There Life? It's Me, Madison.

Madison Slagle



My name is Madison Slagle, I'm 21 years old and I was diagnosed with Ataxia a year ago. A few months ago, my genetic test came back "positive" for Spinocerebellar

Ataxia 8. My cousin

noticed my speech was a little slurred and I began having minor trouble with my balance about 9 months before my diagnosis. The symptoms were subtle at first but became more noticeable as time went on. It took me several months to admit that something was wrong because honestly, I didn't know what was happening. It was very confusing.

I believe everything happens for a reason. Growing up, I was in Advanced Placement classes and went to summer camp every July. I played basketball and volleyball (though I wasn't very good) and enjoyed running with the boys at recess. I loved cheering on the Dallas Mavericks at games and could be seen knee-boarding at the lake with my family almost every weekend. Although I was involved in a lot, my biggest passions were dancing and singing. I was always at dance practice, in a voice lesson, or on stage performing. I danced at Friday night football games with the drill team, traveled to Italy and sang at St. Peter's Basilica with the varsity choir in high school and on many occasions, would be awake from 5:00am until 11:30pm to make it to all my practices, just to wake up the next day and do it all again. I ran on very little sleep, had a very busy schedule, but loved every second of it. Now that I have difficulty with my balance and speech, I get to use a lot of the tools I learned from dance (for my balance) and singing (for my speech) and I catch myself saying "oh, I used to do that in dance" or "that was important in choir" when I learn something new in therapy. There's a reason those were my two favorite extracurricular activities for 15 years.

Ataxia has taught me so much about life. I've learned to be understanding, have patience,

embrace your flaws and to never "sweat the small stuff." I've also learned to be persistent and determined, never underestimate myself and not to use Ataxia as an excuse but instead, an opportunity. My physical and speech therapists often say "you're too hard on yourself!" They also say that's likely the reason I'm making improvements. I do something over and over until I get it right and if I don't get it right, I just keep trying. Sometimes, I get frustrated but I know how rewarding it is when I finally get the hang of it. You see, having Ataxia makes simple tasks seem almost impossible and it took me a while to find that word "almost." At first, I would say I couldn't do something before I even tried it because I feared failure. But with that attitude, I was just letting life happen around me and I felt stuck in a cage-watching everyone have fun. I had to get up, brush myself off and say "I can do this." I'm still able to go out with my fiancée, attend my cousin's softball games and play with my niece. It might take me a while to walk from place to place and I might stumble a few times, but Ataxia doesn't make life impossible. It just makes life interesting.

"Ataxia doesn't make life impossible. It just makes life interesting."

Before I was diagnosed with Ataxia, I was a nanny and a college student at Tarleton State University (Bleed Purple!). I loved to sing, dance, go to hockey games and take my dog on walks. Since I was diagnosed with Ataxia, I've learned that I love documentaries and books, I started a blog and I've taken a huge interest

in my health (and lost a lot of weight by eating healthy!) My hobbies have changed and so have I. Well, maybe I haven't changed. It just took having Ataxia to find my best qualities. I like this version of me, even if I do fall sometimes. I've had Ataxia for only 1 year and my journey has just begun but, I'm ready for whatever life throws at me. "You're gonna be happy," said life, "but first I'll make you strong."

Want to read more from Madison?

Check out her blog: Madison: My Life with Ataxia - <https://madisonslagle.wixsite.com/livingwithataxia>

Madison was born and raised in Dallas, Texas and was diagnosed with Ataxia in September 2016. She enjoys spending time with her family, her friends, and her new fiance.

Ataxia Lesson #213 and Counting

Deborah Levi

Admitting what we need, asking for help, letting our softness show—these are prayers without words that friends, strangers, wind, and time all wrap themselves around. Allowing ourselves to be held is like returning to the womb.

-Mark Nepo, The Book of Awakening

Approximately two years ago I attended a celebration at the Awakening Interfaith Spiritual Center to honor the upcoming summer season. That ritual offered prayers for our earth. I am a lover of the environment, and was anxious to be a part of something larger than I am. But the biggest change had to do with myself and my ongoing challenges with Ataxia. That day turned into an unforgettable lesson, a blessed experience in gratitude.

“I realized that asking for help is not just necessary, but a sign of strength.”

About this same time, I graduated from my cane to walker. My mobility had been progressively worsening, and the cane was no longer enough stability. Even though I needed to use the walker, I was ashamed and embarrassed to be seen with it. Those terrible, nagging words, “what will people think” – came back to haunt me again. I thought they had gone for good. I knew that such beliefs caused me to suffer, so I reminded myself to think of the bigger picture. I wanted to fight my inner demons.

After the usual service, every participant was asked to walk up to the front altar, light a candle, and say a silent prayer. I froze as soon as I heard those instructions. The idea that I needed to be that visible was more than I bargained for. I dare not use my walker! I turned to a friend and asked her if I could borrow her arm as support. As we walked to the front of the room I felt another person, a stranger, grab onto my other arm. It was as if I was being carried by an unexpected, intense, and overwhelming love. Tears ran down my cheeks. For a long time I struggled to understand why I have this disability. Why did this happen?

How could so much suffering possibly help anyone? I realized at that moment my Ataxia had a purpose, and instead of shame I felt gratitude for the compassion.

As I embraced the kindness, I felt inner peace and deeply smiled. All the questions were not important. My Ataxia was bearable.

As I left the day's service, I held onto my walker with tears running down my cheeks. It was a season of change. My tears of self-pity had transformed into a growing sea of joy. I realized that asking for help is not just necessary, but a sign of strength.

Many seasons and celebrations have passed. Each time, I remind myself to ask the people around me for help. They are more than willing to extend an arm or a needed hand. Every time I receive assistance I record it in my gratitude journal. This simple injection of positive energy helps me combat my daily obstacles.

My mobility is still a challenge as my Ataxia continues to progress. I am proud to say my tears of self-pity are no longer with me. They have been replaced with tears of joy. I realize that love and the ability to ask for help from others are precious gifts. My Ataxia helped me learn these valuable lessons.

Want to read more from Deborah?

She wrote her book *Finding Level Ground: My Journey with Cerebellar Ataxia* as a fundraiser for NAF. It is available through Amazon. You can contact her at debbielevi213@yahoo.com.



Deborah is a retired teacher, and currently a writer who lives on the central coast of California. She was diagnosed with Cerebellar Ataxia in 1994..





A clinical study designed for patients with Friedreich's ataxia

A clinical study is now enrolling individual with Friedreich's ataxia. MOXIe is a Phase 2 clinical study evaluating the safety and effectiveness of omeveloxolone (an oral investigational drug) for the treatment of Friedreich's ataxia (FA). The study has two different parts.

MOXIe (Part 1) completed enrollment in February 2017. Key observations from MOXIe (Part 1) are:

- Omeveloxolone significantly improved mFARS (modified FA Rating Scale) from baseline across all doses
- In omeveloxolone-treated patients, mFARS was improved at Week 4 and further improved by Week 12
- Omeveloxolone at 160 mg dose showed large mFARS improvements as early as Week 4
- Omeveloxolone was well-tolerated and adverse events were generally mild in severity

MOXIe (Part 2) is now enrolling.

You may be eligible for this study if you:

- **Are 16 to 40 years of age**
- **Have been genetically diagnosed with Friedreich's ataxia**
- **Are willing to maintain a consistent exercise routine and stable medication doses throughout the study**
- **Are willing to discontinue taking all antioxidant supplements and vitamins, or any other medication intended to treat Friedreich's ataxia, before beginning this study and throughout your participation in the study**

Other eligibility criteria must also be met.

The investigational drug, study-related procedures, and doctor visits will be provided at no cost. If you travel to the site for your study visits, travel expenses will be reimbursed, and compensation for study-related time may be provided.

For more information or to see if qualify, contact.

Reata Pharmaceuticals

Hanh Nguyen

hanh.nguyen@reatapharma.com

(469) 442-4754



This study is being sponsored by Reata Pharmaceuticals. www.clinicaltrials.gov (NCT02255435)
ENG V1.0, Protocol Version 9.0 – 17August2017

Faith and Fighting: A Battle with Ataxia

Annie Ebersole



Hi my name is Annie Ebersole. I have SCA7. My symptoms started in 2001. I was 35 years old then. Now, I'm 51 years old. It attacked my eyes first. When I was 40 years old it started affecting my muscles.

Now, it seems like the Ataxia is so much harder than before. I use a walker since last month when Doctor told me I better start using one. I'm in a government study for 5 years. I have 3 more years until Doctors will start treatment; first on my eyes. The study is at the National Institute of Health in Bethesda, MD. I go once a month for a week of testing each year.

My Neurologist, Dr. David Lynch of the Children's Hospital of Philadelphia in PA referred me to the study which I started in. He told me I'm doing so good. I go up to Allied Services (a rehab. center in my town) twice a week in the pool for my leg exercises, I work out at home and go on the elliptical machine when I feel strong. I drink Bragg's raw apple cider vinegar mixed with 8 oz. of

water daily (it helps with the shakes). I pointed up to God. I told him my faith is very strong and I have a lot of Christian friends and a strong church family. God helps me every second of the day. I pray to him constantly. I'm going to beat this and I know many who have this disease are fighting to beat this too. Keep a positive attitude, have peace in God, and KEEP ON FIGHTING. There are many scientists and Doctors fighting for us.

"I'm going to beat this and I know many who have this disease are fighting to beat this too."

In The Love of Christ,
Annie

Annie Ebersole was born and raised in the greater Scranton, PA area in the borough of Dunmore. She currently resides in Clarks Summit, PA. Her husband, Merle, and three children, Chris, Leah and Nick are the center of her life. She is very active in a local church family and loves her Lord and Savior, Jesus Christ.



JOHNS HOPKINS
MEDICINE

Approved January 31, 2017

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.

My “60 for 60 to Cure Ataxia” Challenge: A Race Against the Coming Winter *Joni Lahr-Moore*

I grew up in the rural Midwest, which meant that I was practically raised on two wheels and with an insatiable appetite for traversing winding country roads, secluded dirt paths, up hills and down on my bike. In my late 20s, I experienced a progressive loss of balance (later diagnosed as spinocerebellar ataxia type 3) that made it unsafe for me to ride a bicycle anymore. I was crushed and fell into depression for a number of years. I fed its masochistic tendencies by watching point-of-view (POV) videos online that reminded me of what it was like to ride. Filmed with GoPro cameras from the perspective of mountain-biking and cyclo-cross enthusiasts, these videos lifted my spirits, but then my depression dropped me back into the harsh reality that that could never be me again. Thanks to my supportive partner, family, and friends, I gradually clawed my way out of my depression and discovered adaptive cycling in the form of a recumbent tricycle. My trike looked very different from my old mountain bike, but I once again had the freedom to go on adventures.

I initially signed up for the “60 for 60 to Cure Ataxia” challenge, because I knew that it would benefit a worthy cause, as well as bring awareness about Ataxia to my friends on social media. (Also, just between you and me, especially with the pain and fatigue associated with my SCA3, I needed a good kick in the pants to get me to do the “E” word—exercise.) With winter fast approaching in the Northland, I figured that this was just the motivation I needed. By making my goal public, I was ensuring that I’d be held accountable for completing it.

As I was planning out trike-friendly routes to fulfill my 60-mile commitment, one day it occurred to me that the POV videos that I had found online were all shot from the perspective of a bicyclist, never from that of a tricyclist. I had an epiphany: had I seen POV videos filmed from the seat of a recumbent tricycle, I may have realized this new potential via adaptive cycling long before my depression had gotten ahold of me. Thus, I set out to make videos from my vantage point and to document the spectacular rides I went on with my trike.

I decided to convert the footage into a time-lapse video for several reasons, the main reason being that I figured that no one would want to watch as I huffed and puffed my way up hills. I added music

to the video to make it more fun and interesting to watch. When I had finished it, I played back what I had created from my first “60 for 60” ride, and realized that it transcended the mere entertainment value that I had intended; I knew in my gut that I had hit on something that could really help a lot of people. I considered that everyone has their own limitations (whether it’s disability, illness, time, finances, location, etc.) that make it difficult or impossible to get outside and enjoy nature. By creating and sharing POV videos of my scenic rides, I was inviting folks to ride vicariously through the magic of online video streaming. By watching my videos, it was like they could conquer their own limitations for a few moments, and participate in this challenge to cure ataxia alongside me.



“I proved to myself that I am stronger than I thought I was, and that I am capable of doing so much more.”

Fourteen videos later, I completed 60 miles within the one-month commitment in my race against the coming winter. I proved to myself that I am stronger than I thought I was, and that I am capable of doing so much more. As I’m writing this, the first snow of the year is falling, so I know that it will probably be a while before I can hop on my trike again. If I get cabin fever this winter (and let’s face it—I will), at least I will have these POV videos to relive my autumn adventures.

Joni Lahr-Moore is a wobbly 30-something, living in northern Wisconsin, who uses humor as a cure-all. She is an artist, a writer, and an amateur stuntwoman.

