

National Ataxia Foundation

GENERATIONS

THE OFFICIAL PUBLICATION OF THE NATIONAL ATAXIA FOUNDATION

You Need to Get Tested – Here's Why

The Scoop on Genetic Testing from an expert

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Time to Get Ready for IAAD!

Ideas for Awareness in Your Community

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Fighting Ataxia

A Board Member's Story of 61
years of service

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Under 30 with Ataxia

A New Way to Connect for
Young Adults

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National Ataxia Foundation
International Ataxia
Awareness Day
September 25th

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Deadline to submit materials for the Fall issue of *Generations* is Monday, August 6.

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:

Jerry Frick , Director of Finance & Operations
 Sue Hagen, Patient and Research Services Director
 Lori Shogren, Community Program and Service Director
 Stephanie Lucas, Communications Manager
 Mollie Utting, Support, Engagement & Advocacy Coordinator
 Leader Printing – Printing and Production
 Jessica Johannes – Design

Generations Schedule:

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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.

NAF Welcomes New Staff

As an organization, NAF is dynamic and has experienced many changes this year. We are proud to welcome three new members to our team. Meet the new crew...

Jerry Frick, Director of Finance and Operations

Jerry joined NAF on January 4, 2018 on a contract basis to review processes and make recommendations. He came to NAF as a seasoned professional, having held senior finance and operations roles in for-profit and non-profit organizations, as well as for his own business. Jerry obtained a B.A. degree in Accounting/Business Management from Anderson University and a Master Science in Accounting from the University of Phoenix. Jerry jumped into NAF operations full throttle; he was quickly viewed as a potential candidate to fulfill the vacant Finance Director role. His knowledge of general operations was found to be helpful. His skillset was identified as an asset to address more than the finance role. On April 16, 2018, Jerry was invited by the Board of Directors to join the staff on a permanent basis as Director of Finance and Operations. Jerry is tasked with overseeing all operations at NAF,

including finance, HR, and Administration.

Mollie Utting, Support, Engagement, and Advocacy Coordinator

On March 14, 2018, Mollie joined the NAF team to offer much needed support to our office and the Ataxia community. Mollie brings a wealth of knowledge and experiences from her prior positions as an Education Outreach Coordinator and Practice Manager. She has worked in the non-profit and medical sectors. She looks forward to engaging with the Ataxia community through NAF's support services and organization publications.

Nick Gullickson, Finance Assistant

NAF's newest employee, Nick, started on May 14, 2018 following the departure of a longtime staff member. Nick is a graduate of the University of Minnesota - Duluth with B.A. in Finance. His previous positions at Wells Fargo and US Bank offered him valuable experience that he is excited to bring to NAF. He's happy to assist with any questions and donation needs.

NAF WELCOMES NEW BOARD MEMBERS

This year, we had two new spots on the Board of Directors open; one with the unexpected passing of longtime member Denise Drake, and the other with Julie Schuur's decision to accept Emeritus Status. At the 2018 Annual Ataxia Conference, two new Board Members were elected:

Linda Snider has Ataxia and has been a longtime advocate. She founded Nebraska Ataxia, a non-profit dedicated to helping those affected by Ataxia. Her experience, both personal and professional are welcomed.

David Brummet is excited to join the Board of Directors as his family is affected by SCA 3. He looks forward to be a part of this leadership group that is targeting a treatment and cure for Ataxia, while working to improve the lives of those living with the disease.



HAPPY RETIREMENT, JAN!

After 12 years of dedicated service, NAF bids farewell to Jan Stewart, who served as our Finance Assistant. Jan retired in May of 2018, for a well-deserved life of leisure. Jan demonstrated a passion for work and the Ataxia community. She worked diligently to make every donor interaction a positive experience. We will miss her drive for excellence and unparalleled knowledge of our constituents. We wish her all the best in her retirement. Thank you for your many years of hard work, Jan.

No Walk in the Park

Navigating High School and College with Ataxia

Lauren Sormani



This past April I attended my first Annual Ataxia Conference. After I registered, I immediately made my hotel reservation, booked my train ticket, and started counting down the days. I had met a few people with Ataxia at

a meeting of the Chesapeake Chapter and I conversed with many others on social media. But what I was really looking forward to, was meeting others who are under 30 and have Ataxia.

I am a 22-year-old student who graduated from American University in Washington, DC this past May. Navigating high school and college with Ataxia was no walk in the park. The entire time I was taking that walk blind—I did not know anyone who had recently paved that path before me. Over the years I came up with my own modifications for most of college life. While my friends are very supportive, it was hard for them to understand what I was going through and how to best help me. After all, how could they if they were not living with Ataxia themselves? Looking back over the last few years, my life would have been infinitely easier if I had other college-aged Ataxians to bounce ideas off of or to ask for advice in certain social situations. While I am extremely grateful for the information I have gathered from all the Ataxians I have met, I felt

“I was elated to be able to give advice to others, especially those who are younger than me”

there was a gap that needed to be filled.

On the final day of the conference the Under 30 with Ataxia Birds of a Feather Group met. There were not very many of us, but we certainly had a lot to talk about—talking from 2pm to almost 6pm. The longest the Under 30 group has ever lasted. I was elated to be able to give advice to others, especially those who are younger than me, about my tips and tricks for navigating high school and college with Ataxia, and I know others were as well. Many gained new friends, including myself. We all agreed that there is a need for more involvement from the younger generation of people living with Ataxia. In order to facilitate this involvement,

NAF created the Under 30 with Ataxia Facebook group. The only two criteria for involvement in this group is (1) you must have Ataxia and (2) you must be under 30*. I hope that many others will engage in this group—make friends, ask questions, and learn.

www.facebook.com/groups/Under30withAtaxia/

Lauren Sormani is a New Jersey native who now resides in Washington, D.C. She was diagnosed with SCA 8 last year at the age of 21 and will be starting law school this fall.

Questions about the group?
Contact Lauren at lasormani@gmail.com

*If you are a parent of a person under 30 with Ataxia, you do not qualify to join the group. We'd be happy for your son/daughter to join though! We love you parents! But we need a space to talk freely about the issues that we face. Thanks for understanding!

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 naf@Ataxia.org so you don't miss out on important information.

Fighting for Ataxia

My History with NAF

Julie Schuur

How did this wonderful organization known as the National Ataxia Foundation get its start? I'd like to tell you our story. In 1915, two Schut brothers went to the Mayo Clinic and asked, "What's wrong with us? There are 9 children in our family. Seven of us have this disease and we don't know what it is. We know that our mother and our grandfather had it. What is it?"

"Someday, some time, we're going to have something that will help and, hopefully, cure the people with Ataxia."

The doctors examined them very thoroughly and said, "What you have is a familial Ataxia. Go home, enjoy your life as long as you live because there is nothing we can do for you. We don't know of anything to cure it; we don't know of anything that will prolong your life in any way." And so that is exactly what they did.

But they knew there were problems because those 7 children already had 39 children in line for the disease. They knew that some of them were going to get it, but they didn't know how many. I was not there at that time but that was the beginning of our struggle with Ataxia.

In 1946, I was a college student and went to visit Henry Schut one weekend because he lived quite close to the school. Dr. John Schut (Henry's brother) came and we spent a lot of time talking. After Henry was finished with the milking and farm chores, we sat at the kitchen table from 8:00pm till 2:00 in the morning. Dr. John said, "I am going to start the National Ataxia Foundation". I thought "NATIONAL! We don't even have it in the county yet." However, this idea was put on hold because he had to complete his obligation to the Army as they had paid for his medical education.

In 1948, I got a call from Dr. John saying he was about to produce a film on hereditary Ataxia with the support of the Armed Forces Institute of Pathology (AFIP). In it he would show how to examine a patient with Ataxia and how to make an accurate diagnosis. He said, "Julie, are you

willing to take 2 weeks off from teaching to help me?" I thought, "Oh, I'll see once", so I went to my school board to ask if I could have this

opportunity to assist my cousin in the making of this film on Ataxia. They said, "Yes, go" because we had 2 families in our school district that had Ataxia and they knew what it was.

So, we went to Sioux Falls, SD, where a group of the cousins met. We produced this film in which he actually showed how to examine a patient with Ataxia. I also went along with him to central Minnesota where we examined more of the cousins, continuing this film. We completed it with a bunch of more cousins in Michigan that I had never had the opportunity to meet. It was a wonderful two weeks for me.

Dr. John completed his stint in the Army and that was followed by a 3-year residency in neurology at the University of Minnesota. During that time, he continued his studies on Ataxia more intently than ever, for at age 29, he, too, began experiencing symptoms of the very disease he was studying.

My work with Ataxia dwindled for a few years. Then in the mid-fifties, Dr. John again called me and said, "Julie, I have laboratory mice that have Ataxia. I need money for cages and feed and for a person to help me with these experiments." So, I wrote to everyone who had some Schut blood in them and asked what they could do to help. Now, remember, this was the 1950s and man, did I get the envelopes with \$1, \$3, and \$5 but, boy, I sent him a check for \$500. He said, "That gets me the cages!" And he went to work studying these mice that had Ataxia.