Fundraiser and Awareness Event Recaps

2017 Tri-State Walk N' Roll to Cure Ataxia

Submitted by Kathleen Gingerelli

On August 26, 2017, the Tri-State Support Group hosted our 2nd Walk 'n' Roll; the event was held at Liberty State Park in Jersey City, NJ. With the downtown Manhattan skyline including the Freedom Tower as our backdrop, along with the Statue of Liberty, the temperature held at a perfect 78 degrees and sunny. The day was all set for everyone to enjoy themselves while raising awareness for Ataxia. Music was supplied by Tina Connolly, who was able to keep everyone entertained with her singing and playing tunes. Tickets were sold for baskets to be raffled off with some fantastic prizes including a beauty basket valued at \$300, a signed NY Yankees baseball & others.

The event drew over 150 people from the NY/NJ area; all participating to raise funds and awareness about Ataxia as part of teams or walking as individuals. What a perfect day for everyone to meet others, introduce themselves & make some new friends. Along with all the family, friends & participants we were fortunate enough to have Joel Sutherland, the Executive Director at NAF, join us for the day. Joel tried to meet everyone and had some words for the entire group after the walk.

After totaling all online donations along with donations accepted the day of the walk and raffle ticket money, the Tri-State Walk 'n' Roll raised \$39K.....we can't wait to do it next year! Same location in LSP on August 25, 2018.....see you then!!



2017 NEO Walk N' Roll to Cure Ataxia Raises More than \$13,000

Submitted by Mike Hammer

Thank you!

The Northeast Ohio Chapter of the National Ataxia Foundation wishes to express our sincerest thanks for your support in this year's Walk n' Roll at Edgewater Park. Thank you for joining us and sharing in the fun, friendship and the fight to cure Ataxia



The Northeast Ohio Walk n' Roll to Cure Ataxia took place Sunday, Aug. 27, at Edgewater Park in Cleveland, and the National Ataxia Foundation (NAF) Northeast Ohio area support group raised more than \$13,000 for research and services from the NAF. The event was attended by more than 145 people helping raise awareness for Ataxia. They were able to socialize and have a fundraising Walk N' Roll in beautiful Edgewater Park.

Event attendees enjoyed meeting with each other, discussing and learning about developments in Ataxia research and ways to live with Ataxia, watching a performance from the Olmsted Performing Arts dance team, hearing information from guest speakers, including Beth Glass of Maximum Accessible Housing of Ohio an organization that belongs to the ADA Cleveland group, had refreshments and went on a wonderful walk n' roll through Edgewater, enjoying the park, overlooking sparkling Lake Erie on a picture perfect day.

There was music throughout the day from DJ Eazy, of Eazy-N-Crew Music Productions, who also was MC for the auction and raffles throughout the day that raised more than \$3,000 for the NAF. There were auction and prize items from the Cleveland Cavaliers, the Rock n' Roll Hall of Fame, the Cleveland Browns, the Lake Erie Monsters, Fount Leather Goods, Levin Furniture, Playhouse Square, Lush and Lovely Floristry, Maxi's Restaurant Little Italy, the Lake County Captains, Planet Fitness, Trader Joe's and more.

Fundraisers and Awareness Events (continued)

Local businesses Hyland Software, MC Mobility, PLIDCO (the Pipe Line Development Company) and Levin Furniture, along with Hillary Taylor, Laura Ospanik and Patt Denihan were the sponsors of the 2017 NEO Walk n' Roll to Cure Ataxia. All the money from sponsors and donated at Northeast Ohio Walk n' Roll to Cure Ataxia went to the NAF.

Rockin' for Ataxia

Submitted by **The Fight Ataxia Project**

150 people came together on Sunday, August 27th for Rockin' for Ataxia. We had excellent food and spirits served by excellent staff at an excellent place. We partied with excellent people who won lots of excellent raffle prizes, all while watching excellent live entertainment. An excellent balloon twister and an excellent face painter were there, and they made kids and adults happy.

It was incredibly fun. Thanks to those who did individual fundraising...my daughter raised \$500 and made good on her word getting her hair cut off at the event. Altogether, this campaign raised over \$8000 for The National Ataxia Foundation.

A hearty thanks goes out to my family and volunteers who made it happen. Thanks to all who donated. Thanks to the Bryzgalski family (Crushing It With Bo) for all the hard work and coming out in droves. A special thanks to all friends and former band mates for excellent performances, and donating time and effort, some who I haven't seen in 44 years.



Ataxia Awareness BBQ at Happy's Home Centers

Submitted by **Jan Colon**

The Ataxia Awareness event held on September 2nd, 2017 at Happy's Home Centers was a success. We handed out Ataxia Awareness rocks and Living with Ataxia brochures. Although it rained we were able to accomplish our mission to raise Ataxia awareness. Many people had questions about Ataxia and we were able to provide answers.

Thanks to Happy's Home Centers for allowing me and my Ataxia Support Group to participate in their BBQ and use the opportunity to raise Ataxia awareness. We got another invitation for the next BBQ. It doesn't matter if it's in October, November or next year ...Tampa Bay Ataxia Support Group will be there to RAISE ATAXIA AWARENESS.

Thanks to Linda Farrow and Sharon Farley for their support. Thanks to my husband, my mom, daughter, family, friends and my neighbors for their participation and their support.



5th Annual Walk for Dave

Submitted by **Marc Alessi**

This year's Walk was a huge success. Held on Saturday, September 9, 2017, Walk for Dave was dedicated to the memory of David Alessi, who passed away in October 2011 from complications of Spinocerebellar Ataxia Type 2. We managed to raise over \$1700 on just the day of the Walk! With more businesses donating, we made it past \$5k for a grand total.



Lancaster Barnstormers Game for IAAD

Submitted by **Mike Cammer**

On Saturday, September 9th the Central PA Ataxia Support Group had an awesome evening at the Lancaster Barnstormers baseball game. Our early IAAD Ataxia Awareness table was well represented with a total of 29 present in our group! Everyone took turns at the table spreading Ataxia awareness to a record crowd of 8,500 people, over 5,000 more than average attendance! The evening was a little chilly for early September and required jackets and sweatshirts, but everyone had a great time

Fundraisers and Awareness Events (continued)

together and enjoyed fireworks after the game that rivaled the 4th of July!



7th Annual Denver Run, Walk, N' Roll to Cure Ataxia in Honor of Mike Williams

Submitted by Charlotte DePew

September 10th, 2017 began over the lake with a colorful and cloudless Colorado sunrise at the scenic Denver City Park Pavilion. There was a scurry of activity in preparation for the 7th Annual Denver Run, Walk n' Roll (RWnR). Led by our support group leader, also our RWnR Chairperson, and with the planning committee's hard work, these wonderful volunteers put on yet another successful and fun Ataxia awareness/fundraising event.

At this year's event, we honored a passed support group member, Mike Williams (1972-2017). His father gave a brief compassionate and humorous account of Mike's life and Ataxia's effect on the family's SCA-3 history. Mike was a professional caricature artist and his father donated several pieces of Mike's art to our silent auction. A bidding contest resulted in \$300.00 for Mike's zodiac pencil drawing. Mike was a delightful person with a playful smile and gleam in his eyes; even within the past couple years.

The day attracted a large group of over 275 participants. There were activities for everyone from the vendor fair to the generous donation of iced coffee and doughnuts from Dunkin Donuts as well as lively music by a DJ that generated some dancing. An amazing array of items were donated for our drawing and silent auction. To our surprise, the twelve silent auction items earned \$1,000.00. We also welcomed and introduced Lori Shogren from the National Ataxia Foundation HQ who attended our event and answered questions at our Ataxia Information table. I think it is safe to say that everyone had a good time

based on accolades as people departed. Our group was once again thankful to have a neurologist interested in Ataxia from The University of Colorado Health Sciences (UCHS) at our event. Dr. Trevor Hawkins participated in the run and then spoke about Ataxia research in general and at UCHS. The UCHS Ataxia Clinic is now an approved site to gather information for a natural history study of several Ataxias. We, the Denver RWnR Committee, thank our gracious and dedicated members who attended, provided volunteers, and generated donations over \$25,000.00 to-date.

The 8th Annual Denver RWnR will be September 9, 2018 in Denver's City Park at 8:00 am.



2017 Orange County Walk N' Roll to Cure Ataxia

Submitted by Cindy De Mint

Orange County hosted its 9th Annual Walk n' Roll for Ataxia on Saturday, September 16th, 2017. We had a great turnout with over 500 walkers. The morning began by volunteers from Eastside Christian Church and BSA Troop #99 helping set up booths and carnival games. Michele Gile of CBS News was our Emcee and she made the event fun and kept us on time. We walked 1 mile around a beautiful man-made lake in the city of Yorba Linda. Opportunity baskets and Silent Auction items were abundant this year but the big hit was the miniature pony from Happiness on 4 Hooves. We raised \$80,000 of our \$85,000 goal for research to find a cure. so far. It's not too late to donate at www.ataxia.org/walk/oc. See you all next year on Sat. Sept. 15th, 2018



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

Fundraisers and Awareness Events (continued)

Glow in the Park

Submitted by Jalean Retzlaff

Held on September 16th at Hap McLean Park in Park City, KS, the Glow in the Park event was a success. The evening of fun included a chance to win raffle prizes, small carnival for kids, Zumba, and dress contests. I had about 60 people in attendance and raised about \$800.00. I even got some media coverage for the first time in 6 years!



2017 Atlanta Walk N' Roll to Cure Ataxia

Submitted by Greg Rooks

The seventh annual Greater Atlanta Walk n' Roll to Cure Ataxia was held on September 23rd at Shorty Howell Park in Duluth, GA. We could not have asked for better weather and had a great turn out. About 125 walker and rollers followed the trail around the perimeter of the park. We had 11 teams of walkers participating this year. After the walk a short program was presented thanking all participants and recognizing the top fundraising teams and individuals. It was also explained the Walk n' Roll is in recognition of International Ataxia Awareness Day and the proclamation for the governor was read. Refreshments were served to all participants. Afterward lunch was had at a local pizza parlor with 20% donated back to the Walk n' Roll. The event raised approximately \$24,000 to benefit the National Ataxia Foundation.



A Little Bit Country...A Little Bit Rock N' Roll

Submitted by Joe DeCrescenzo

A Little Bit Country...A Little Bit Rock n' Roll, an Ataxia fundraiser, was held in Bear, Delaware on September 23, 2017. It was hosted by Joe and Cathy DeCrescenzo, with Wayne and Virginia Hanna. Close to 250 of our families and friends enjoyed an evening of food, beverages, dancing, raffles, cake, and cookies. Dave Cornwell provided the music, which made for a fun evening of dancing to many types of music. There was no admission fee charged, instead, attendees were asked to make a donation to NAF. The event met, and exceeded, our financial goal. Over 40 items were included in the raffles, ranging from hand-made jewelry, hand-carved woodwork, crochet items, gift cards, gift baskets, a weekend in the Pocono Mountains, Weber grills and a 32" television. Susan Cook told of her grand-nephew, who is seven years old and has lived with the symptoms of Ataxia since birth, raising Ataxia awareness.



2017 Utah Walk N' Roll to Cure Ataxia

Submitted by Lisa Ord, PhD, LCSW

The Utah Walk N' Roll to Cure Ataxia on Saturday, September 23, 2017 was a hit, raising more than \$11,000. Held at Layton Commons Park Pavilion, the event featured food, live music, and fun. Thank you to all who attended or donated. Hope to see everyone back next year!



Fundraisers and Awareness Events (continued)

2017 Western PA Walk, Run N' Roll to Cure Ataxia

Submitted by Madalyn Gottschalk

The WPA Walk on Saturday, September 23, 2017 was a huge success! It was such a beautiful day and we had a great turnout! We raised nearly \$15,000 when it was all said and done. The WPA Walk N' Roll was hosted by the Western PA Ataxia Support Group in recognition of International Ataxia Awareness Day and in memory of Richard Reimond, Michael Freund, Larry Hillenbrand, and Regis Gottschalk.



Kansas City Ataxia Support Group IAAD Picnic

Submitted by Stephanie Wilkins and Laurie Colby, Kansas City Area Ataxia Support Group Co-Leaders

The Kansas City Area Ataxia Support Group held their 2nd annual IAAD picnic on Sunday, September 24, at Longview Lake with 120 friends and family attending. It was a great social event for the group to enjoy time with each other, share awareness, eat great BBQ and recognize IAAD.

The group surpassed their \$5K goal, with over \$6K as the final donation to NAF. We had a wonderful time, on a bright sunny day by the lake with a fabulous Silent Auction, Raffle, Door Prizes, Bake Sale, Chair Massages, Caricature Artist and yard games for all the children who game too.



Students Run LA

Submitted by Lora Morn

Volunteers represented NAF at the Students Run LA (SRLA) 5k on Sunday, September 24, 2017. SRLA Cares held a penny collection for United Cerebral Palsy and National Ataxia Foundation. Volunteers helped raise awareness about Ataxia and provided information about Ataxia and chapstick to runners. The event went well and many stopped to learn more.