In 1957, he called me again and said, "I've got the National Ataxia Foundation set up. I want you to join us, Julie - will you?" I said, "Yes, of course" and in September 1957, I joined the board and remained its secretary for the next 22 years even though some of those years we were dysfunctional



Fighting for Ataxia (continued)

due to Dr. John's illness and the lack of someone to take over. When we began, there were 2 types of Ataxia that we knew of - Schut's Ataxia which eventually became SCA1 and Friedreich's Ataxia. That's all we knew about the classification of Ataxia.

A monumental task was before us. I said to the people in my community we've got to do something to help him in these experiments. So, we set up bake sales, I went to Community Chests and to many churches every chance I got, I spread the news about Ataxia, but, after a few years, NAF became dormant because Dr. John could no longer function. Everything came to a standstill and that's the way it remained until 1970. That fall we received what I believe to be divine intervention.

Dr. Dean Johnson, a chiropractor in Sioux Falls, was treating 2 Swier brothers with Ataxia but he realized that their affliction was beyond his scope of care. He contacted the National Genetics Foundation in New York City and asked the director, Ruth Berini, for help. She located 2 neurologists, Drs. William Nyhan and Roger Rosenberg, at the University of California in San Diego. She also learned of Dr. Lawrence Schut, a neurologist in Minneapolis, a second cousin of the 2 brothers. He was taking care of his uncle, Dr. John Schut, who was in the last stages of "Schut's Ataxia".

Ms. Berini suggested that these 3 neurologists attend a clinic at Dr. Johnson's office. In 2 days, they examined 45 members of the Schut/Swier

families. Twelve of these young men and women in their 20s were diagnosed with the dreaded disease. Ms. Berini also arranged for a crew from WCCO-TV in the Twin Cities to film the event. Shortly after New Year's Day 1971, the documentary was shown on *Moore on Tuesday*. It was so compelling that Ms. Berini called for a press conference in New York. Reporters from the Associated Press, Time, Ladies Home Journal and other outlets attended.

Time magazine and the associated press ran articles about the conference and Ataxia, these articles brought forth an explosion of letters from around the United States and Canada. Some people sent expressions of sympathy but most letters, in essence, stated, "I have the same disease" or "This disease affects many in our family".

This is when Dr. Lawrence Schut realized the full impact of Ataxia. He asked his father, Henry, if there was any money left in the NAF bank account. "I guess about \$3200" was the reply. Underwhelming to say the least - but the problem was overwhelming. They agreed that the NAF should be reactivated, and a new board reconstituted with Henry as president.

Dr. Lawrence called me, saying, "Julie, we welcome you, no, urge you to come back on the board again. We have to do something about this because we need to examine people again so get the cousins ready in southwestern Minnesota." So, we got as many as we could to come together to learn what they could do to help. The chapters were set up again and everyone was very enthusiastic about it.



JOHNS HOPKINS
M E D I C I N E

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.



THE DEADLINE FOR SUBMITTING MATERIALS

for the Fall issue of *Generations* is Monday, August 6. Please send articles, your personal story, recaps of Ataxia-related events, photos and reports to naf@Ataxia.org. Thank you.

Fighting for Ataxia (continued)

Everyone who had Ataxia or was at risk to get it, along with their families, was invited to a free clinic held twice a year at the Minneapolis Clinic of Neurology in Golden Valley where Dr. Lawrence had his office. Over the course of 10 years, over 700 people benefitted from this opportunity. A team consisting of a physical therapist, speech pathologist, financial counselor, psychologist, genetics counselor, nurse and neurologists (adult and pediatric) provided a wealth of information and comfort to a full spectrum of Ataxians and their families.

Once again, I got the relatives together - we organized bake sales, Community Chests and talent contests; we spoke to Chambers of Commerce and in churches - anyone who would listen and give us a chance to get our foot in the door.

We had 2 very special projects - one was called "Cash for Trash". In those days, it cost 13 cents to send a letter. If you bought, for example, 2 boxes of Wheaties and sent the box tops to the company, they'd send \$1.00 back to you. I organized the people in my church as well as other churches around us to save their "garbage" which they brought to us. Volunteers helped to sort the items which were sent to the proper companies using as many names as we could provide and as often, each address could receive only one refund. Thousands of dollars were raised over 20 years until the program was discontinued.

The second project was collecting newspapers. Someone had invented making insulation out of them. You know it gets mighty cold in Minnesota so there was a great demand for insulation. We collected newspapers in all the towns around us and sold them to companies making the insulation. Again, we raised 1,000s of dollars that kept NAF on its feet.

Yes, there were rough spots in the 80s, rough spots

because the economy went down. There were times when I would get a call from the office saying they were completely out of money and we can't even pay our secretary. "Do you have anything you can send us?" I would send what little we had. Always something came through; somebody would send in enough so that we were able to keep it going. NAF struggled valiantly but we made it.

In our family, there were 65 people over 4 generations who died of Ataxia. Today we have one person who has it and one at risk for it. That hasn't been easy because many people had to forego having a family of their own. The only way we knew of stopping Ataxia was to stop having children. It was a very difficult decision to make for many, many families. But it was our only hope.

Today we know where we stand with Ataxia. I know there are some of you who have the same fire burning in your hearts as burned in mine to stop the progress of this disease. I'm 90 years old; it's time I retire from this board. It's been a very hard decision for me to make because I love the NAF with every ounce of my body. I want you to fight this disease with every ounce of your strength as I have throughout the years. Keep up this fight. Someday, some time, we're going to have something that will help and, hopefully, cure the people with Ataxia, the Good Lord willing.

*This is an edited version of Julie's talk at the 2018 AAC. .

Julie Schuur Julie Schuur's mother was one of the 39 Schut cousins at risk for the disease Ataxia. Her brother got the disease, but Julie's mother and her sister did not. Because her mother was spared, Julie and her brothers and sisters did not inherit Ataxia. Julie felt such gratefulness that she was spared that she had tried to help in any way that she can to assist NAF in the eradication of Ataxia. Julie joined the Board of Directors when NAF was founded in 1957. She has remained on the Board since, even having served as Board President in 1980-82. In 2018, Julie became the first Board Member to accept Emeritus status.



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 omaveloxolone (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:

- Omaveloxolone significantly improved mFARS (modified FA Rating Scale) from baseline across all doses
- In omaveloxolone-treated patients, mFARS was improved at Week 4 and further improved by Week 12
- Omaveloxolone at 160 mg dose showed large mFARS improvements as early as Week 4
- Omaveloxolone 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



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 naf@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).

NAF Funded Research

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.

CLINICAL RESEARCH TRAINING FELLOWSHIP



Antisense FMR1 splice variant: a predictor of Fragile X-associated tremor/Ataxia syndrome (FXTAS)

Padmaja Vittal MD, MS.
Rush University Medical Center, Chicago, IL

Fragile X Associated Tremor/Ataxia Syndrome (FXTAS) is an inherited degenerative disorder causing tremor, Ataxia and memory issues. FXTAS is caused by a 55-199 CGG repeat expansion (premutation) in the fragile X mental retardation 1 (FMR1) gene located on the X chromosome. This gene is essential for normal brain development.

The long CGG repeat resulting makes the RNA and protein product of the FMR1 gene toxic to the cell. The prevalence of premutation carriers in the population is about 1 in 500 men and 1 in 250 women. It is estimated that 1.6/2000 men in the United States over the age of 55 are at risk for developing FXTAS and this number is lower for women.

Not all premutation carriers get FXTAS. The main purpose of this study was to identify molecular markers to help predict which premutation carriers will get the disease.

AGG interruptions (typically separated by 9-11 CGG repeats) within the CGG repeat in the FMR1 gene are known to disrupt the otherwise pure CGG tract. Normal FMR1 alleles typically possess 2-3 AGG interruptions; premutation alleles generally possess two or less interruptions, while

NAF Funded Research (continued)

larger premutation alleles tend to have fewer AGG interruptions

A second gene, antisense fragile X mental retardation gene (ASFMR1) represents a portion of the FMR1 gene that goes in the reverse direction from FMR1. ASFMR1 makes 5 different RNAs (called splice variants) of unclear clinical impact. One of the variants previously described ASFMR1 splice variant 2 (ASFMR1 transcript variant 2 or ASFMR1-TV2) was further explored in this study. This study reports elevated levels of ASFMR1-TV 2 in FXTAS and a loss of AGG interruptions in men with FXTAS. Additionally, this study also showed that FXTAS-Rating Scale and Neuropathy Scale scores were higher in patients with FXTAS compared to premutation carriers and controls.

Although we found that ASFMR1-TV2 and lack of AGG were more common in FXTAS, the power to discriminate between premutation carriers and FXTAS was not high enough to use diagnostically

or in a predictive manner. Future studies will be needed to determine whether these variables can provide useful diagnostic or predictive information.

We thank The American Brain Foundation and the National Ataxia Foundation for their funding support for the Clinical Research Training Fellowship Award in Ataxia.

Dr. Vittal's Clinical Research Training Fellowship in Ataxia was funded by the American Brain Foundation and National Ataxia Foundation. The award was presented during the American Academy of Neurology's 66th Annual Meeting, the world's largest meeting of neurologists. At the time, Padmaja Vittal, MD, MS, was a first-year fellow at Rush University Medical Center in Chicago and received this award for her investigation into the role of antisense FMR1 in the development of Fragile X-associated tremor/Ataxia syndrome.

REMEMBERING THE NAF IN YOUR WILL

Throughout the years, individuals have named the National Ataxia Foundation as a beneficiary in their wills. Their thoughtfulness and foresight has enabled the NAF to provide more research studies, more services to patients and families and more education and Ataxia awareness to the public. We are grateful for the impact that has been made by these compassionate acts. If this is something you would like to consider, please contact Joel Sutherland at joel@Ataxia.org or call (763) 553-0020.



Walk N' Roll season has arrived! Be part of the National Ataxia Foundation's largest national grassroots fundraising campaign. Thousands of families, friends, co-workers, neighbors, and communities come together each year to support the NAF's mission to fight Ataxia.



2018 Walk N' Roll Events:

Treasure Coast Walk n' Roll

Port St. Lucie, FL - May 19

Contact: Lisa Cole
lisacoleAtaxia@gmail.com
www.Ataxia.org/walk/
treasurecoast

Western NC Walk n' Roll

Brevard, NC - June 23

Contact: Jodie Kawa
jodiekawa@comporium.net
www.Ataxia.org/walk/WNC

Tri-State Walk n' Roll

Jersey City, NJ - August 25

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

Northeast Ohio Walk n' Roll

Lakewood Park, OH - August 26

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

Minnesota Walk n' Roll

St. Louis Park, MN - September 8

Contact: Wendy Sweeney
Wendysweeney1@comcast.net
www.Ataxia.org/walk/minnesota

New England Walk n' Roll

Bristol, RI - September 8

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

Denver Run Walk n' Roll

Denver, CO - September 9

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

Orange County Walk n' Roll

Orange County, CA - September 15

Contact: Cindy De Mint
cindyocAtaxia@gmail.com
www.Ataxia.org/walk/oc

Atlanta Walk n' Roll

Duluth, GA - September 22

Contact: Greg Rooks
atlantaAtaxia@gmail.com
www.Ataxia.org/walk/atlanta

Tennessee Attacks Ataxia Walk n' Roll

Hendersonville, TN - September 29

Contact: Ondie Mitchell
3mitchells@bellsouth.net
www.Ataxia.org/walk/TN

Western PA Walk Run n' Roll

Millvale, PA - September 29

Contact: Madalyn Gottschalk
samgotts32@gmail.com

Utah Walk n' Roll

Layton, UT - September 29

Contact: Lisa Ord
lisa.ord@hsc.utah.edu
www.Ataxia.org/walk/utah

Michigan Walk n' Roll

Ann Arbor, MI - Date TBD

Contact: Elizabeth Sullivan
elizsull@med.umich.edu

New Hampshire Walk n' Roll

Londonderry, NH - October 6

Contact: Douglas Place
Douglas.place@comcast.net

Fort Wayne Walk n' Roll

Ft. Wayne, IN - October 6

Contact: Jessica Lebrato
jclebrato711@gmail.com

To start a Walk N' Roll event in your community contact Lori Shogren, Community Program and Service Director at lori@Ataxia.org or (763) 231-2743.

Fundraiser and Awareness Event Recaps

Tri-State Ataxia Support Group Represents at NY Abilities Expo

Submitted by Kathleen Gingerelli

The Tri-State Ataxia Support Group exhibited on behalf of NAF at the NY Abilities Expo. At the event, 11 volunteers raised awareness about Ataxia while learning about new and exciting products and services for people with disabilities. A big thank you to our volunteers; Kathleen Gingerelli, Judy Gingerelli, Ed Brand, Erin Peterson, Ian Bouras, Barbara Tinari, Frank Tinari, Scott Rosenberg, Lynn Rosenberg, Antonia Bermudez, and Kristina Bermudez.



Strike Out Ataxia Charity Bowling Event

Submitted by Neddroy Bent

The Annual Strike Out Ataxia fundraiser was held on April 29, at AMF Sky Lanes in Orlando, FL. This event, which is filled with bowling, birthdays, and music, is attended by friends and family of Neddroy “DJ Headbussa” Bent in honor of his birthday and mother. The 7th annual charity bowling event not only raised Ataxia awareness,



they also raised nearly \$300 for the National Ataxia Foundation and its mission.

Dodgeball for Ataxia

Submitted by Andrew Haluska

Severe weather was not going to hold these supporters back from having a ball raising money for Ataxia. Inside the Burnt Hills-Ballston Lake high school in Burnt Hills, NY, participants and spectators got together on May 4, for the 9th Annual Chuck n Duck Dodgeball Tournament for Ataxia coordinated by Andrew Haluska. Thanks to the support of the community, from the school district, students, staff and supporters this event raised over \$7000 towards fighting Ataxia.



Treasure Coast Walk N' Roll

Submitted by Lisa Cole

Over 120 passionate participants made it out to the 1st Annual Treasure Coast Walk N' Roll to Cure Ataxia at Tradition Square and Lake in Port St. Lucie, FL. The rain held off just long enough and we were able to have a wonderful event raising awareness and funds to fight Ataxia. Thanks to Lisa Cole and the Treasure Coast Ataxia Support group for all your hard work and dedication to the event. We look forward to seeing everyone again next year!



Fundraisers and Awareness Events (continued)

Praveen's Vermont City Marathon

Submitted by Praveen Bahadduri

On May 27, 2018 Praveen Bahadduri ran the Vermont City Marathon to raise awareness and funds for the National Ataxia Foundation. Praveen ran in honor of his friend's son, Neil, who is diagnosed with SCA3. Praveen did an amazing job getting the word out there about Neil and Ataxia, raising over \$2,000 for his fundraiser. Congratulations to Praveen for such a great effort raising awareness about SCA3, NAF and the Ataxia community.



raise money. Of course, it helps to meet a really wonderful and caring person like Captain Crystal and her Chrysalis Foundation. Watch for the podcast, to be announced by NAF after Paula's ride is scheduled. We are ALL going up up and away with her!

Funds raised in this contest were raised by contestants through Facebook Fundraisers. To find out more about Facebook Fundraising please see the Facebook Fundraising article on page 16.



Hot Air Balloon Contest

Submitted by Cherilyn McLaughlin

After a month of online fundraising, the winner of the three-hour Hot Air Balloon experience is Paula Wood from the Western Washington Support Group.

Paula will enjoy a flight in the large free flying balloon piloted by Captain Crystal Stout, of Sequim Washington. Captain Stout and her Chrysalis Foundation have partnered with NAF to provide a "dream flight" high in the clouds. There will be an incredible backdrop of the Olympic Mountains on one side and the Strait of San Juan De Fuca and British Columbia on the other. When this event happens, Captain Stout will treat NAF members to a live podcast of the lift off.

Lots of credit goes to the other brave souls who entered their names to fly high. Lori Shogren, Diane Cross, Mike Cammer and Sherry McLaughlin all helped to bring in over \$3100 directly to NAF. I believe that any support group, regardless of how small, can find creative ways to

Tee Off for a Great Cause - 1st Annual WPA Golf Outing to Cure Ataxia

Submitted by Madalyn Gottschalk

The 1st Annual WPA Golf outing to cure Ataxia was held on May 26 at LakeVue North Golf Course. The shotgun start event was hosted by the Western PA Ataxia Support Group to raise awareness and funds for Ataxia. Those who attended played 18 holes of golf, enjoyed lunch at the turn and a steak dinner to cap it all off. Turn out for this first-time event was incredible and there was great support from the community raising over \$12,000 for Ataxia. It was truly worth all the effort.





Michael Curtis, PhD
President & CEO of
Cadent Therapeutics

Cadent Therapeutics Phase 1 Clinical Trial Launched for Compound to Treat SCA

Cadent Therapeutics, a neuroscience company developing medicines to restore movement and cognitive function in patients with neurological and psychiatric disease, initiated an exciting new study that could develop new therapies for people with movement disorders, including Ataxia.

The Phase 1 clinical study for its lead product candidate Cad-1883 was announced in early March. “This is an important step in the development of meaningful new therapies for people with movement disorders,” said Michael Curtis, PhD, President and CEO of Cadent Therapeutics. “We have shown that allosteric modulation of the SK channel restores cadence to neuronal firing and is efficacious in disease models of Ataxia and tremor. Our hope is that by precisely tuning dysregulated neuronal firing, we can reduce disability and restore motor function in patients with spinocerebellar Ataxia and essential tremor.”