Tampa Bay Support Group's IAAD Partnership with Local Businesses

Submitted by Lisa Cole

For IAAD, we had several local businesses help us raise Ataxia awareness. Gold's Gym, Saint Lucie West location, allowed us to put up 9-10 signs about Ataxia. We also had more signs posted at several eye doctors' offices and a couple of local Dunkin' Donuts.

In addition, two local comedian hosts mentioned that September 25 is International Ataxia Awareness Day before the show started. It was nice to have local support from area businesses.



2017 New England Walk N' Roll to Cure Ataxia

Submitted by John Mauro

The 10th Annual New England Walk and Roll to Cure Ataxia was held at Bristol Town Beach on Saturday September 30th, 2017 with the support of

Fundraisers and Awareness Events (continued)

the Rhode Island Chapter. The walk has raised more than \$37,000 so far and was attended by many. Over the years John Mauro and his wife Dana have tirelessly worked to promote awareness. Not only did they begin the 1st ever Walk N' Roll to Cure Ataxia in Central Mass., they also created the Central MA Ataxia Support Group. With the help of a small group of family and friends (or friends they consider family) they worked with the state house, Senator Michael Moore, and Representative Paul Frost, to recognize September 25 as Ataxia Awareness Day in Massachusetts as well.



Denise Higdon Guest on “Priority Talk Radio with Greg Davis” for IAAD

Submitted by Denise Higdon

Denise Higdon talked Ataxia with Greg Davis for a radio spot on IAAD. She, along with her mother, Sarah Guercio, her sister, Jackie Guercio, and John Higdon (not pictured), visited with host Greg Davis to help spread awareness about the disease.



S.B. 143

Submitted by Susan Kresnye

The idea of S.B. 143 started in June of 2016, when

my youngest son received a letter from State Senator Eklund's office congratulating him on making the Dean's List. I called the Senator's office about a Proclamation from the state recognizing IAAD for the Ohio Walk N' Roll. I made several calls to his office; at the end of February of 2017, the Senator came to my house.

I consulted John Mauro throughout the process, he was truly the voice of knowledge. He made sure I had NAF literature so the senator had something to take with him back to Columbus. Imagine my surprise when S.B. 143 (the bill) was introduced to the Ohio Senate floor on May 2, 2017. The proposed bill was to change the Ohio Revised Code (ORC) to reflect September 25 as IAAD in the state of Ohio. I was surprised again. Senator Eklund learned about the difficulties that people with Ataxia live with and he joined the battle for awareness.

On June 27, Senator Eklund introduced the bill to Committee. He gave wonderful sponsor testimony. On October 3, 2017, I was in Columbus and testified for the bill as well. On October 16, 2017 a vote was taken and the bill was passed to be considered on the Ohio Senator floor. The very next day the senate passed the bill with a vote of 32-0. It now crosses the building for consideration by the Ohio House of Representatives. To be continued...

2017 Fort Wayne Walk N' Roll to Cure Ataxia

Submitted by Cheri Bearman

The 2017 Fort Wayne Walk N' Roll was a HUGE success. Held on Saturday, October 7th, it was a beautiful sunny, breezy, fall morning. All in all, everyone had a great time! So many friends and family came out to Foster Park in support of myself and Tom Dobey, and in support of all those affected by Ataxia. We were all united and excited to be walking for a cure for Ataxia.

Our event organizer, Jessica Lebrato, Tom's daughter, did an excellent job of preparing for the event. We enjoyed live guitar music, Starbucks

Coffee to fire us up before the walk, 18 door prizes from local businesses, pre-walk stretching routine led by yoga teacher Mary Newell, water and cookies (donated by Sam's Club), yummy homemade muffins and sweet rolls (prepared by a friend), and all kinds of fresh fruit after the walk. Approximately 100 people attended and we raised more than \$6,000 for the National Ataxia Foundation!!



Jessica is already making plans to make next year's event even bigger and better!

Italian Night for a Cure 2017

Submitted by Mary Fuchs

On Saturday, October 7th, the Arizona Ataxia Support Group held our International Ataxia Awareness Day (IAAD) event to raise awareness of Ataxia and how it affects our lives. We raised funds to benefit the National Ataxia Foundation's (NAF's) mission to provide information on Ataxia, fund Ataxia research, and provide support.

We had 49 people attend our event this year and we took advantage of the gathering to visit with friends we haven't seen in awhile. Good food and a great time was had by all (plus lots of prizes)!!! Thank you to all our family and friends who attended and have generously donated to the NAF in this fight against this terrible family of diseases. We greatly appreciate all of you very much!

We were also VERY blessed to have Joel Sutherland, who is the Executive Director of NAF, fly in from Minneapolis, MN. He shared the vision of NAF, research updates, new logo and new office. The evening ended with our raffle drawing.



L-R Angela Li, Joel Sutherland, Mary Fuchs

Tea Time to Cure Ataxia

Submitted by Jane Joffe

Everyone had a wonderful time at Tea Time to Cure Ataxia on October 7, 2017. Held at Aubrey Rose Tea Room, both tea times scheduled for the event sold-out. Lisa (pictured) is the face of Ataxia to all of my friends and family. Her smile is what makes me continue to organize the Tea each year!



Lisa Jaffe at Tea Time to Cure Ataxia

Ataxia Trophy Race for IAAD

Submitted by Cathy DeCrescenzo

Joe & Cathy DeCrescenzo sponsored an International Ataxia Awareness Day (NAF) Trophy Race at Delaware Park on October 14, 2017. It was a fun-filled day with family and friends, raising Ataxia awareness, enjoying lunch, and watching the races. Our daughter, Amy Lowe, stood in for Joe in the Winner's Circle, presenting the jockey and trainer with a trophy!



AttackAtaxia 60 for 60

Submitted by Katelyn Leader

The AttackAtaxia 60 for 60 to Cure Ataxia Team surpassed their \$5000 goal - raising nearly \$6500 thus far! The Leader Family and team completed more than 60 miles, in honor of their sister/daughter/friend Jen, to help in the search for a cure. They shared selfies throughout their journey to AttackAtaxia and had a great time while raising funds for NAF!



Best Buy Headquarters Welcomes NAF to their Abilities Awareness Event

Jill Bigelow, Fraud Work Coordinator at Best Buy Corporation, invited NAF to exhibit at Best Buy's Abilities Awareness



L-R Jill Bigelow, Stephanie Lucas

event on October 25, 2017. The event encourages its employees to stop by each vendor's booth to learn about rare diseases or various types of disabilities. Jill and Communications Manager Stephanie Lucas of NAF were excited for the opportunity to teach Best Buy employees about Ataxia and the effects it has on a person.

NAF Exhibits at CFC Charity Fair in Fort Lee, VA

A huge thank you to Jim Cropper and Ali Dryden, who volunteered their time on November 2, 2017 to represent NAF at the CFC Charity Fair in Fort Lee, VA. They handed out information, answered questions, and raised awareness about Ataxia.



2017 Minnesota Walk N' Roll

Submitted by Bill Sweeney

Over 500 enthusiastic participants joined Twin Cities Support Group members on September 9, 2017 for the 9th Annual MN Walk N' Roll to Cure Ataxia. We obviously have good connections with the weatherman, as we enjoyed sunny skies on a warm fall day. A first for our event was a live auction of Mexico vacation trips and a Vikings Tailgate Party. Special thanks to our Mississippi friend Mike Anderson, the Montana & Washington "cousins" and event co-chairs Wendy and Carla Sweeney. Over \$126,000 was raised this year from more than 600 donors. Thanks to all for their generous support!



✓ ATAXIA TIPS Hints and Tricks for Ataxians, from Ataxians

- 1** Tired of spilling drinks? "The Incredible Spill Not" is a drink carrier that allows you to carry a cup without spilling. It's available on Amazon. (Submitted by Mike Cammer and Ginny Atwell)
- 2** Small travel size bottles are easier to handle than full size shampoo and conditioner. Try refilling travel sizes to avoid dropping heavy, slippery bottles in the shower. (Submitted by Shawn Barnett)
- 3** The little tie closures on bread are impossible to handle! Try using a clothes pin instead to close the bag. (Submitted by Donna Roysdon)
- 4** Transfer things into plastic containers instead of glass - that way, if you drop them, you won't have to clean up glass too. (Submitted by Mary Mattison)
- 5** A 30" shoehorn can help you pull the door closed behind you when you're in a wheelchair. (Submitted by Ann Marker)
- 6** If/when your shower chair gets too slippery, cover the seat with a washcloth. (Submitted by Roxanne Summers)
- 7** Ankle weights can be strapped on to the bottom of your walker or rollator for a little weighted resistance if it's getting away from you too easily or tipping when you try to stand or walk. (Submitted by Teresa Bredberg)

Do you have any tips or tricks you've learned along the way that might help others with Ataxia?

We want to hear them!
Send your tips to stephanie@ataxia.org.

2018 NAF Annual Ataxia Conference (AAC) Schedule – Overview

WED
April 4

9:00am-5:00pm | NAF Registration | 5th Floor Registration 1

9:00am-5:00pm | Silent Auction Item Drop-off

2:00pm-4:30pm | Leadership and Fundraising Session

5:15pm-6:45pm | Research Poster Session

THUR
April 5

8:00am-5:00pm | NAF Registration | 5th Floor Registration 1

8:00am-5:00pm | Exhibitors/Activity Area

8:15am-9:15am | Continental Breakfast | Grand Ballroom E & F

8:30am-4:00pm | Silent Auction Item Drop-off

8:30am-5:00pm | Silent Auction Bidding

9:15am-12:15pm | General Sessions | Grand Ballroom Salon E & F

2:00pm-5:00pm | Birds of a Feather | See Conference Program

5:00pm | Meet & Greet Reception* | Grand Ballroom Salon E & F
**Light appetizers*

8:00am-4:00pm | NAF Registration | 5th Floor Registration 1

8:00am-4:00pm | Exhibitors/Activity Area

8:00am-9:00am | Continental Breakfast | Grand Ballroom E & F

8:30am-2:00pm | Silent Auction Bidding

9:00am-12:00pm | General Sessions | Grand Ballroom E & F

12:10p -12:30pm | NAF Member Business Meeting | Grand Ballroom Salon E & F

2:00pm-5:00pm | Birds of a Feather | See Conference Program

7:00pm | Banquet** | Grand Ballroom Salon A-F
*** Plated Meal and DJ*

FRI
April 6

Please Note: Due to circumstances beyond our control, this conference schedule is subject to change. Attending sessions is optional. There are no "official" breaks. Please review the schedule in advance to plan breaks for yourself as needed. If there are sessions of interest to you that you are not able to attend please request that those sessions be offered again on the conference survey.



APRIL 5-6, 2018 • PHILADELPHIA, PA

2018 NAF AAC Schedule - Details

Birds Of A Feather Sessions Overview

These small breakout groups are facilitated by experienced clinicians. Rather than presentations, they are interactive conversations that allow individuals to share concerns, ask questions, and discuss topics relevant to the group. Questions regarding Birds of a Feather sessions may be directed to Sue Hagen, NAF Patient and Research Services Director susan@ataxia.org or (763) 231-2742. Birds of a Feather Sessions will meet from 2 - 5 p.m. in various meeting rooms. Please check the conference program and hall signs for your specific group's location. Paid PCAs are welcome to attend the Birds of a Feather session with their client, but not required unless client requires it.

Attention Parents: Children under 12 years old should not attend a Birds of a Feather session. Birds of a Feather Sessions noted for attendees "under 30 years old" are not intended for those who are under 12 years old. Mature subject matter may be discussed.

Thursday

- SCA1
- SCA2
- SCA3
- SCA6
- SCA7
- All Other SCAs including SCAs 5,8, and DRPLA
- AOA
- Spouses/Partners without Ataxia

Friday

- Unknown with Family History, EA and Other Rare Recessive Ataxias
- Unknown without Family History, Sporadic, Gluten, and/or MSA
- Over 30 Years Old with Friedreich's Ataxia
- Under 30 Years Old with Ataxia
- Parents (Friedreich's Ataxia)
- Parents (Non-Friedreich's)
- Family Members Without Ataxia

Wednesday Session Descriptions:

Leadership and Fundraising Development Session Meeting: This session is for NAF Ambassadors, Chapter Presidents, Support Group Leaders, and Fundraiser Organizers. This session will provide resources and networking opportunities to those involved with providing support in their areas and raising awareness and funds to further NAF's mission. Contact lori@ataxia.org to attend this session.

Research Poster Session: This is a great opportunity for you to view research posters that are being presented at the 7th NAF Ataxia Investigators Meeting (AIM). Ataxia investigators will be present to answer questions about their posters and Ataxia research projects. Don't miss the opportunity to meet face-to-face with the Ataxia researchers from around the world.