**For more
information
regarding the
clinical trial visit:
www.cadenttx.com
or email:
info@cadenttx.com**

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 koeppesa@mail.amc.edu

2,019 by 2019

Power in Numbers

The message from researchers has been loud and clear – they need our help! We must amp up our research recruitment efforts to help push new studies along as fast as possible. Ataxia research is moving forward rapidly, like never before. There are studies and clinical trials in progress or in the pipeline – with even more soon to come. One road block for researchers, however, is when there is a lack of access to participants for their critical research. Research that may lead us to treatments and a cure. How can we help? By providing them better access to us! The Ataxia patient registry was coordinated for just that purpose. Signing up gives researchers a way to reach out to see if you are interested in new studies or trials. Your information is kept private and you have complete control over whether you choose to participate in studies for which you qualify.

To help researchers, NAF made a commitment, along with Coordination of Rare Diseases at Sanford (CoRDS), to increase the Ataxia patient registry enrollment. In response, NAF is starting the “2,019 by 2019” initiative! The Ataxia patient registry, maintained jointly with CoRDS, had 1,496 participants fully enrolled as of May 1, 2018. We’d like our community to help out by enrolling and asking their family to enroll as well. Persons affected by Ataxia and these at risk should enroll. Let’s get our Ataxia enrollment numbers up to 2,019 by January 1, 2019!

The logo for CoRDS (Coordination of Rare Diseases at Sanford) features the text "CoRDS" in a large, white, sans-serif font against a dark blue rectangular background.The logo for Sanford Research features the text "SANFORD RESEARCH" in a white, sans-serif font, with "SANFORD" on the top line and "RESEARCH" on the bottom line, set against a dark blue rectangular background.

Enroll at www.sanfordresearch.org/SpecialPrograms/cords/

Questions? Contact CoRDS at cords@sanfordhealth.org or (605) 312-6423

RECRUITMENT FOR RESEARCH STUDY

As an extension of the National Ataxia Foundation’s natural history study and the federally funded early stage Ataxia clinical trials readiness study, and as a response to results of recent clinical trials, Dr. Christopher Gomez, at the University of Chicago, together with investigators at UCLA, Johns Hopkins, Harvard University, and Oregon Health Sciences University are currently preparing to launch a two-year Study involving wearable inertial sensors that is focused on developing more accurate and efficient ways to measure the severity and progression of Ataxia. The goal of this study is to make it easier for clinical trials to move forward and test the effectiveness of drugs developed to possibly treat Ataxia. The Ataxia types involved in this study are SCA1, SCA2, SCA3, SCA6 and Friedreich’s Ataxia. The study is due to begin in the summer or early fall, pending full IRB approval and funding.

Recruitment for this study, as many of the Ataxia research studies and clinical trials, will be through the CoRDS Ataxia Patient Registry. If you would like to participate in this upcoming study, enroll in the Ataxia Registry by accessing this link <http://www.sanfordresearch.org/SpecialPrograms/cords/> or calling (605)312-6423. Thank you.

A NEW WAY TO MAKE A DIFFERENCE



5 Easy Steps to Starting a Facebook Fundraiser for NAF

Facebook recently rolled out a feature that allows individuals to raise money for their favorite non-profits. If you've been looking for a simple way to help support the Ataxia community, but have limited time or resources, this may be an option for you! It's as simple as posting a status update and allows funds to be donated directly through the Facebook platform. You can tell your story, why supporting NAF is important to you, and invite your friends to support your cause. Your followers can choose to donate to your cause directly on the Facebook platform. All donations collected on Facebook are submitted to NAF. Many people choose to donate their birthday to a non-profit by asking their family and friends to donate on their behalf in lieu of a gift. To start a fundraiser on Facebook, follow the 5 easy steps:

1 **DESKTOP:** Select "Fundraisers" in the left menu of your News Feed.
MOBILE APP: Open the menu with the bottom right menu icon. Select "Fundraisers."

2 **DESKTOP:** Select "Raise Money for a Nonprofit Organization."
MOBILE APP: Select "Raise Money."

3 **DESKTOP:** Select "Get Started."
MOBILE APP: Select "Nonprofit."

4 **DESKTOP and MOBILE:** Type "National Ataxia Foundation" in the search bar. Select NAF.

5 **DESKTOP and MOBILE:** Enter your fundraiser details. Select a goal, end-date, fundraiser name, and fundraising details. Tell your friends why raising money for Ataxia is important to you.

Thank you to everyone who created a fundraiser!

**In 2018: 142 Facebook Fundraisers
= \$36,937**

Clinical Research needs Participants with SCA 1, 2, 3, 6, 7, or 8

With a very generous donation from the Gordon and Marilyn Macklin Foundation, the Clinical Research Consortium for the Study of Cerebellar Ataxia will continue the important research needed to prepare sites for clinical trials as pharmaceutical companies begin developing treatments for Ataxia. The three-year commitment will provide funds for 13 sites across the United States to perform Natural History Study on research participants who have a genetically confirmed diagnosis of SCA 1, 2, 3, 6, 7 or 8. This new funding will allow NAF to add two sites to the consortium very soon. In addition, those with SCA 7 and SCA 8 are now included in this important research.

The funding is in place; the sites are ready to perform the clinical research, now the need is for research participants. There are several pharmaceutical companies who are devoting resources to develop therapies specifically for the SCAs. It is absolutely essential that the Ataxia community have robust natural history data and biomarkers. Drug development needs patient participation in the earliest stages. This is an opportunity for anyone in the United States with those forms of SCA at any stage of the disease to participate.

The National Ataxia Foundation encourages anyone with those forms of SCAs to contact the research coordinator at a site near you to learn more about how you might be able to participate.

Columbia University

Darya Tomishon
dvt2101@cumc.columbia.edu

Johns Hopkins University

Ann Fishman
Ataxiaresearch@jhu.edu

University of Chicago

Jackie Hill
jhill11@neurology.bsd.uchicago.edu

Emory University

Rebecca McMurray
rebecca.s.mcmurray@emory.edu

Northwestern University

ZsaZsa Brown
zsazsa.brown@northwestern.edu

University of Michigan

Elizabeth Sullivan
elizabethsull@umich.edu

Mass General/Harvard

Jason Macmore
jmacmore@partners.org

University of California LA

Aaron Fisher
ADFisher@mednet.ucla.edu

University of Minnesota

Diane Hutter
hutte019@umn.edu

Houston Methodist

Titilayo Olubajo
tolubajo@houstonmethodist.org

University of Florida

Amanda Cowsert
Amanda.Cowsert@neurology.ufl.edu

If you have questions about participation in the natural history study, email the research coordinator at the site where you might participate.

If you are affected with a different type of SCA or other form of Ataxia, you may be eligible for studies or clinical trials in the future. The best way to be informed of future studies is to enroll in the CoRDS Ataxia Patient Registry. To enroll, go to <https://cordsconnect.sanfordresearch.org/BayaPES/sf/screeningForm?id=SFSFL>. If you have questions about enrollment in the registry, contact the CoRDS staff at 877-658-9192.

Development of treatments for the Ataxias has gained momentum but it will take the entire Ataxia community to participate. The National Ataxia Foundation is grateful to the Gordon and Marilyn Macklin Foundation for funding the consortium, to the clinician researchers who are dedicated to perform the research and to research participants. We are getting closer to treatments and therapies for the Ataxias. Let's keep the momentum going!

Ataxia Tips

Hints and Tricks
for Ataxians...from
Ataxians

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

- 1** Go on-line and look for a handyman in your area to help you do the things you can't. (Submitted by Nancy McCullough)
- 2** I keep an elbow touching the shower wall while rinsing my hair. Once I close my eyes if I don't have a part of my body touching something I completely lose my balance. I also use my elbow as a guide along the wall especially when walking up or down the stairs in my house. Basically, I just lightly keep my elbow touching the wall, so it keeps me walking in a straight line. (Submitted by Charlotte Braden)
- 3** I purchased from Amazon a motion detected light that runs around my bed. It lights up automatically whenever I get up during the night, then turns off shortly after. It sells for \$19.99 and I love it. (Submitted by Carol Tate)
- 4** Here's the reason to make boat bags your best friends. Your arms are important to your balance. When you carry items, it can take your arms out of the balance equation, especially if you are holding them chest-high or using both hands. Using a boat bag allows you to carry multiple items held below the waist by the cloth handle and thus keeping your arms ready for balance. Boat bags, or any cloth bag with a handle, come in many sizes and fabrics so it's easy to keep them handy. (Submitted by Patrick Callahan)
- 5** Things got so much easier when we installed a second bannister on the stairs in our home. Can't move to single story at this point but railing on both sides makes it safer! (Submitted by Christine Bielski)
- 6** I really struggle with putting my earrings in. After one-half hour, I still don't have the earring studs in. The occupational therapist helped me, but still no luck. So now I take earrings with me to the beautician and she puts them in for me after she cuts my hair. It only takes her a minute or two. (I choose earring that are comfortable enough to sleep in and also to leave in for a while.) I really like my earrings and this way I don't have to give them up! (Submitted by Marcia Chesser)
- 7** I have SCA 6 and am participating in a research program. I have been walking in a brace that goes up to my knee on my weaker leg that has a carbon support insert under the pad of my shoe to front of leg up to my knee. Within hours I was able to walk much more securely. It helps me to spring up so I can maneuver the stairs instead of dragging my body up the railing. (Submitted by Carol Vance)

***Ataxia Tips must be submitted by 8/6/18 to be eligible for inclusion in the next issue of *Generations*.
Submit them via email to naf@Ataxia.org.**

Researching Ataxia with Passion

Dr. Vincenzo Alessandro Gennarino's Journey



When I joined the lab of Dr. Huda Zoghbi for postdoctoral study, I knew I wanted to learn to apply my background in RNA biology to understanding the brain. But it was the 2014 Ataxia Investigators Meeting in Las Vegas that made me decide to specifically study Ataxia. That Wednesday night during the “night with patients,” a woman my age came to ask me questions about her SCA1 mutation. Being able to talk with someone who was facing a lifetime of degeneration profoundly moved me, and I decided to devote my skills to solving the problem of Cerebellar Ataxia.

Elevated levels of certain proteins are toxic to the brain. I soon discovered that the RNA-binding protein (RBP) PUM1 regulates the expression of ataxin-1 protein, and that a 50% reduction of PUM1 increases wild-type ataxin-1 levels by 30%-40%, which is enough to cause cerebellar degeneration. I also discovered that this degeneration can be rescued by normalizing ATXN1 levels. This work indicated that PUM1 should be involved in neurological disease in human beings.

Thanks to the support of the National Ataxia Foundation, I was able to collaborate with medical geneticists in North America and Australia to identify 20 people who carry loss-of-function mutations in PUM1. The mutations that reduced PUM1 levels by 50-60% cause the most severe disease (early-onset PUM1-associated developmental delay and seizures, or PADDAS), while a mutation that lowers PUM1 levels only 25% produces a mild, late-onset pure Ataxia (PUM1-related cerebellar Ataxia, or PRCA). OMIM recently decided to name both diseases as SCA47. This work was published a few months ago in *Cell*, with grateful acknowledgement of the National Ataxia Foundation.

This work was also the centerpiece of my applications for faculty positions. My wife and

I had twins three years ago, so it was even more challenging to go on interviews while trying to finalize the experiments that would go into my paper. But all the work was worth it when on May 10, at 1pm, Dr. Gerard Karsenty called to offer me a position in the Department of Genetics & Medicine at Columbia University Medical Center. I was thrilled. I'd gotten to know Gerard through several visits to Columbia, and he really took me under his wing. He lessened the stresses of moving and doubled the joys. My new lab is now located at the Hammer Building 14 floor, and I have hired my first two lab members. We just began doing experiments last month, when the lab renovations finished.

My colleagues are doing amazing work on everything from development to cancer. I'm also thrilled to say that since the publication of the *Cell* paper, I've been contacted by scientists in Germany and clinical colleagues at Columbia who have identified new patients with mutations in PUM1. We are now going to develop an online resource so we can collect information, compare notes, and get a better understanding of all the forms of SCA47. We hope this will speed us along the way to developing treatments.

I am extremely grateful to the National Ataxia Foundation, whose support enabled me to do the work that led to my becoming an independent investigator. My greatest desire now is to understand and develop treatments for neurodegenerative disease and teach future generations to follow their curiosity.

7th Ataxia Investigators Meeting (AIM)

From Bench to Bedside: Entering a New Era of Ataxia Therapies

The 2018 AIM brought together over 160 Ataxia researchers from 12 countries and from all over the United States. The purpose of each AIM is to bring Ataxia researchers together to exchange ideas and knowledge to move the field toward developing effective treatments and therapies for those living with Ataxia. In addition to researchers, the AIM 2018 was attended by representatives from 15 pharmaceutical companies and from four Ataxia patient advocacy groups.

The meetings' objectives were to:

- 1) refine our understanding of cerebellar function and dysfunction;
- 2) develop and evaluate therapeutic strategies;
- 3) facilitate development of robust clinical trials in Ataxias;
- 4) help to establish future leaders of Ataxia research by facilitating the involvement of young investigators;
- 5) bring trainees into contact with Ataxia patients and their families.

To achieve the fifth objective, a poster session was designed specifically for those present at the Annual Ataxia Conference to attend the session to view the scientific discoveries and personally meet and speak with Ataxia researchers who were presenting their research. Researchers were also invited to attend the Birds of a Feather sessions to interact with those affected by Ataxia and family members. A highlight for the researchers was during the final dinner when three individuals from the Ataxia community shared their stories of living with Ataxia or caring for a child who has Ataxia. Thank you to Linda Snider, Michael and Karen Leader, and Kyle Bryant for speaking at the AIM dinner.

The post-meeting survey included the question “What did you like best about this meeting?” Below are some of the responses:

“Contact with patients at the dinner was very impactful.”

“I loved the patient interactions and poster sessions.”

“The patient interactions and especially the dinner where patients and family members gave testimonials. This is the most impactful part of the meeting for me.”

“Meeting patients and hearing them talk at dinner.”

“The patient talks were truly inspiring and moving.”

The National Ataxia Foundation is grateful to the AIM Chair, Gulin Oz, PhD, and Co-Chair, Albert La Spada, MD, PhD, and the Steering Committee members, Marija Cvetanovic, PhD, Patricia Maciel, PhD, Harry Orr, PhD, Jeremy Schmahmann, MD, Vikram Shakkottai, MD, PhD, and George (Chip) Wilmot, MD, PhD for the countless hours they spend to apply for an NIH meeting grant, develop the program, invite speakers, review abstracts, chair the scientific oral sessions at the meeting and many other tasks that make the AIM so successful.

A meeting such as the AIM, cannot take place without the generous support of donors, patient advocacy groups and industry sponsors.

The National Ataxia Foundation and meeting organizers thank:

The Clementz Family Foundation
National Institutes of Neurological Disorders and Stroke at the National Institutes of Health
National Center for Advancing Translational Sciences/Office of Rare

Diseases
Biogen Inc.
Biohaven Pharmaceuticals
BioMarin Pharmaceutical
Cadent Therapeutics
Cydan II
Ionis Pharmaceuticals, Inc.
Reata Pharmaceuticals
Steminent Biotherapeutics Inc

Takeda Pharmaceuticals International, Inc.
Ultragenyx
A-T Children’s Project
Ataxia UK
Bob Allison Ataxia Research Center (BAARC)
Friedreich’s Ataxia Research Alliance (FARA)

One final quote from the survey responses truly summarizes the quality of the AIM 2018. “Collegiate and friendly. Cutting edge clinically relevant topics.”

1 - Patient Perspective Speakers Mike Leader, Linda Snider and Kyle Bryant, 2 - AIM Chair, Gulin Oz, PhD, 3 - AIM Co-Chair, Albert La Spada, MD, PhD, 4 -2018 AIM Group Photo



You need to get tested: Here's why

Genetic Testing

Dr. Jeremy D. Schmahmann



Dr. Schmahmann
speaking at AAC

At the 2018 Annual Ataxia Conference, Dr. Jeremy D. Schmahmann, a member of NAF's Medical Research Advisory Board and Director of the Massachusetts General Hospital Ataxia Unit, gave a presentation titled: "Genetic Testing - You need to get tested: Here's why." Below is a brief synopsis of what he presented.

Genetic testing for Ataxia patients and families can be both simple and complicated. Simple because it is accomplished by a blood test in the same way that you routinely have blood tested at your doctor's office for medical care. And complicated because of the issues it raises, and the hoops the insurance companies make us all jump through to accomplish this. Ataxia is a family affair. Not only because family members care for the Ataxia patient, but because family members may be at risk of inheriting the gene, becoming affected by the illness, and passing it on.

Not all Ataxias are genetically mediated or hereditary. Your neurologist will determine whether it is likely that your Ataxia is caused by a gene, based on your family history and the results of neurological examination and selected special investigations such as brain imaging and laboratory data. If it is likely that you have a genetic cause of your Ataxia, knowing your gene status can give you greater clarity about the course and progression of your Ataxia. It can affect which kinds of medicine may work for you. It is powerful information for members of your family, and for future members of your family because it puts in your hands the ability to stop the disease from being passed on to the next generation using new technologies such as preimplantation genetics. It is the critical step for you to enroll in natural history studies and in clinical trials, and for the use of gene-targeted treatments that are now on the horizon.

Geneticists tell us that about 50 - 60% % of the predictive power of the course of your disease is conveyed by the details of your gene diagnosis. That means that the rest is determined by other genes, by the way you live your life in your own environment or, most likely, a combination of these factors. Many lifestyle factors are under your control, and knowing your gene status empowers you to take early and active preventive measures to improve long term physical and psychological health, both for you and your family.

To hear the complete presentation, go to <https://Ataxia.org/18aacpresentations-videos/>

Do you know about GINA? Employers can't discriminate against you and health insurers can't raise your rates because of your genetics - it's the law!

Knowing the protections, you have with a genetic disease, such as Ataxia, is important. Learn about your genetic rights! For more information visit: <https://www.youtube.com/watch?v=V4BMwvApZYA>.