Thursday, April 5, 2018 Detailed Schedule

Time	Session
9:15am	Welcome & Announcements - Camille Daglio, NAF AAC Chair
9:30am	NAF Update - Bill Sweeney, NAF President
10:00am	Clinical vs. Basic Science Research - Harry Orr, PhD and George (Chip) Wilmot, MD, PhD
10:30am	Living with Ataxia Moderator: Kyle Bryant Panelists: Jonas Cepkauskas, Cathy DeCrescenzo, and Linda Snider, MD <i>You are invited to submit topics or questions you would like discussed in this session. Submit your suggestions to lori@ataxia.org.</i>
11:15am	Barriers to Exercise - Jennifer Millar, MSPT, and Jennifer Keller, MSPT <i>You are invited to submit topics or questions you would like discussed in this session. Submit your suggestions to lori@ataxia.org.</i>
11:45am	Financial Planning - Kelly Piacenti, Assistant Vice President, MassMutual Special Care

Thursday Birds of a Feather Sessions: (2:00pm - 5:00 pm)

*The following groups have been designed for those who are affected with Ataxia:

SCA1: This Birds of a Feather are for those who have been diagnosed with SCA1
Facilitators: Dr. Orr, Dr. Öz and Dr. Wilmot

SCA 2: This Birds of a Feather are for those who have been diagnosed with SCA2
Facilitator: Dr. Rosenthal

SCA3: This Birds of a Feather are for those who have been diagnosed with SCA3
Facilitator: Dr. Paulson

SCA6: This Birds of a Feather are for those who have been diagnosed with SCA6
Facilitator: Dr. Shakkottai

SCA7: This Birds of a Feather are for those who have been diagnosed with SCA6
Facilitator: Dr. LaSpada

ALL Other SCAs (Including SCA 5 and SCA 8) & DRPLA: For this Birds of a Feather you need to have a diagnosis of SCA other than SCA 1, 2, 3, 6, 7 or DRPLA. If you do not have a diagnosis of hereditary Ataxia please attend the Unknown without Family History BOF session.
Facilitators: Dr. Ranum and Dr. Schmahmann

AOA: This Birds of a Feather is for those who have been diagnosed with AOA. Facilitator: Dr. Fogel

*The following group has been designed for non-affected family members:

Spouses & Partners Without Ataxia: This Birds of a Feather will be attended by spouses and partners to share with other spouses and partners their experiences and concerns. For the privacy of the issues talked about in this session we ask that those with ataxia attend the BOF sessions for Ataxians.
Facilitator: Donna DeLeno Neuworth, Health Educator and Amanda Gallagher, MA, CCC-SLP

Thursday Silent Auction Deadline: All items being donated for the Silent Auction are due in the Silent Auction room by Thursday, April 5 at 4pm.

Friday, April 6, 2018 Detailed Schedule

Time	Session
9:00am	FRDA and other childhood ataxias – David Lynch, MD, PhD
9:30am	Genetic Testing – You need to get tested: Here’s why – Jeremy Schmahmann, MD
10:00am	Ataxia Investigators Meeting (AIM) Highlights – Gülin Öz, PhD and Albert LaSpada, MD, PhD, FACMG
10:30am	Management of Ataxia Moderator: TBD Panelists: Amanda Gallagher, CCC-SLP, Jennifer Keller, PT, MS, and Liana Rosenthal, MD <i>You are invited to submit topics or questions you would like discussed in this session. Submit your suggestions to lori@ataxia.org.</i>
11:10am	Home Safety Based Modifications – Jessica Wilchinski, OTR/L and Marlena Casey, OTR/L, CLT
12:00pm	NAF Member Business Meeting - Bill Sweeney, NAF President

Friday Birds of a Feather Sessions: (2:00pm - 5:00 pm)

*The following groups have been designed for those who are affected with Ataxia:

Unknown With Family History, EA and Other Rare Recessives:

This Birds of a Feather is for those who have been diagnosed with an Unknown Type of Ataxia with Family History, Episodic Ataxia, or other rare recessive ataxias.
Facilitator: Dr. LaSpada

Unknown Without Family History – MSA, Sporadic & Gluten:

This Birds of a Feather are for those who have been diagnosed with an Unknown Type of Ataxia without Family History, including MSA, Sporadic, and Gluten Ataxia
Facilitators: Dr. Schmahmann and Jennifer Millar, DPT, NCS

Over Age 30 With Friedreich: This Birds of a Feather session is for those with Friedreich Ataxia that are over the age of 30. Facilitators: TBD, Dr. Wilmot, and Marlena Casey, OTR/L, CLT

Under Age 30 With Ataxia: This Birds of a Feather session will be attended by those with any type of Ataxia who are under the age of 30.
Facilitator: Dr. Fogel

*The following group has been designed for parents of children who are affected with ataxia:

Parents (Friedreich): For this Birds of a Feather group time will be used to listen and share experiences. This will be a powerful time for

everyone. The session will begin with identifying some expectations of the group members and addressing their issues/concerns.
Facilitator: Dr. Lynch

Parents (Non- Friedreich): This Birds of a Feather will be attended by parents whose child(ren) are affected by any form of Ataxia other than Friedreich’s Ataxia. For this Birds of a Feather group time will be used to listen and share experiences. This will be a powerful time for everyone.
Facilitators: Dr. Rosenthal and Jennifer Keller, PT, MS

* The following group has been designed for non-affected family members:

Family Members Without Ataxia (Other Than Parents, Spouses, or Partners): This Birds of a Feather will be attended by family members (siblings, children, etc.) of those with Ataxia to share experiences and concerns. For the privacy of the issues talked about in this session we ask that those with Ataxia attend the BOF sessions for Ataxians.
Facilitators: John Dyer, BS, MA and Jessica Wilchinski, OTR/L.

Friday Silent Auction Deadline: Winners MUST pick-up and pay for their items on Friday from 3-7pm.

Thursday and Friday Activity Area:

The Activity Area is in the Exhibitor Room. Persons under the age of 12 must be accompanied by a parent or guardian who is age 18 or older. Temporary NAF Tattoos, Coloring, Chair Stretching and Adaptive Crafts like decorating Ataxia Rocks and Planters will be available during Activity Area hours.

Adaptive Crafts: Get ready for the growing season by decorating your own planter! All supplies are provided while they last. Personalize your own Ataxia Rock to post on the Ataxia Rocks Facebook Page <https://www.facebook.com/groups/864677347039596/>. All supplies are provided while they last.

Nintendo Wii: An opportunity to observe and play the Nintendo Wii game system will be available Thursday and Friday during Activity Area hours. You can try out the Nintendo Wii game system for yourself and ask questions about the Nintendo Wii system. The Nintendo Wii system is being used around the world by those with limited movement abilities who want to stay active. Please limit your time on the Nintendo Wii system so that everyone interested in this product is provided the opportunity to try it.

Coloring: Coloring activities will be available during Activity Area hours. Coloring is a therapy recommended for handwriting. Information describing the benefits of coloring will be available.

Temporary Tattoos: Get your NAF Tattoo with NAF's new logo applied to wear throughout the conference.



Things to Know About ACC Registration

When: April 5-6, 2018

Where: Philadelphia Marriott
Downtown, 1201 Market Street,
Philadelphia, PA 19107

Register: Online at www.ataxia.org or by mail (registration form starting on page 48)

Cost:

Early Registration - Before February 13, 2018 - \$125/member or \$180/non-member
February 13, 2018 to March 30, 2018 - \$150/member or \$205 non-member
After March 30, 2018 (and at door - \$200/member or \$255/non-member

- Registration cost covers access to ALL areas of the conference: General sessions, small sessions, Birds of a Feather sessions, Thursday evening reception (light snacks), Friday banquet (plated dinner), Exhibit Hall.
- You're in control! Pick and choose which sessions or features you'd like to attend. Note: Registration cost does not change if you opt not to attend the reception or banquet.
- Conference Registration Cost DOES NOT include hotel or transportation.
- Travel Grants available for those in need that will reimburse up to \$400 of your travel costs. Applications due by January 6, 2018. Available on the 2018 AAC page at www.ataxia.org

Wanted: Those with SCA1 and SCA3

In early 2018, 20 study sites in the United States and 2 in Europe will be asking those with SCA1 or SCA3 whether they or any of their family members are willing to participate in an important study.

To be eligible for the study:

- 1.** You must be a member of a family with SCA1 or SCA3.
- 2.** You have a parent, a sibling(s) or a child(ren) who is (are) affected with SCA1 or SCA3 and you have no noticeable gait imbalance, hand clumsiness or slurred speech.
- 3.** You are between the ages of 18 to 65 years old.
- 4.** And you can walk independently without any support (that means no touching a wall, furniture, person, cane, walker or other assisting device).

It does not matter if you have had gene testing or not for SCA1 or SCA3. The research sites will provide free DNA testing. In addition, multiple members from the same family are welcome to participate.

For more information, enroll in the CoRDS Ataxia Patient Registry. By enrolling in the registry, when the details are available about the upcoming study for SCA 1 and SCA3, you will be notified and can make your own decision about whether to participate or not. It will be totally up to you. But if you don't enroll, you may not learn about this study and other studies for which you may qualify.

Go to Sanfordresearch.org, click on the Special Programs tab and select CoRDS from the drop-down menu. Follow the directions to enroll and if you have any questions or problems about enrollment, call Sanford directly at 1-877-658-9192.

If you want to learn more about the SCA 1 and SCA 3 study, please contact the National Ataxia Foundation. Sue Hagen, NAF's Patient and Research Services Director, will be happy to answer your questions. Send an email to susan@ataxia.org or call **763-231-2742**.

Don't Miss the Opportunity



Registration is now open for the 2018 AAC! We're headed to the wonderful city of Philadelphia and have a schedule packed full of great topics, fun activities, and renowned speakers for you. If you've never been to the conference before, prepare yourself for a two-day social and educational extravaganza for those affected by Ataxia like you've never seen! First-time attendees are often relieved to finally be in a place where they don't have to explain what Ataxia is. If you've been to the AAC before, we can't wait to see you again! Here are just a few highlights of the upcoming 2018 AAC:

Living with Ataxia Panel

Photo credit:
Rick Guidotti,
Positive Exposure



This year, we are joined by Kyle Bryant, Ride Ataxia Founder and Director.

He is an athlete, speaker, and advocate. Kyle was diagnosed with FA at age 17 and has since started one of the most successful campaigns for FA research "Ride Ataxia", is a co-host for the popular podcast series "Two Disabled Dudes", has completed numerous long distance bike rides, and has participated in a variety of forums as an advocate for persons with ataxia and treatment development. Kyle will moderate a discussion centered around living with Ataxia. Panelists include: Jonas Cepkauskas, Cathy DeCrescenzo, and Linda Snider, MD. This dynamic panel of people affected by Ataxia will discuss the topics that YOU want to hear about. WE NEED YOUR INPUT! Submit your questions or topic suggestions to lori@ataxia.org



A moderated Q&A panel a Q&A panel that will offer information about managing Ataxia from a medical perspective. Panelists include: Amanda Ghallagher, CCC-SLP, Jennifer Keller, PT, MS, and Liana Rosenthal, MD. This group of knowledgeable professionals will address the questions that you have about Ataxia care and treatment. Submit your questions or topic suggestions to susan@ataxia.org.

Management of Ataxia Panel

Friday to “Fight for Freedom”

Featured Highlights of the 2018 AAC

Friday Banquet



After two days of learning and networking, it's time to let loose! Join us for the Friday night banquet that features a plated dinner, award ceremony, and dance. Your registration fee includes the meal – cash bar will also be available. It's a night of fun and great conversation that you won't want to miss!

Research Poster Session



Every other year, world-leading Ataxia scientists and clinicians meet before the

Annual Ataxia Conference to discuss Ataxia research and care. They work together to accelerate the pace of Ataxia research, better understand the disease, and discuss developing therapies. More than 100 professionals attend – and you get the benefit! On Wednesday, April 4, 2018 you will get the opportunity to meet many of those researchers in person at the Research Poster Session. Introduce yourself, ask questions, or just browse the posters about their wide-ranging research projects.

AAC Exhibitors



Step into the AAC Exhibitor hall

to meet our various vendors and informational booths. Last year our attendees even had the opportunity to make some money by visiting some of the exhibitors and participating in research/questionnaires! With booths ranging from pharmaceutical companies and assistive device product demos, to Ataxia clinics and rare disease patient advocacy groups – there is lots of info for any interest.

Location



We'll be gathering at the Philadelphia Marriott Downtown,

located just 10 miles from the Philadelphia International Airport in the heart of downtown Philadelphia. When you aren't learning from Ataxia researchers or socializing with other attendees you can explore

the home of the Philly Cheesesteak or get some much-needed rest in the comfy accommodations. Check out visitphilly.com for tourist information.

Philadelphia Marriott Downtown – Group Rate Starting at \$189+tax
1201 Market Street • Philadelphia, PA 19107 • Reservations: 877-901-6632
(Group Rate Password: National Ataxia Foundation) or
<https://aws.passkey.com/go/NATIONALATAXIAaac>



**HARRY
ORR, PHD**



**GEORGE "CHIP"
WILMOT, MD, PHD**



NAF'S FIRST EVER DEBATE-STYLE SHOWDOWN! CLINICAL VS. BASIC SCIENCE RESEARCH

As we celebrate 2018 AAC by “Fighting for Freedom,” we’ll watch Dr. Harry Orr and Dr. Chip Wilmot duke it out in a debate over the best approach to Ataxia research. Is it better to focus on clinical practices and treatments? Or focus on understanding the basic science that causes Ataxia in the first place? We’ll watch a few brilliant minds wrestle each other with words to prove their points. You be the judge!