National Ataxia Foundation

62nd Annual Ataxia Conference

March 29-30, 2019

Registration & Room Reservations

Open November 13, 2018

12 PM Central Time



Flamingo Hotel and Casino

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

61st Annual Ataxia Conference

April 5-6, 2018

Philadelphia, Pennsylvania

“Fighting for Freedom”

The 2018 Annual Ataxia Conference (AAC) had over 500 attendees, from 37 states across the United States and 5 countries including, United Kingdom, Canada, Australia, Denmark and Spain. More than 200 attendees joined us for their first time. The AAC is where some of NAF’s most important life-changing work is realized. Our goal is to bring people impacted by Ataxia together, to empower them with resources, and give a message of hope. This is the heart of NAF and we exist to provide a community that can be counted on to support one another. The Annual Ataxia Conference continues to inspire and open our minds and hearts to new possibilities.

NAF would like to extend a special thank you to all the attendees, speakers, facilitators, exhibitors, and the outstanding volunteers of the 2018 NAF Annual Ataxia Conference. Especially the Northeast region for hosting such a successful event. We at NAF recognize the resources, sacrifices, and challenges that many attendees face to attend the AAC. Your attendance is abundantly appreciated. This conference would not have been possible without the time, contributions, and efforts given by so many. Thank you very much for the wealth of information and knowledge that was brought to the conference by all the speakers, facilitators, and exhibitors. The information and skills taken away from this conference by the attendees is invaluable.

This year’s AAC program was very exciting and well received. For the first time ever, the General Sessions were broadcasted live on Facebook. Those that could not attend were able to be a part of the conference. The General Sessions were scheduled in the mornings and Birds of a Feather Sessions were offered in the afternoons on Thursday and Friday. This provided those in attendance part of the afternoon free to visit the exhibitor booths, check out the activity room or, visit with other attendees. Conference attendees had an opportunity to meet Ataxia researchers

- 1 - Dedicated Service Award, Julie Schuur
- 2 - Exceptional Service Award, George Wilnot, MD, PhD
- 3 - I am the Strength Behind the National Ataxia Foundation Award, Lisa Cole
- 4 - I am the Strength Behind the National Ataxia Foundation Award, The Johns Hopkins University Ataxia Center



on Wednesday night to view scientific posters and ask questions about their research. With the seventh Ataxia Investigators meeting (AIM) held prior to the AAC, Poster Session was planned to allow those affected with Ataxia and their families to interact and engage with researchers who normally don't get the opportunity to interact with those affected by Ataxia.

The conference concluded on Friday night with a formal dinner and dancing for all those who attended. As well as a presentation where the NAF recognized individuals for their dedication and commitment to NAF's mission. "I am the Strength Behind the National Ataxia Foundation" awards went to Lisa Cole and The Johns Hopkins University Ataxia Center. George (Chip) Wilmot, MD, PhD, received an Exceptional Service awards for his commitment to NAF and Ataxia families. Julie Schuur received a Dedicated Service award for more than six decades as a Board Member of the National Ataxia Foundation.

Considerable appreciation and gratitude goes out to this year's sponsors Biohaven Pharmaceuticals, Reata Pharmaceuticals, MassMutual SpecialCare, and Retrophin.

SpecialCare
a special needs program developed by MassMutual

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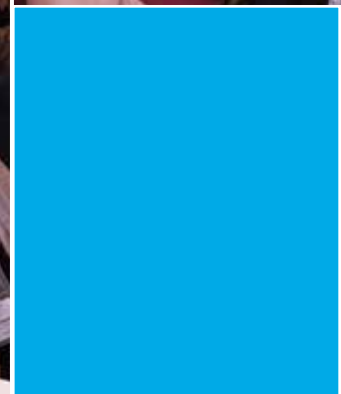
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“Fighting for Freedom” Snapshots

Annual Ataxia Conference
Philadelphia, PA • April 5-6, 2018





NAF National Ataxia Foundation
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 ANNUAL ATAXIA CONFERENCE
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IAAD ATAXIA FIGHTERS

#IAAD18

International Ataxia Awareness Day (IAAD) is on Monday, September 25, 2018. It is a coordinated effort from individuals and Ataxia organizations around the world to help shed light to this rare disease. What better way to get involved in the fight against Ataxia than IAAD? The NAF is committed to leading the way on this outreach effort - but we need your help! We encourage individuals, groups, and Ataxia advocacy organizations to join us by planning events and/or awareness campaigns for IAAD. The NAF will release an official campaign kit for 2018 in the coming month that will provide ideas for key messages to use at your events or in your campaigns. This kit can be used as a guide or just for ideas to get you started in planning your own messages. Please watch for more info on our website and in our monthly e-newsletter! Not subscribed to that? Sign up at <http://bit.ly/NAFemail>. Report your IAAD events to the NAF to get them listed on our events calendar.

Get Involved in IAAD - Make a Difference • ataxia.donorpages.com/2018IAAD/

Organize or Join an Activity

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

Post on Social Media

An easy and free way to help with Ataxia awareness is social media. You can post a personal story, facts, or information about Ataxia to help with the awareness efforts. The NAF's IAAD campaign kit will offer social media post ideas and images. You can follow the NAF on Facebook, Twitter, and LinkedIn to share our IAAD messages as well. Use #IAAD18 for your

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

Use the NAF's Campaign Materials

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

The 2018 IAAD Campaign Kit will also provide facts about Ataxia and suggestions for awareness topics. You can use the pieces of the kit that you find helpful and ignore the pieces that you don't need. It



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

Support Group News



Alabama Ataxia Support Group

Submitted by Becky Donnelly

The Alabama Ataxia Support Group held its April 28th meeting and luncheon at Covenant Presbyterian Church in Homewood, AL. The featured speaker was John Parnell, EMC Insurance Company, who shared his life journey with Ataxia. John's diagnosis of Ataxia came in 2013 and he shared his symptoms and frustrations with life-changes that occurred. John is a musician and music helps him to cope. There was much interaction in the group as they listened and identified with John and gave encouragement one to another.

After a short business meeting, the group broke for an hour of fellowship and shared a delicious luncheon coordinated by Pat Guercio. Break-out sessions of those with Ataxia and those who are caregivers followed. This time is a favorite part of our meeting, a time to share concerns, coping tips, medicine updates, and encouragement.

Inspiration leader, Juanita Dorroh, closed our meeting with a short talk on "The Dandelion." She asked each member their birth month and then identified a beautiful flower to match that month and how each one of us can brighten our world and others just as their flower does. She then gave the attributes of the dandelion, really a weed with flowers, which we can see in our yards, gardens, and the roadside. But, this little old dandelion can do things other flowers cannot...when the wind blows, the flowers blow in all directions! Our next meetings are Saturday, September 22, Ataxia Awareness Event at the Galleria, Hoover, AL. Saturday, October 27, meeting/luncheon; speaker: Jane M. Bush, CVRT, AL Sept. of Rehabilitation Services. Saturday, December 1, Christmas Social, BA Warehouse, Birmingham, AL.



Arizona Ataxia Support Group

Submitted by Mary Fuchs

The Arizona Support Group held a meeting on May 5, at Ability 360, in Phoenix. We had a short meeting: during which Larry & Margaret Baker told us about the Philly conference. This was their first time. Both were very impressed and are looking forward to the

2019 convention in Vegas.

Joanne Loveland talked about the purpose and importance of a personal donation page, when we have our next fundraiser.

Rita Anand, from Health Care Management "ONE STOP CARE", was our guest speaker. She talked about many different health needs, legal needs, housing needs, etc. She comes to your home and evaluates your needs. Then her team of trusted professionals will come to help. Our next meeting is August 4th, contact Mary Fuchs for details.



Cincinnati Area Ataxia Support Group

Submitted by Julia Soriano

The Cincinnati Area Support Group or CASG is meeting again for the first time in years! We will meet the third Sunday of each month at 2:00 p.m. Even numbered months will be support only meetings and odd numbered months will be programmed. Each meeting will include introductions and a show and tell time. All meetings are confidential, except for agendas and presenter materials.

We will meet at the offices of Sharp Turn Institute, 201 E. 5th St, Suite 1901, Cincinnati, OH 45202. This accessible building is downtown Cincinnati across the street from Government Square, the end point for many Cincinnati public bus routes and a transfer point for the TNAK system serving Northern Kentucky. Parking is available on the street or in a parking structure attached to the building (fee). If you have any questions, call the Cincinnati Area Support Group leader, Julia Soriano.



Delaware Ataxia Support Group

Submitted by Joe DeCrescenzo

The Delaware Ataxia Support Group held its last meeting on May 5, 2018 at Christiana Hospital in Newark, Delaware. Our featured speakers included Dr. Daniel G.C. Lane, Dr. Brice S. Jackson and Nurse Leslie Wuenstel.

Daniel G. C. Lane, (Adv) BS DC CCEP DACNB FABBIR and Brice S. Jackson, DC FACFN

FABBIR are the co-founders of Mid-Atlantic Brain & Neurologic Rehabilitation Center. Both functioning neurologists; their practice attempts are to offer hope and results. Their presentation dispelled the myth that the brain cannot be changed. The brain can be wired and rewired and can be trained to work more efficiently. Leslie Wuenstel, RN is the Co-Chair, Dysautonomia International, Delaware Support Group. Dysautonomia is an umbrella term used to describe various conditions that cause a malfunction of the Automatic Nervous System. Her presentation explained dysautonomia and its components in Parkinsons and the SCAs.

It was encouraging to hear that there may be positives with these alternative approaches. Our next meeting is not yet scheduled but will most likely be in October.



Greater Denver Area Ataxia Support Group

Submitted by Charlotte DePew

Perhaps due to the April snowy/rainy weather, our quarterly meeting group was smaller than usual with 22 attending. Two new families were welcomed. It was a chicken and sub-sandwich dominant potluck with a spinach salad, mixed fruit, and cookies, making it a well-balanced delicious lunch. A "thinking-of-you" card for a group member was passed around for signatures and brief message, who is now in a long-term care facility. We miss him and send best wishes and love.

Ellen Belle, Physical Therapist from The Colorado Neurological Institute, was our speaker on the weighted vest. Ellen fitted 4 to 5 persons with the vest and weights after a brief discussion on balance that often improves with strategic application of weights. Each person trying the vest gained improved balance. In one case, the person wearing the vest did not feel an improvement; however, all of us saw significant improvement. His wife told him she was going to get the vest for him. Our next quarterly meeting is July 21, 2018.



Greater Houston Area Ataxia Support Group

Submitted by Dave Cantrell

Greater Houston Area Ataxia Support Group met on May

20th at Methodist Hospital - Sugar Land. 21 of our members showed up for an extremely informative meeting. David Brunnert started us off with a report on the NAF convention, (sounds like a good time was had by all). David has been appointed to the NAF Board of Directors and he gave us some insight into the inner workings of NAF at the national level. Having David there is going to really help us stay informed and up to date. We had a special participant today, Karen Toenis and her son Joe, Karen is a nurse and 25-year professional care-giver. Her husband had ALS and she cared for him as they went through many of the same trials and tribulations Ataxians do. A short time after her husband passed away she was asked to go to work with ALS patients in helping them get the care and tools they need along with participating in support groups and fund raising. Karen's son Joe, who was also in attendance, was in a serious car accident 5 years ago and has suffered a serious brain injury so her caregiving work continues. She had many interesting and new ideas for how to acquire the help needed and shortcuts to receive help quicker. A fantastic lady and all in attendance learned a great deal.

We proceeded with our traditional round table in a square room and was it ever fun. We had very lively discussions on a variety of topics from Machado, SCA 2, 6, 1, MSA and everything in between. Several great hints and ideas were passed along. Discussion turned to using the tools available to you to make your life easier and safer and to set the ego aside when it comes to the next phase of your life.

Towards the end of the meeting Eddie Zelaya helped show our members some martial arts stances that help with balance and walking, the results were incredible for a couple of people that were human guinea pigs and gave it a try. Thanks Eddie!

Karen showed us a convertible walker/wheelchair made by DRIVE that goes from walker to wheelchair in less than a minute eliminating the need for two separate units. Tomoko was sporting a new wheelchair that she can assemble and reassemble on her own and took a trip to Seattle by herself by air with no assistance. Amy demonstrated her new walker recommended by Robert Acevedo when he was down for our last meeting, it is called the "One Step" and

has reverse locking brakes. They are constantly engaged until you squeeze the “brake handles” and then they release. She loves it, makes it much safer when getting up out of a chair because the walker doesn’t move until you squeeze the handles.

Thanks to all that attended for your support and enthusiasm. Our next Meeting is July 21st at Methodist Woodlands from 1:00 – 3:00.



Kansas City Area Ataxia Support Group

Submitted by Laurie Colby

The KC Wobblers met on April 14, at the KC Public Library - Trails West Branch in Independence, MO. We had some support group business to get through first, but it wasn’t all work. We had an informative talk about balance wear vests as there are 4 people in our group who currently have them and many more who are interested. We also had some fun playing Bingo for small prizes. Just a reminder that we meet every other month, the 2nd Saturday of the month from 12-2. We hope to see you there.



Support Group leaders, Stephanie Wilkins - right, Laurie Colby - Left



South Eastern Florida Ataxia Support Group

Submitted by Jose Fernandes de Castro

The South Eastern Florida Ataxia Support group held their second support group meeting on Saturday, May 12, at Baptist Hospital in Miami. Those in attendance heard a presentation by a physical therapist and speech therapist on the benefits of therapy as well as areas to focus on. Feedback from the meeting was very positive and group members gained much information from the meeting and look forward to future meetings.

Tampa Bay Ataxia Support Group

Submitted by Jan Colon and Darlene Harris

The Tampa Bay Ataxia Support Group held their annual picnic on May 12, at the Al Lopez Park in Tampa, Fl. We decorated Ataxia Rocks, played board games and fellowshiped with each other. We had grilled hamburgers, hot dogs, baked beans, yellow rice, potato salad and a host of desserts. Thank you to everybody that participated at the Al Lopez Park picnic, we had a great time!



Tampa Bay Support Group

Treasure Coast Ataxia Support Group

Submitted by Lisa Cole

The Treasure Coast Ataxia Support Group held a meeting on Saturday, April 21, at the Florida Movement Therapy Center in Palm Beach Gardens. The meeting was very energetic and informative, everyone had a great time. This meeting is in North Palm Beach, FL; however, we may have another meeting here in November 2018. The Treasure Coast Ataxia Support Group will meet in West Palm Beach, Fl at least once a year.



Treasure Coast Support Group



Western Washington Ataxia Support Group

Submitted by Sherry McLaughlin

The Western Washington Ataxia Support Group met on May 12 to be introduced to Dr. Pravin Khemani, who has opened his practice at the Swedish

Hospital in Seattle. The level of excitement was very high at the prospect of welcoming a new neurologist who specializes in Ataxia. Even more exciting was the doctor's presentation, including his vision for an Ataxia clinic here in the Pacific Northwest. We look forward to hearing from Dr. Khemani again in the near future and we also plan to be "a force" when it comes to bringing his vision to reality.

Every support group leader needs the assistance of other group members. Sometimes, people help out with small projects and, sometimes, you are very lucky to have a member who possesses a great talent and is more than willing to share those talents for the benefit of the group. Sunny Prom was awarded a certificate of appreciation for not only, designing an incredibly beautiful new brochure for our group, but also serving as our technical advisor on other projects. We appreciate Sunny's contributions more than a certificate can say. Thank You, Sunny Prom from the Western Washington Ataxia Support Group.



Top: Western Washington Support Group,
Bottom: Dr. Pravlin



Northern California Ataxia Support Group

Submitted by Brian Wong

The Northern California Ataxia Support Group held a meeting on April 14, 2018 where Alexandra Nelson, MD, PhD, UCSF Ataxia Neurologist and Researcher gave a presentation and shared handouts. She gave an

update on the status of current treatment studies of prescription drugs, Riluzole, Trigriluzole, and reported on a study of Deep Brain Stimulation (DBS). Information about animal research studies related to Ataxia were also shared. There is an ongoing observation study of SCA1 and SCA3 patient in preparation for planned clinical trials. She distributed a flyer for the Huntington's Disease and Ataxia Clinic at UCSF. For more information go to: memory.ucsf.edu



Twin Cities Ataxia Support Group

Submitted by Lenore Schultz

Our group meets every third Saturday of the month in a centrally located, accessible and free meeting space for 2 hours.

Our group has generally mapped out for the year what we will be doing at each meeting. Over the last few years we are having less guest speakers at our meetings, and more meetings that we now call "Living with Ataxia". We start the meeting with the entire group. We do introductions and announcements. Our meeting room has a room divider that we have pulled out before the meeting begins. Once intros. and announcements have concluded, the caregivers, family members, and/or friends associated with someone who has Ataxia take their chairs to the other side of the split room while those of us with Ataxia form a circle in the current room. A person to facilitate each group has been determined beforehand.

After an hour, the 2 groups reunite. This type of meeting has become so popular, that it was decided that this year we do six "Living with Ataxia" meetings. Members always point out how much they learn about coping with Ataxia from each other.

We will be having our 9th Annual Walk, Stroll, 'n Roll in September. Last year over 500 people attended. It involves lots of time and effort to make our fundraiser happen. The growth in attendance is a testament to how the awareness of Ataxia has increased. And last year our fundraising goal was \$100,000 which we attained and then some. This year the goal is \$130,000. www.ataxia.org/wask/minnesota

We do not have a meeting in September because of our fundraiser. But we will have a meeting in October and November. We then end the year with a holiday party in December.