Harry Orr, PhD directs the Institute for Translational Neuroscience and is the Tulloch Professor of Genetics in the Department of Laboratory Medicine and Pathology at the University of Minnesota Medical School. Dr. Orr received a BA degree from Oakland University in Rochester, Michigan. He earned his PhD in neurobiology at Washington University, St. Louis, Missouri and completed a Research Fellowship at Harvard University. Dr. Orr is known as the researcher who, along with Dr. Huda Zoghbi, found the first gene for ataxia, now known as SCA1. Dr. Orr’s research program is focused on the molecular genetics of mammalian development and neurodegenerative diseases. He is a published author of more than 120 articles, many on the genetics of ataxia. Dr. Orr is a member of the National Ataxia Foundation’s Board of Directors and Research Director on NAF’s Medical and Research Advisory Board.

George “Chip” Wilmot III, MD, PhD received his MD, PhD from the University of Michigan, did a neurology residency at Emory University, and then remained at Emory as faculty in the Department of Neurology. Although trained in basic science and initially focusing his research on mechanisms of axonal stability and regeneration, Dr. Wilmot is currently most active in clinical research in Ataxia. He is a member and past leader of the Cooperative Ataxia Group, a member of the Collaborative Clinical Research network in Friedreich’s Ataxia. Dr. Wilmot is a member of NAF’s Medical Research Advisory Board.

NAF National Ataxia
Foundation

FIGHTING *for* FREEDOM

ANNUAL ATAXIA CONFERENCE
2018

APRIL 5-6, 2018 • PHILADELPHIA, PA

CHECK OUT SOME OTHER SPEAKERS THAT WILL BE PRESENTING AT 2018 AAC!



Gülin Öz, PhD is a brain imaging scientist who specializes in magnetic resonance spectroscopy (MRS). She graduated from Bosphorus University in Istanbul, Turkey with BS degrees in Physics and Chemistry and obtained her PhD in Biochemistry at the University of Minnesota. She continued with postdoctoral training at the Center for Magnetic Resonance Research at the University of Minnesota where she joined the faculty in 2006. Dr. Öz's research focuses on the application of

MRS techniques to detect chemical changes in the cerebellum in ataxias. MRS non-invasively measures levels of many brain chemicals including neurotransmitters and antioxidants. Such information can facilitate early detection of neurodegeneration and provide an objective means to monitor disease progression and response to therapies. Dr. Gulin Oz, with the 2018 AIM Steering Committee, has developed the 7th Ataxia Investigators Meeting which will draw researchers from around the world. Her leadership has been instrumental in making this premier ataxia research meeting an opportunity to bring young investigators into the field as well as provide a world-class agenda of speakers.



Kelly Piacenti, MA is an Assistant Vice President with MassMutual, based in Somerset, New Jersey. In this role she is responsible for the MassMutual Special Care program which includes over six hundred Special Care Planners. Kelly serves on the National Board of Directors for The Arc, a national non-profit organization advocating for people with disabilities. She also serves on the Advisory Board for The Academy of Special Needs Planners, as well as The American College

MassMutual Center for Special Needs. As a mother of a child with special needs, Kelly possesses the knowledge, insight and empathy to act as a mentor and resource for families facing similar challenges.

Support Group News



Northern California Ataxia Support Group (NCASG)

Submitted by Shirley Hanks

Nancy Cai, Coordinator of clinical trials at UCSF, presented at our July 8th NCASG meeting. She works with Dr. Alexander Nelson and Dr. Michael Gerchwind at UCSF. Her presentation was mainly on the work being done on the drug, Riluzole. The clinical trial is for BHV-4157, a prodrug of Riluzole, which is available on the market but may affect the liver. Through this clinical trial, they're testing if the new drug (similar to Riluzole, but with different added compounds/chemicals) will be safer.

It is being developed to help with movement and balance issues. It may help slow the progression of Ataxia. Riluzole should help with all SCA's. It appears to be a safe drug and does not seem to have any bad side effects. If this clinical trial works, the results should be known later in 2017. Before approval a lot of analyses is done. The SARA test for Ataxia patients is done measuring effects on physical movements. Lab data of Ataxia patients is taken into account. The FDA comes to UCSF and does its questioning. By the end of 2018 results will show if this is a drug for the market.



Chesapeake Chapter and the JHU Ataxia Center Support Group

Submitted by Carolyn Davis

The Chesapeake Chapter of the National Ataxia Foundation joined with the Johns Hopkins University Ataxia Center to host a meeting held September 23rd and attended by over fifty people affected by Ataxia. Donna DeLeno

Neuworth, the Ataxia Center Health Educator, secured a hall for our meeting at the Unitarian Universalist church in Rockville, Maryland. Following Donna's welcome, all participants were asked to introduce themselves to give us a sense of why people were there. Carolyn Davis, President of the Chesapeake Chapter, then introduced Sue Hagen, NAF's Patient and Research Services Director and our featured speaker. We appreciated her coming from Minnesota to speak on "Clinical Trial Readiness: Moving Ataxia Research into Treatment Discoveries."

Sue led us through a brief history of how research has been accelerated through collaboration of researchers and clinicians with a common goal and how funding and patient participation are critical to moving toward clinical trials. Joining the CoRDS Registry was stressed as an important piece to have in place as clinical trials are anticipated.

Following Sue's presentation, Ann Fishman, Research Coordinator at the Ataxia Center at Johns Hopkins, joined Donna to highlight research opportunities in which those with ataxia could participate locally.

The meeting concluded with lunch, offering an opportunity to renew old friendships and make new ones.



Chesapeake Chapter Ataxia Support Group



India Ataxia Support Group (SAMAG)

Submitted by Chandu George

Hello all, want to share that I had been nominated to “Rare Champion of Hope”-2017

Nominee by Global Genes in California. Though I did not make the final cut, I was appreciated for my work on raising awareness on Ataxia in Indian society. As a token of honor, I was sent a Letter of Appreciation and a beautiful Bookmark. I would like to dedicate this achievement to IAAD-September 25th. A New Day with new beginnings to positively look forward for a bright future. Lets all raise Ataxia Awareness for an Ataxia-free world. Thank you all!



Chandu George



Central PA Support Group

Submitted by Michael Cammer

At our last meeting in October we had a “let’s just talk” meeting! We usually have a speaker and over the past couple of years have had some pretty awesome and engaging speakers, but this time we just sat around the conference table and had a wonderful group discussion. We had our agenda and discussed several fundraising events that we raised over \$12,000 for the NAF as a group!

We discussed our Walk n’ Roll for next May. We started the “Manny, Mike and Mary, Ride to Cure Ataxia” this past May, but thought it would be better to have a Walk n’ Roll shortly after the conference in Philadelphia to be able to keep people engaged, especially for the ones attending their first conference.

We recapped our IADD event at the Lancaster Barnstormers baseball game on September 9th. This summer and fall has been very odd alternating between “hot and dry” weeks and “cool and damp” weeks. The day of the game was dry, but we hit a cool evening! It dipped down into the 40’s more like late season high school football weather, but that didn’t deter people as we had 28 in attendance!! It was definitely an awesome event and we look forward to next season maybe even adding a 2nd game.

We talked about the different research opportunities and the importance of CoRDS enrollment. There is just under 1,300 people enrolled in CoRDS and we need to increase that number! The NAF has an outstanding network of Ataxia researchers, but if we are to find a treatment and eventual cure for Ataxia, we need to let Pharma and researchers know we are out there by increasing the number of CoRDS enrollees!!! I was at the Life Sciences Future conference in Philadelphia last month and they stressed Patient Registries and Family History Studies as key drivers as to what research they will invest their time and resources in. So, in a nutshell, if you enroll they will come!

We discussed the Annual Ataxia Conference in Philadelphia next spring and the importance of our group members attending and volunteering. Our visibility will help ensure the success of the conference and grow the support group and the NAF!

We finished up with our wonderful “let’s just talk” discussion around the table with donuts! I sure hope it wasn’t the donuts that made it an awesome meeting!!!



Central PA Ataxia Support Group



North Carolina Ataxia Support Group

Submitted by Ron Smith

We had our North Carolina Ataxia Support Group meeting on Saturday, October 28. Our speaker was Dr. Adam Jacks, associate professor in the Speech and Hearing division of the Department of Allied Health Sciences at UNC-CH. Dr. Jacks’s training background includes work in communication sciences and disorders at the University of Texas at Austin, postdoctoral research in behavioral neuroimaging and clinical experience in long term acute care and outpatient rehabilitation settings. Dr. Jacks focused his talk on “Speech and swallowing changes with Ataxia.” He shared with us practical tips to improve speech and swallowing, along with advice for caregivers.



North Carolina Chapter Ataxia Support Group



Tampa Bay Ataxia Support Group (Fall Update)

Submitted by Jannete Colon

The Tampa Bay Ataxia Support group met on May 20, 2017 at the Morsani Center at USF. Our guest speaker was Shelly Adams, an Occupational Therapist. She showed us some exercises using theraputty, a resistive hand exercise material that is used in occupational material to increase our strength and coordination. She gave theraputty for each member of our group to practice with at home. She also showed us some Stepwise Techniques using weighted utensils and weighted pens to teach us how to stabilize our wrists and hands.



Tampa Bay Ataxia Support Group

Tampa Bay Ataxia Support Group (Winter Update)

Submitted by Lisa Cole

Our Support Group Meeting was on Saturday October 7th. Even though we did not have a guest speaker that day, we still enjoyed meeting new people and watched several videos when the internet cooperated. Also, painted rocks were available to take. See you in December.

Our next meeting is on Saturday December 9th plus we will have a joint Ataxia Support Group Meeting with Tampa Bay Support Group in Orlando on Saturday Dec 2nd. It will be a Meet & Greet and we will have Dr. Subramony Skype that day.



Tampa Bay Ataxia Support Group



Tri-State Ataxia Support Group

Submitted by Kathleen Gingerelli

The Tri State Support Group held our meeting on 9/14/17 in NYC. We used this meeting to speak mostly about our 2nd Walk 'n' Roll Event that was on 8/25/17 at Liberty State Park in Jersey City, NJ. I told everyone how much of a success our walk was not only raising almost \$39K but spreading the word out to many people who formed teams & participated in the walk. I spoke about how much there is to do and let everyone know that volunteers are needed for those not interested in walking but would love to be involved. Our date for the 2018 Walk 'n' Roll Event is August 25, 2018 at the same location...Liberty State Park in Jersey City, NJ.

A member asked about the vitamins & supplements you take and any positive effects. Everyone compared notes as to what they take and why. As always, the importance of exercise was talked about and how it's hard to keep the motivation going especially with the colder months coming. The buddy system was recommended as it's a plus to have someone push you when needed.

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 NAF. Thank you.

DO YOU HAVE HEREDITARY ATAXIA?

The Masters in Genetic Counseling Program at the University of Maryland School of Medicine is conducting a new research study to better understand how people communicate with their family members about their condition.

We need your help and want to hear **your** story!

Participate from the comfort of your home

The study includes just a short survey and a phone interview.

If you are interested in learning more about this study, please follow the link below:

https://umaryland.az1.qualtrics.com/jfe/form/SV_4NoQNDUdT70qCih

You can also get information about the study by contacting:

Shannan Dixon, MS, CGC
SDelany@som.umaryland.edu
410-706-4713

We hope to hear from you!



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 an NAF ambassador. If you are interested in these volunteer positions please contact Lori Shogren of the NAF staff at lori@ataxia.org or (763) 553-0020.

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

NAF Staff Directory:

Joel Sutherland, Executive Director	(763) 231-2748 joel@ataxia.org
Sue Hagen, Patient and Research Services Director	(763) 231-2742 susan@ataxia.org

Lori Shogren, Community Program and Service Director	(763) 231-2743 lori@ataxia.org
--	--

Stephanie Lucas, Communications Manager	(763) 231-2744 stephanie@ataxia.org
---	--

Jan Stewart, Office Assistant	(763) 231-2746 jan@ataxia.org
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Social Networks

 NAF Facebook Page
www.facebook.com/ataxiafoundation/

NAF Facebook Group
www.facebook.com/groups/NAFmail

 NAF YouTube Channel
www.youtube.com/user/NatlAtaxiaFound

 NAF Twitter
www.twitter.com/NAF_Ataxia

 NAF LinkedIn
www.linkedin.com/company/nationalataxiafoundation

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.

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 Support Group Calendar of Events

Alabama

Alabama Support Group Leader

Becky Donnelly-Hover, AL

(205) 987-2883

E-mail: donnelly6132b@aol.com

www.ataxia.org/chapters/Birmingham/

Facebook Page: <https://www.facebook.com/alataxia/>

Facebook Group: <https://www.facebook.com/groups/154027955194806/>

Ambassador

Dianne Blain Williamson-Huntsville-AL

(256) 429-9092 or (256) 520-4858

E-mail: diannebw@aol.com

www.ataxia.org/chapters/DianneWilliamson/

Arizona

Phoenix Area Support Group Leaders

Angela Li-Peoria, AZ

(847) 505-4325

E-mail: angelalii010@gmail.com

Mary Fuchs- Casa Grande, AZ

(480) 212-6425

E-mail: mary11115@msn.com

Facebook Group:

www.facebook.com/groups/arizonaataxia/

www.ataxia.org/chapters/Phoenix/

Ambassador

Bart Beck-Tucson, AZ

(520) 885-8326

E-mail: bbeck15@cox.net

www.ataxia.org/chapters/Tucson/

Arkansas

Ambassadors

Judy and David King-Hot Springs Village, AR

E-mail: drkingpd@suddenlink.net

www.ataxia.org/chapters/JudyKing/

California

Los Angeles Area Support Group Leaders

Lora Morn-Santa Monica, CA

E-mail: loramorn@gmail.com

www.ataxia.org/chapters/LosAngeles/

Harvey Kahn-Whittier, CA

(562) 789-5776

E-mail: jkhk@aol.com

N. California Area Support Group Leaders

Brian Wong - Santa Clara, CA

Blwong7@gmail.com

Fernando & Rocy Wu-Danville, CA

fwu@pacbell.net

Support Group Website: <http://norcalataxia.org>

Facebook Group: <https://www.facebook.com/groups/592006361008986/>

Sacramento Area Support Group Leader

Teresa Bredberg-Sacramento, CA

E-mail: tbredberg@sbcglobal.net

S.G. Website: norcalataxia.org

Facebook Group:

<https://www.facebook.com/groups/592006361008986/>

www.ataxia.org/chapters/NorthernCalifornia/

Secondary Contact: Darrell Owens - Davis, CA

916-215-2686

Email: droopydog36@hotmail.com

Orange County Area Support Group Leaders

Cindy De Mint-Yorba Linda, CA

(714) 970-1191

E-mail: cindyocataxia@gmail.com

Daniel Navar-Montebello, CA

(323) 788-7751

E-mail: danieln27@gmail.com

S.G. Website: <http://orangecountyataxia.org/>

www.ataxia.org/chapters/OrangeCounty/

Facebook Group: <https://www.facebook.com/groups/1980393985511432>

Palo Alto Support Group Leaders

Victoria Tanoury, RN, CNRN - Stanford, CA

(650) 736-1399

E-mail: vtanoury@stanfordhealthcare.org

Sarah Kahn-Stanford, CA

E-mail: skahn@stanfordhealth.org

www.ataxia.org/chapters/PaloAlto/

Ambassadors

Deborah Levi-Morro Bay, CA

(805) 407-0437

E-mail: Debbielevi213@yahoo.com

www.ataxia.org/chapters/CentralCA/

Deborah Omictin-Hayward, CA
(510) 783-3190
E-mail: rsisbig@aol.com
www.ataxia.org/chapters/DeborahO/

Martha Elliott-Camarillo, CA
(805) 987-2490
E-mail: DOCElliott268@gmail.com
www.ataxia.org/chapters/Camarillo/

Colorado

Greater Denver Area Support Group Leader
Charlotte DePew-Aurora, CO
(720) 379-6887
E-mail: cldepew77@comcast.net
Facebook Group: www.facebook.com/groups/denverataxia2011/
www.ataxia.org/chapters/Denver/

Connecticut

Tri-State Support Group Leader
Kathy Gingerelli-Parsippany, NJ
(201) 681-7639
E-mail: kgingerelli@msn.com
www.ataxia.org/chapters/Tri-State/

Delaware

Delaware Support Group Leaders
Joe & Cathy DeCrescenzo-Newark, DE
(302) 369-9287
E-mail: jdecr26@verizon.net
E-mail: cdecres@verizon.net
www.ataxia.org/chapters/DeCrescenzo/

Florida

Tampa Bay Support Group Leader
Darlene Harris -Tampa, FL
(813) 431-2859
E-mail: Msdee004@gmail.com
www.ataxia.org/chapters/TampaBay/
Facebook Group: <https://www.facebook.com/groups/204933669913963/>

Treasure Coast Support Group Leader
Lisa Cole- Port St. Lucie, FL
(772) 370-3041
E-mail: lisacoleataxia@gmail.com
www.ataxia.org/chapters/PortStLucie/
<https://www.floridatreasurecoastataxiasupportgroup.club/>

Facebook Group: <https://www.facebook.com/groups/572410932959895/>

Ambassadors

Carol Neff-Edgewater, FL
(386) 424-4192
E-mail: cmneff2@yahoo.com
www.ataxia.org/chapters/Edgewater/

Jose Fernandez de Castro - Plantation, FL
954-864-1436
E-mail: jfcmv@yahoo.com

Meghan McBrearty-Tallahassee, FL
(850) 524-9060
E-mail: megra10@hotmail.com
www.ataxia.org/chapters/McBrearty/

Georgia

Greater Atlanta Support Group Leaders
Dave Zilles-Atlanta, GA
(678) 596-6751
E-mail: dzilles@earthlink.net

Greg Rooks-Atlanta, GA
(404) 822-7451
E-mail: rooksgj@yahoo.com

Lealan Sims -Hilton Head Island, SC
(678) 234-6600
E-mail: Lealan@mac.com
S.G. E-Mail: atlantaataxia@yahoo.com
Facebook Group:
www.facebook.com/groups/317380459539/
www.ataxia.org/chapters/Atlanta/

Ambassador

Kristie Adams-Savannah, GA
E-mail: opal1011@comcast.net
www.ataxia.org/chapters/KristieAdams/

Illinois

Chi-Town Friendship Group Leader
Jonas Cepkauskas- Matteson, IL
(708) 381-5555
E-mail: Jonas@fightataxia.org
www.ataxia.org/chapters/Chicago/

Chicago Metro Friendship Group Leader

Christopher (Topher) Marsh-Chicago, IL

(312) 662-1127

E-mail: 512crockett@gmail.com

www.ataxia.org/chapters/ChicagoMetro/

Ambassador

Elaine Darte-Coffeen, IL

(618) 397-3259

E-mail: elainedarte@yahoo.com

www.ataxia.org/chapters/SouthernIllinois/

Indiana

Indiana Support Group Leader

Cheryl (Cheri) Bearman-Hoagland, IN

(260) 452-6231

E-mail: cheribearman@gmail.com

www.ataxia.org/chapters/Indiana/

Iowa

Ambassador

Emily Medina-West Des Moines, IA

(515) 727-8713

E-mail: emily061578@yahoo.com

Facebook Group:

www.facebook.com/groups/107944351294/

www.ataxia.org/chapters/EmilyMedina/

Kansas

Ambassador

Jalean Retzlaff-Park City, KS

(316) 303-2351

E-Mail: jlr trolls@yahoo.com

www.ataxia.org/chapters/Retzlaff/

Kentucky

Ambassador

Janice Johnson-Brownsville, KY

(270) 597-3854

www.ataxia.org/chapters/JaniceJohnson/

Jennifer Mueller-Lexington, KY

(859) 554-5939

E-mail: jenmu@yahoo.com

Maine

Maine Support Group Leader

Alan and Paula Nadeau-Belgrade, ME

E-mail: psn92871@roadrunner.com

www.ataxia.org/chapters/Maine/

Maryland

Chesapeake Chapter President

Carolyn Davis-Vienna, VA

(703) 759-2008

E-mail: ccnafpres@gmail.com

www.ataxia.org/chapters/Chesapeake/

Mid-Atlantic Social Support Group Leader

Donna DeLeno Neuworth, Ataxia Clinic Health Educator

(410) 616-2811

Lutherville, MD

E-Mail: ddeleno1@jhmi.edu

www.ataxia.org/chapters/JHASG/

Ambassador

Karen DeVito-Frederick, MD

(301) 682-5386

E-mail: karen.devito@yahoo.com

www.ataxia.org/chapters/KarenRosenberger/

Massachusetts

Boston Area Support Group Leaders

Denise Mindle-South Dartmouth, MA

508-369-7925

John Mauro-Auburn, MA

(508) 736-6084

Email: john@ataxia.org

S.G. E-mail: ngataxia@outlook.com

www.ataxia.org/chapters/Boston/

Central Ma Support Group Leaders

John and Dana Mauro-Auburn, MA

(508) 736-6084

Email: john@ataxia.org

Email: danamauro63@msn.com

Facebook Group:

www.facebook.com/ataxiadidyouknow?ref=hl

www.ataxia.org/chapters/CentralMA/

Michigan

Detroit Area Support Group Leader

Tanya Tunstull-Detroit, MI

(313) 736-2827

E-mail: tinyt48221@gmail.com

www.ataxia.org/chapters/Detroit/

Western Michigan Support Group Leader

Lynn K. Ball-Grand Rapids, MI

(269) 330-1975

E-mail: lynnkball@aol.com

www.ataxia.org/chapters/LynnBall/

Minnesota

Central MN Support Group Leader
Marsha Binnebose-St. Cloud, MN
(320) 248-9851
E-mail: mbinnebose@hotmail.com
www.ataxia.org/chapters/StCloud/

Twin Cities Ataxia Social Group

Lenore Healey Schultz-Minneapolis, MN
(612) 724-3784
E-mail: schultz.lenore@yahoo.com

Maryann Sweeney-Minneapolis, MN
(612) 924-4947
E-mail: maryann.sween@gmail.com
www.ataxia.org/chapters/TwinCities/

Ambassadors

Julie Schuur-Luverne, MN
(507) 283-2555
E-mail: jschuur@vastbb.net
www.ataxia.org/chapters/JulieSchuur/
Lori Goetzman-Rochester, MN
(507) 990-4506
E-mail: logoetz@gmail.com
www.ataxia.org/chapters/LoriGoetzman/

Mississippi

Mississippi Chapter President
Camille Daglio-Hattiesburg, MS
E-mail: daglio1@bellsouth.net
www.ataxia.org/chapters/Mississippi/

Missouri

Kansas City Support Group Leaders
Stephanie Wilkins
Lee's Summit, MO
(816) 623-3318
E-Mail: fwilkins@yahoo.com
Laurie Colby
Kansas City, MO
(816) 429-6456
Lcolby61@gmail.com
www.ataxia.org/chapters/KansasCity/

St. Louis Area Support Group Leader

Shannon Dunphy-Lazo - St. Louis, MO-ADD
(202) 306-22738
Shan_d@hotmail.com
www.ataxia.org/chapters/StLouis/

Ambassadors

Roger Cooley-Columbia, MO
(573) 474-7232 before noon
E-mail: rogercooley@mediacombb.net
www.ataxia.org/chapters/RogerCooley/

Nebraska

Nebraska Ataxia Support Group Leader
Linda Snider-Omaha, NE
(402) 212-3060
E-mail: lindasnider@cox.net
www.ataxia.org/chapters/Omaha/

Nevada

Ambassador
Debbie Grant-Las Vegas, NV
(770) 885-3092
E-mail: grantgirl2004@aol.com
<http://www.ataxia.org/chapters/Nevada/>

New Hampshire

New Hampshire Support Group Leader
Jill Porter-Manchester, NH
(603) 626-0129
E-mail: jilleporter@comcast.net
<http://www.ataxia.org/chapters/Manchester>

New Jersey

Tri-State Support Group Leader
Kathy Gingerelli-Parsippany, NJ
(201) 681-7639
E-mail: kgingerelli@msn.com
www.ataxia.org/chapters/Tri-State/

New York

Tri-State Support Group Leader
Kathy Gingerelli-Parsippany, NJ
(201) 681-7639
E-mail: kgingerelli@msn.com
www.ataxia.org/chapters/Tri-State/

North Carolina

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/
Facebook Group: <https://www.facebook.com/groups/539411309575761/>

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/

Cleveland Area Support Group Leader

Carmen Pieragastini-Willowick, OH

(216) 272-5588

E-mail: willowpier@roadrunner.com

www.ataxia.org/chapters/Cleveland/

Oklahoma

Central Oklahoma Ataxia Support Leader

Carrie Stanley

(405) 735-0037

E-mail: cdstanley1977@gmail.com

Facebook Group: <https://www.facebook.com/groups/421890291503549/>

[permalink/428669084159003](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/

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/

Western PA Support Group Leaders

Ed Schwartz- McMurray, PA

(724) 941-2210

E-mail: eds@ataxia.org

Facebook Group: www.facebook.com/wpaataxia

nafwesternpasupportchapter.weebly.com/

www.ataxia.org/chapters/SouthPark/

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/

South Carolina

Ambassador

Brad Forth - Greenville, SC

(864) 415-8147

E-mail: bradf@photoforth.com

www.ataxia.org/chapters/Greenville/

South Dakota

Ambassador

Mary Beth Farley - Sioux Falls, SD

(605) 941-2913

E-mail: englishteacher1116@gmail.com

Facebook Group: <https://www.facebook.com/groups/1462298470518329/about/>

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/

Texas

Greater Houston Area Support Group Leader

Dave Cantrell - Montgomery, TX

936-588-5179; Cell: 936-206-1504

E-mail: dcantr7358@aol.com

Facebook Group:

<https://www.facebook.com/groups/ataxia.houston/>

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/

Ambassadors

Dana LeBlanc - Orange, TX

(409) 883-5570

E-mail: tilessal@yahoo.com

www.ataxia.org/chapters/GoldenTriangle/

Debra Whitcomb - El Paso, TX

(915) 329-0721

E-mail: debrawhitcomb@hotmail.com

www.ataxia.org/chapters/Whitcomb/

Utah

Utah Support Group Leaders

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/

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DISABILITY.GOV CAN HELP YOU

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Disability Resources

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

Virginia

Chesapeake Chapter President

Carolyn Davis -Vienna, VA

(703) 759-2008

E-mail: ccnafpres@gmail.com

www.ataxia.org/chapters/Chesapeake/

Washington

Western Washington Support Group Leader

Sherry McLaughlin

(360) 344-2445

E-mail: ccherilynmc@yahoo.com

www.ataxia.org/chapters/Olympic/

Ambassador

Linda Jacoy - Spokane, WA

(509) 482-8501

E-mail: linda4727@hotmail.com

www.ataxia.org/chapters/Spokane/

Wisconsin

Wisconsin Support Group Leader

Kory Macy - Madison, WI

(608) 628-2700

E-mail: kstab77@yahoo.com

www.ataxia.org/chapters/Wisconsin/

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/

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: <https://www.facebook.com/groups/135999194491/>

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

Pakistan

Ambassador

Sajjad Haider - Karachi, Pakistan

0092-(300) 828-1784

E-mail: sajjadhaiderb@hotmail.com

2017/18

ATAXIA SUPPORT GROUP 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

Wednesday, December 13, 2017

Willamette Valley Ataxia Support Group Meeting - Albany Location

Time: 11:30 am - 1:00 pm

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

More Info: Jason Wolfer at 503-502-2633 or wolferjason@gmail.com

Saturday, December 16, 2017

Twin Cities Ataxia Social Group Meeting

Time: 10:00 am - 12:00 pm

Location: Langton Place, 1910 W. CTY. RD. D., Roseville, MN 55112

Details: Family and friends of an afflicted individual are always welcome! We meet on the third Saturday of every month. Please join us, and make new connections!

More Info: Lenore Healey Schultz at 612-724-3784 or schultz.lenore@yahoo.com

Nebraska Ataxia Support Group Meeting

Time: 11:00 am - 1:00 pm

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

More Info: Linda Snider at 402-212-3060 or lindasnider@cox.net

Western Washington Ataxia Support Group Holiday Party

Time: 11:30 am - 2:30 pm

Location: Madison Assisted Living Center, 12215 NE 128th Street, Kirkland, WA 98034

Details: Please bring a potluck item. Beverages will be provided.

More Info: Sherry McLaughlin at ccherilynmc@yahoo.com

Sacramento Area Ataxia Support Group Meeting

Time: 1:00 pm - 4:00 pm

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

Details: We meet on the third Saturday of each month.

More Info: Teresa Bredberg at 916-215-2686 or tbredberg@sbcglobal.net

Saturday, January 6, 2018

New Hampshire Annual Luncheon

Time: 11:30 am - 1:30 pm

Location: Fratello's Italian Grill, 155 Dow Street, Manchester, NH 03101

More info: Jill Porter at 603-626-0129 or jilleporter@comcast.net

Sunday, January 7, 2018

Willamette Valley Ataxia Support Group Meeting - Portland Location

Time: 3:00 pm - 4:30 pm

Location: Capitol Hill Library, 10723 SW Capitol Hwy, Portland, OR 97219

Details: At this meeting, we will have the distinct pleasure to Skype with Dr. Perlman. She is one of the leading Neurologists in the field of Ataxia and is located in San Francisco will be discussing current medication treatment and upcoming drug trials. This is a great opportunity for us to hear the latest on this disease and it is a chance that I hope many of you will be able to take advantage of.

More Info: Jason Wolfer at 503-502-2633 or wolferjason@gmail.com

Saturday, January 13, 2018

Central Minnesota Ataxia Support Group Meeting

Time: 9:45 am - 11:45 am

Location: Harvest Bank, 24952 County Rd 7, St. Cloud, 56301

More Info: Marsha Binnebose at 320-248-9851 or mbinnebose@hotmail.com

North Texas Ataxia Support Group Meeting

Time: 10:00 am - 12:00 pm

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

Details: There is lots of parking and it is handicap accessible. The meeting room is in a separate bldg from the church.

More Info: David Henry at rcheve11e@sbcglobal.net

Indiana Ataxia Support Group Meeting

Time: 11:00 am - 2:00 pm

Location: St. Vincent Fishers Hospital, 13861 Olio Rd, Fishers, IN 46037

Details: Join our support group for Ataxians and families. Bring something to share for lunch plus your own drink. Paper goods supplied. We will meet in Conference Room #A & B (Park & enter at entrance One - follow the hallway to the right). Please RSVP.

More Info: Amy Draves: 765-610-2866 or

amy4kids@msn.com | Teresa Cocco: 317-439-2512 or tcocco12@gmail.com

St. Louis Ataxia Support Group Meeting

Time: 11:00 am - 1:00 pm

Location: The Center for Advanced Medicine, 4921 Parkview Place, St Louis, MO

Details: We meet the second Saturday of every month at The Center for Advanced Medicine on the 3rd Floor in Conference Room 1.

More Info: Shannon Dunphy Lazo at 202-306-2738 or shan_d@hotmail.com

Central PA Ataxia Support Group Meeting

Time: 11:00 am - 1:00 pm

Location: Penn State Hershey Medical Center, 30 Hope Drive - Entrance A - Room 1710, Hershey, PA

Details: Facebook Group: <https://www.facebook.com/groups/1475283086068548/>

More Info: Michael Cammer at 610-873-1852 or michael.cammer62@hotmail.com

Northern CA Ataxia Support Group Meeting

Time: 11:00 am - 3:00 pm

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

Details: For more information or to be added to this group's mailing list please contact Brian Wong.

More info: Brian Wong at blwong7@gmail.com

Saturday, January 20, 2018

Twin Cities Ataxia Social Group Meeting

Time: 10:00 am - 12:00 pm

Location: Langton Place, 1910 W. CTY. RD. D., Roseville, MN 55112

Details: Family and friends of an afflicted individual are always welcome! We meet on the third Saturday of every month. Please join us, and make new connections!

More info: Lenore Healey Schultz at 612-724-3784 or schultz.lenore@yahoo.com

Denver Area Ataxia Support Group Meeting

Time: 1:00 pm - 4:00 pm

Location: Swedish Medical Center, 2nd Floor Conference Rooms, 501 E Hampden Ave, Englewood, CO 80113

More info: Charlotte DePew at 720-379-6887 or cldepew77@comcast.net

Sacramento Ataxia Support Group Meeting

Time: 1:00 pm - 3:00 pm

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

Details: We meet on the third Saturday of each month. For more information or to be added to this group's mailing list contact Teresa Bredberg.

More info: Teresa Bredberg at 916-215-2686 or tbredberg@sbcglobal.net

Sunday, January 21, 2018

Greater Houston Ataxia Support Group Meeting

Time: 2:00 pm - 4:00 pm

Location: Methodist Hospital - Sugar Land, 16655 Southwest Freeway, Sugar Land, TX 77479

Details: For more information or to be added to the mailing list for this group contact Dave Cantrell.

More info: Dave Cantrell at Home: 936-588-5179, Cell: 936-206-1504, E-mail: dcantr7358@aol.com

Saturday, January 27, 2018

Los Angeles Ataxia Support Group Meeting

Time: 2:00 pm - 4:00 pm

Location: Disability Community Resource Center, 12901 Venice Blvd, Los Angeles, CA 90066

More info: Lora Morn at lloramorn@gmail.com or Harvey Kahn at 562-686-9720

Saturday, February 10, 2018

Central Minnesota Ataxia Support Group Meeting

Time: 9:45 am - 11:45 am

Location: Harvest Bank, 24952 County Rd 7, St. Cloud, 56301

More info: Marsha Binnebose at 320-248-9851 or mbinnebose@hotmail.com

KC Area Ataxia Support Group Meeting

Time: 12:00 pm - 2:00 pm

Location: KC Public Library - North East Branch, 6000 Wilson Road, Kansas City, MO

More info: Stephanie Wilkins at 816-623-3318 or Laurie Colby at 816-745-4549 to RSVP

North Texas Ataxia Support Group Meeting

Time: 10:00 am - 12:00 pm

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

Details: There is lots of parking and it is handicap accessible. The meeting room is in a separate bldg from the church.

More info: David Henry at chevelle@sbcglobal.net

St. Louis Ataxia Support Group Meeting

Time: 11:00 am - 1:00 pm

Location: The Center for Advanced Medicine, 4921 Parkview Place, St Louis, MO

Details: We meet the second Saturday of every month at The Center for Advanced Medicine on the 3rd Floor in Conference Room 1.

More info: Shannon Dunphy Lazo at 202-306-2738 or shan_d@hotmail.com

Saturday, February 17, 2018

Twin Cities Ataxia Social Group Meeting

Time: 10:00 am - 12:00 pm

Location: Langton Place, 1910 W. CTY. RD. D., Roseville, MN 55112

Details: Family and friends of an afflicted individual are always welcome! We meet on the third Saturday of every month. Please join us, and make new connections!

More info: Lenore Healey Schultz at 612-724-3784 or schultz.lenore@yahoo.com

Sacramento Ataxia Support Group Meeting

Time: 1:00 pm - 3:00 pm

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

Details: We meet on the third Saturday of each month. For more information or to be added to this group's mailing list contact Teresa Bredberg.

More Info: Teresa Bredberg at 916-215-2686 or tbredberg@sbcglobal.net

Saturday, February 24, 2018

Mid-Atlantic Social Group Meeting

Location: RSVP for Time and Location

Details: Ataxia Genetics: From Basic Principles

to Newest Updates Towson, Maryland Weiyi Mu, ScM, CGC, Genetic Counselor at Johns Hopkins University, Institute of Genetic Medicine and the Johns Hopkins Ataxia Center will be presenting information on Ataxia genetics followed by a Q & A. To register, contact Donna DeLano Neuworth. **More info:** Donna DeLano Neuworth at cddeleno1@jhmi.edu or 410-616-2811

New Hampshire Ataxia Support Group Meeting

Time: 10:00 am - 12:00 pm
Location: Villa Crest Nursing and Retirement Home, 1276 Hanover St, Manchester, NH
More info: Jill Porter at 603-626-0129 or jilleporter@comcast.net

Saturday, March 10, 2018

Central Minnesota Ataxia Support Group Meeting

Time: 9:45 am - 11:45 am
Location: Harvest Bank, 24952 County Rd 7, St. Cloud, 56301
More info: Marsha Binnebose at 320-248-9851 or mbinnebose@hotmail.com

North Texas Ataxia Support Group Meeting

Time: 10:00 am - 12:00 pm
Location: Ben Washington Baptist Church -Rev Jr Sheppard Educational Center, 615 Davis St, Irving, TX 75061
Details: There is lots of parking and it is handicap accessible. The meeting room is in a separate bldg from the church.
More info: David Henry at chevelle@sbcglobal.net

Indiana Ataxia Support Group Meeting

Time: 11:00 am - 2:00 pm
Location: St. Vincent Fishers Hospital, 13861 Olio Rd, Fishers, IN 46037
Details: Join our support group for Ataxians and families. Bring something to share for lunch plus your own drink. Paper goods supplied. We will meet in Conference Room #A & B (Park & enter at entrance One - follow the hallway to the right). Please RSVP.
More info: Amy Draves: 765-610-2866 or amy4kids@msn | Teresa Coccaro: 317-439-2512 or tcoccaro12@gmail.com

St. Louis Ataxia Support Group Meeting

Time: 11:00 am - 1:00 pm
Location: The Center for Advanced Medicine, 4921 Parkview Place, St Louis, MO
Details: We meet the second Saturday of every month at The Center for Advanced Medicine on the 3rd Floor in Conference Room 1.
More info: Shannon Dunphy Lazo at 202-306-2738 or shand@hotmail.com

Saturday, March 17, 2018

Twin Cities Ataxia Social Group Meeting

Time: 10:00 am - 12:00 pm
Location: Langton Place, 1910 W. CTY. RD. D., Roseville, MN 55112
Details: Family and friends of an afflicted individual are always welcome! We meet on the third Saturday of every month. Please join us, and make new connections!
More info: Lenore Healey Schultz at 612-724-3784 or schultz.lenore@yahoo.com

Sacramento Ataxia Support Group Meeting

Time: 1:00 pm - 3:00 pm
Location: Sutter Roseville Medical Center - Meeting Room 8, 1 Medical Plaza Dr., Roseville, CA 95661
Details: We meet on the third Saturday of each month. For more information or to be added to this group's mailing list contact Teresa Bredberg.
More info: Teresa Bredberg at 916-215-2686 or tbredberg@sbcglobal.net

Greater Houston Ataxia Support Group Meeting

Time: 1:00 pm - 3:00 pm
Location: Methodist Hospital - Woodlands, 17201 Interstate 45, The Woodlands, TX 77385
Details: For more information or to be added to the mailing list for this group contact Dave Cantrell.
More info: Dave Cantrell at Home: 936-588-5179, Cell: 936-206-1504, E-mail: dcantr7358@aol.com

Los Angeles Ataxia Support Group Meeting

Time: 2:00 pm - 4:00 pm
Location: Disability Community Resource Center, 12901 Venice Blvd, Los Angeles, CA 90066
More info: Lora Morn at loramorn@gmail.com or Harvey Kahn at 562-686-9720

Upcoming Informational, Awareness Events, and Fundraisers

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

Saturday, January 13, 2018



Tampa Bay Ataxia Group 60 for 60 Walk n' Roll to Cure Ataxia

Time: 8:30 am - 11:45 am

Location: USF Marshall Student Center, 4103 USF Cedar Circle, Tampa, FL 33620

Details: 8:30am Registration | 9:30am Walk (3.5 Miles) | From 11:00 - 11:45am Visitation of the various vendors and door prize giveaways | 11:45am Closing remarks and Thank yous. To donate or join our team visit our event website: <https://ataxia.donorpages.com/201760For60/TampaBayAtaxiaSupportGroup/>

More info: Darlene Harris at Msdee004@gmail.com or call 813-431-2859

Wednesday, February 28, 2018

Rare Disease Day

Details: : The main objective of Rare Disease Day 2018 is to raise awareness with policy makers and the public of rare diseases and of their impact on the lives of patients, and to reinforce their importance as a public health priority.

More info: <https://www.rarediseaseday.org/>

Saturday, March 24, 2018

Hu-Manifest Spring Summit

Time: 9:00 am - 11:30 pm

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. The Spring Summit will focus on natural self-care and wellness. All donations and a portion of event ticket sales benefit the National Ataxia Foundation (NAF). For event tickets or more information please contact Playground Productions Studio

More info: Playground Productions Studio at 317-678-7529 or info@PlygroundProductionsStudio.com

Thursday, April 5, 2018 - Friday, April 6, 2018
61st Annual Ataxia Conference (AAC)

Time: 9am - 5pm

Location: Marriott Philadelphia Downtown, 1201 Market Street, Philadelphia, PA

Details: See page 20-25

More info: Contact NAF at 763-553-0020 or email naf@ataxia.org



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 Stephanie at stephanie@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 and a brief author bio (1-2 sentences).

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 August 2017 through November 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.

Ardella Tate	Jason Michael Aiello	Mary Jane Clement
Brent Masserant	Jean Anderson	Michael Makohon
Lawrence Mandela	Jean S. Versteeg	Mike Smith
Alice Ruth Rooney	Jennifer Reintjes	Mike Williams
Amber Arguelles	Jeremy Stephen Harkulich	Mishka
Amy Messigian-Legault	Jim Richards	Mrs Arguelles
Barbara P. Smilow	Jim Shelstad	Nan Vail
Beth Johns	Joey Staiger	Norman Eugene Outcalt
Bill Gardner	John E. "Buck" Turnbull	Pat Anderson
Carly Hill	John Ebron, Jr.	Patricia A. "Pat" Lambright
Carmen Pieragastini	John Marten	Patricia Hogan
Clair and Betty Beck	Judith Bray Beck	Patsy Earnhart
Colleen Coffey Yosick	Kathryn D Smithers	Pearl Workley Straub
Conway Family	Kelly Tambourino	Peggy Marquis
Dale Roy Ellis	Kim Tambourino	Peter Caparelli II
Daniel Eustache	Kerstin Safari	Richard Strojny
Deborah G. Snyder	Kevin Hartley Whitaker	Mike Strojny
Denise van Voorhis	Kevin Whitaker	Rita Lobascio
Dolores Morello	Kim Michael	Robert Chin
Donald Stanosheck	Kristie Samuels	Robert D Currier, MD
Edith Chille	Krista Humes	Robert F Bossung
Eileen Berkowitz	Kylie and Kruz Shimabukuro	Roberta Santa Croce
Elaine Mannion	Leslie Miles	Roger Cooley
Elsie Amanda Poon	Linda Meier	Roger Teske
Ernest G. Prince	Lindy J. Thibodaux	Rokeya Islam
Evelyn Ligutom	Lisa Jaffe	Sadie Rosenthal
Florence Hoffman	Lopamudra Bhaduri	Sandee Berst
Frank Coffey	Lorraine Lerner	Sharlene, Clarice
Gary Zweig	Louise Buchwald	Sheila Weiss
Gerald Meyer	Marcia Cox Vaughey	Teddi Vaile
Gloria Cavanaugh	Marcia Saltmarsh	Teresa Ann Donnelly
Gottschalk	Marie Cooper	Teresa Drakos
H Wayne Amberson	Joe Coffey	Terry Marie Underwood
Ikue Pollak	Joey Stager	The Leader Family
Jack Moore	Marlene Greenwood	Thomas F. Tschida
Jacqueline DeVito	Marlene Miller	Tom Harris
James E. Baldwin Jr.	Marlene Patricia Greenwood	Una Damon
James Glenford Shelstad	Marty Greenwood	Usha Shahapurkar
James Walter Dover	Mary Ann Patulak	Verne K Allen
Janet Bair	Mary Fuchs	Will D. Thornton

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 koeppa@mail.amc.edu

2018 NAF Annual Ataxia Conference Registration

Online Registration available at www.ataxia.org

All conference materials will be sent through email. For those who do not have access to email, materials will be mailed out. A limited number of hard copy handouts will be available at the meeting upon request.

1. *Full Name: _____ Name on Badge: _____
 *Address: _____ *City/ State/ Zip: _____
 Country: _____ *Phone: _____ E-mail: _____
 Adult (18+) Teen/Child (3-17) Infant (2 & under) PCA Is this your first NAF AAC? Yes No

2. *Full Name: _____ Name on Badge: _____
 *Address: _____ *City/ State/ Zip: _____
 Country: _____ *Phone: _____ E-mail: _____
 Adult (18+) Teen/Child (3-17) Infant (2 & under) PCA Is this your first NAF AAC? Yes No

3. *Full Name: _____ Name on Badge: _____
 *Address: _____ *City/ State/ Zip: _____
 Country: _____ *Phone: _____ E-mail: _____
 Adult (18+) Teen/Child (3-17) Infant (2 & under) PCA Is this your first NAF AAC? Yes No

4. *Full Name: _____ Name on Badge: _____
 *Address: _____ *City/ State/ Zip: _____
 Country: _____ *Phone: _____ E-mail: _____
 Adult (18+) Teen/Child (3-17) Infant (2 & under) PCA Is this your first NAF AAC? Yes No

Please complete the following for each person:	#1	#2	#3	#4
1. Are you attending the Friday evening banquet? (included with your registration fee) Y or N				
2. If you are attending the Banquet, you have the following meal options: Beef Selection (B) or Vegetarian/Vegan Selection (V) Both are gluten free. Your meal selection for the Friday Banquet is only available on this registration form and cannot be made at the meeting B or V				
3. Will you be using a Scooter (S), Manual Wheelchair (M), Electric Wheelchair (E), or a Walker (W)? Blank, S, M, E or W				
4. Will you be bringing an assistance dog? Y or N				
5. Are you a current paid member of NAF? (If you are unsure of your membership status, contact NAF before submitting your registration form.) Y or N				

*Indicates required information. PCA = Personal Care Attendant.

Copy this form if registering more than four attendees

2018 NAF Annual Ataxia Conference Registration

Please indicate the Birds of a Feather (BOF) session you plan to attend in question 6 below.

- BOF Session Options -

- | | | |
|--------------------|---|--|
| A. SCA1 (Thursday) | F. All Other SCAs (including SCAs 5, 8, & DRPLA) (Thursday) | K. Unknown without Family History, Sporadic, Gluten, MSA (Friday) |
| B. SCA2 (Thursday) | G. AOA (Thursday) | L. Parents (Friedreich's Ataxia) (Friday) |
| C. SCA3 (Thursday) | H. Spouses/Partners Without Ataxia (Thursday) | M. Under 30 Years Old with Ataxia (Friday) |
| D. SCA6 (Thursday) | I. Unknown with Family History, EA and other rare Recessive Ataxias (Friday) | N. Parents (Ataxia other than FA) (Friday) |
| E. SCA7 (Thursday) | J. Over 30 Years Old with Friedreich's Ataxia (Friday) | O. Family Members without Ataxia (Friday) |

Please complete the following for each person (continued):	#1	#2	#3	#4
6. Please indicate the letter of Birds of a Feather session you plan to attend from A-O Take note of the day of your BOF Session (Thursday or Friday) <div style="text-align: right;">Select one session only</div>				

TRAVEL INFORMATION

Flying? Yes No If no, how will you be traveling (i.e., driving, bus)? _____

If driving, does your vehicle exceed 6' 8": Yes No

Air Carrier/Flight Number: _____ Arrival Date/Time: _____

Departure Date: _____

VOLUNTEER INFORMATION

Volunteers donating their time contribute greatly to the success of each National Ataxia Foundation Annual Ataxia Conference. To sign up as a volunteer at the 2018 AAC or to get more information about the volunteer opportunities, please contact NAF at (763) 553-0020 or naf@ataxia.org.

IMAGE CONSENT POLICY

By attending the 2018 NAF Annual Ataxia Conference you give your consent to use your image captured during the conference through video, photographs, or digital imagery, to be used by the National Ataxia Foundation in promotional materials, publications, and web site and waive any and all rights to these images.

VIDEOTAPING/FILMING/RECORDING POLICY

The recording of any audio/or video taping of conference sessions, or at any venue of the NAF Annual Ataxia Conference is forbidden, without prior approval in writing by the National Ataxia Foundation. PowerPoint presentations will be available on the NAF website after the completion of the conference. Attendees at the Annual Ataxia Conference expect, and deserve, the right to privacy. The NAF does photograph and record at the AAC, and will make photographs and other media available for news, educational, and promotional purposes.

SOLICITATION POLICY

Soliciting funds for organizations other than the National Ataxia Foundation or for individual benefit is prohibited at all NAF events. Any materials distributed seeking funds for other organizations or for individual benefit will be removed.

2018 NAF Annual Ataxia Conference Registration

Not sure if your membership is current?

Review the back cover of this issue of *Generations* for your membership status and expiration date.

Take advantage of the MEMBER RATE and JOIN TODAY!	Quantity	Total
<p>Yes, I would like to be a member of NAF! Please add an ADDITIONAL</p> <p><input type="checkbox"/> \$40 (Annual Individual) <input type="checkbox"/> \$60 (Annual Household)</p> <p><input type="checkbox"/> \$100+ (Annual Patron) <input type="checkbox"/> \$500 (Lifetime) <input type="checkbox"/> \$65 (Annual Professional)</p> <p><input type="checkbox"/> \$55 (Individual Outside U.S.) <input type="checkbox"/> \$75 (Household Outside U.S.)</p> <p><input type="checkbox"/> Recurring membership \$_____ /month (for more information, please call the NAF)</p> <p>You may register for the conference as a member if you sign up today!</p> <p><i>*Household, Patron and Lifetime memberships include all individuals who share the same residence.</i></p>		
<p>Yes, I'd like to support the Annual Conference Fund (provides travel grants, offsets registration fees, helps cover costs associated with the conference)</p> <p>Here is my sponsorship contribution!</p> <p><input type="checkbox"/> \$125 (Offset of Registration) <input type="checkbox"/> \$400 (Travel Grant)</p> <p><input type="checkbox"/> Other: \$_____ (Any amount is helpful!)</p>		

REGISTRATION FEES (includes all General Sessions, reception, and banquet)	Before 2-13-2018	From 2-13 to 3-30-2018	After 3-30-2018 At the door	Quantity	Total
<input type="checkbox"/> NAF Member (applies to NAF members who have an Individual, Household, Patron, Recurring or Lifetime membership <i>(member rate is applied to one caregiver per individual member with ataxia)</i> No registration refunds will be made after March 21st	\$125	\$150	\$200		
<input type="checkbox"/> Non-Member No registration refunds will be made after March 21st	\$180	\$205	\$255		

TOTAL CHARGES:

PAYMENT INFORMATION: Visa MasterCard Discover AMEX Check enclosed

Name of Card Holder: _____

Address: _____

City: _____ State: _____ Zip: _____ Country: _____

Phone Number: _____ E-mail: _____

Credit Card Number: _____ Expiration Date: _____

3- or 4-Digit Number on Back: _____ Signature of Card Holder: _____

Early Registration Deadline is February 13, 2018

Please complete all pages of the registration form and return to the following address:

NAF, 600 Highway 169 South, Suite 1725, Minneapolis, MN 55426-1205

Phone: 763-553-0020 | Fax: 763-553-0167 | Email: naf@ataxia.org

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 _____



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(763) 553-0020

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