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:

Jerry Frick Director of Finance and Operations Manager	(763) 231-2745 jerry@Ataxia.org
Nick Gullickson, Finance Assistant	(763) 231-2746 nick@Ataxia.org
Sue Hagen, Patient and Research Services Director	(763) 231-2742 susan@Ataxia.org

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

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

Joel Sutherland,
Director of
Development (763) 231-2748
joel@Ataxia.org

Mollie Utting
Support, Engagement
& Advocacy
Coordinator (763) 231-2741
mollie@Ataxia.org

Social Networks



NAF Facebook Page

www.facebook.com/Ataxiafoundation/

NAF Facebook Support Group

www.facebook.com/groups/NAFmail

Under 30 with Ataxia

www.facebook.com/groups/under30withAtaxia



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-Hoover, AL

(205) 987-2883

E-mail: donnelly6132b@aol.com

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

Arizona

Phoenix Area Support Group Leaders

Angela Li-Peoria, AZ

(847) 505-4325

E-mail: angelali1010@gmail.com

Mary Fuchs- Casa Grande, AZ

(480) 212-6425

E-mail: mary11115@msn.com

Facebook Group:

www.facebook.com/groups/arizonaAtaxia/

Ambassador

Bart Beck-Tucson, AZ

(520) 885-8326

E-mail: bbeck15@cox.net

Arkansas

Ambassadors

Judy and David King-Springdale, AR

E-mail: davidrkingpd@cox.net

California

Los Angeles Area Support Group Leaders

Lora Morn-Santa Monica, CA

(310) 664-8808

E-mail: loramorn@gmail.com

Harvey Kahn-Whittier, CA

(562) 789-5776

E-mail: jkhk@aol.com

Northern California Area Support Group Leaders

Brian Wong

Santa Clara, CA

Fernando and Rocio Wu

Danville, CA

S.G. E-mail: info@norcalataxia.org

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

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

Sacramento Area Support Group Leader

Teresa Bredberg-Sacramento, CA

(916) 215-2686

E-mail: tbredberg@sbcglobal.net

S.G. Website: norcalataxia.org

Facebook Group:

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

Secondary Contact: Darrell Owens - Davis, CA

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/>

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

Ambassadors

Deborah Levi-Morro Bay, CA

(805) 407-0437

E-mail: Debbielevi213@yahoo.com

Deborah Omictin-Hayward, CA

(510) 783-3190

E-mail: rsisbig@aol.com

Martha Elliott-Camarillo, CA

(805) 987-2490

E-mail: DOCElliott268@gmail.com

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/

Connecticut

Connecticut Support Group Leader

Susan Masse - Broad Brook, CT
(860) 528-1875
E-mail: smasse1875@gmail.com

Tri-State Support Group Leader

Kathy Gingerelli-Parsippany, NJ
(201) 681-7639
E-mail: kgingerelli@msn.com

Delaware

Delaware Support Group Leaders

Joe & Cathy DeCrescenzo-Bear, DE
(302) 369-9287
E-mail: jdecr26@verizon.net
E-mail: cdecres@verizon.net

Florida

South Eastern FL Support Group Leader

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

Tampa Bay Support Group Leader

Darlene Harris -Tampa, FL
(813) 431-2859
E-mail: Msdee004@gmail.com
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
<https://www.floridastreasurecoastAtaxiasupportgroup.club/>
Facebook Group: <https://www.facebook.com/groups/572410932959895/>

Ambassadors

Carole Neff-Edgewater, FL
(386) 424-4192
E-mail: cmneff2@yahoo.com
Meghan McBrearty-Tallahassee, FL
(850) 524-9060
E-mail: megra10@hotmail.com

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/

Illinois

Chi-Town Friendship Group Leader

Jonas Cepkauskas- Matteson, IL

(708) 381-5555

E-mail: jonas@chitownAtaxia.org

www.fightAtaxia.org/Chitown

Chi-Town Metro Friendship Group Leader

Christopher (Topher) Marsh-Chicago, IL

(312) 227-7737

E-mail: 512crockettt@gmail.com

Ambassador

Elaine Darte-Coffeen, IL

(618) 397-3259

E-mail: elainedarte@yahoo.com

Indiana

Indiana Support Group Leader

Cheryl (Cheri) Bearman-Hoagland, IN

(260) 452-6231

E-mail: cheribearman@gmail.com

Iowa

Ambassador

Emily Medina-West Des Moines, IA

(515) 727-8713

E-mail: emily061578@yahoo.com

Facebook Group:

www.facebook.com/groups/107944351294/

Kansas

Ambassador

Jalean Retzlaff-Park City, KS

(316) 303-2351

E-Mail: jlrtrolls@yahoo.com

Kentucky

Ambassador

Janice Johnson-Brownsville, KY
(270) 597-3854

Maine

Maine Support Group Leader

Alan and Paula Nadeau-Belgrade, ME
E-mail: psn92871@roadrunner.com

Maryland

Chesapeake Chapter President

Carolyn Davis-Vienna, VA
(703) 759-2008
E-mail: ccnafpres@gmail.com

Johns Hopkins Ataxia Center Support Group Leader

Donna DeLeno Neuworth, Ataxia Clinic Health Educator
(410) 616-2811
Lutherville, MD
E-Mail: ddelenoi@jhmi.edu

Ambassador

Karen DeVito-Frederick, MD
(301) 682-5386
E-mail: karen.devito@yahoo.com

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

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

Michigan

Detroit Area Support Group Leader

Tanya Marshall-Detroit, MI
(313) 736-2827

E-mail: tinyt48221@gmail.com

Western Michigan Support Group Leader

Lynn K. Ball-Grand Rapids, MI
(269) 330-1975
E-mail: lynnkball@aol.com

Minnesota

Central MN Support Group Leader

Marsha Binnebose-St. Cloud, MN
(320) 248-9851
E-mail: mbinnebose@hotmail.com

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

Ambassadors

Julie Schuur-Luverne, MN
(507) 283-2555
E-mail: jschuur@vastbb.net

Lori Goetzman-Rochester, MN

(507) 990-4506
E-mail: logoetz@gmail.com

Mississippi

Mississippi Chapter President

Camille Daglio-Hattiesburg, MS
E-mail: daglio1@bellsouth.net

Missouri

Kansas City Support Group Leaders

Stephanie Wilkins
Lee's Summit, MO
(816) 623-3318
Cell: (949) 463-6102
E-Mail: stwilkins@yahoo.com

Laurie Colby

Kansas City, MO
(816) 429-6456

Cell: (816) 745-4549
Lcolby61@gmail.com

St. Louis Support Group Leader

Shannon Dunphy-Lazo - St. Louis, MO
(202) 306-2738
Shan_d@hotmail.com

Ambassadors

Roger Cooley-Columbia, MO
(573) 474-7232 before noon
E-mail: rogercooley@mediacombb.net

Nebraska

Nebraska Ataxia Support Group Leader

Linda Snider-Omaha, NE
(402) 212-3060
E-mail: lindasnider@cox.net

Nevada

Ambassador

Debbie Grant-Las Vegas, NV
(770) 885-3092
E-mail: grantgirl2004@aol.com
Facebook Group: <https://www.facebook.com/groups/2090650814550409/>

New Hampshire

New Hampshire Support Group Leader

Doug Place - Melrose, MA
(781) 307-0800
E-mail: douglas.place@comcast.net

Donna Gorzela - Billerica, MA

(978) 490-9552
E-mail: donna.gorzela@gmail.com

New Jersey

Tri-State Support Group Leader

Kathy Gingerelli-Parsippany, NJ
(201) 681-7639
E-mail: kgingerelli@msn.com

New Jersey Support Group

Priya Mansukhani - Manville, NJ
(908) 342-5675
E-mail: priyamans@gmail.com

New York

Tri-State Support Group Leader

Kathy Gingerelli-Parsippany, NJ
(201) 681-7639
E-mail: kgingerelli@msn.com

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

Western NC Support Group Leader

Jodie Kawa - Brevard, NC

(828) 384-8414

E-mail: jodiekawa@comporium.net
Facebook Group: <https://www.facebook.com/groups/919905244740316/>

Ohio

Cincinnati Support Group Leader

Julia Soriano-Cincinnati, OH
(513) 899-1195
E-mail: julia@epivision.com
Group Blog: [Ataxiafoundationcleveland.blogspot.com/](http://ataxiafoundationcleveland.blogspot.com/)

Cleveland Area Support Group Leader

Carmen Pieragastani - Willowick, OH
(216) 272-5588
E-mail: willowpier@roadrunner.com
Blog: <http://ataxiafoundationcleveland.blogspot.com/>

Oklahoma

Central Oklahoma Ataxia Support Leader

Carrie Stanley
(405) 387-9227
E-mail: cdstanley1977@gmail.com
Facebook Group: <https://www.facebook.com/groups/421890291503549/permalink/428669084159003>

Oregon

Willamette Valley Support Group Leader

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

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/

Western PA Support Group Leaders

Ed Schwartz- McMurray, PA
(724) 941-2210
E-mail: eds@Ataxia.org
Facebook Group: www.facebook.com/wpaAtaxianafwesternpasupportchapter.weebly.com/

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

South Carolina

Ambassador

Brad Forth - Greenville, SC

(864) 415-8147

E-mail: bradf@photoforth.com

South Dakota

Sioux Empire Support Group Leader

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

Texas

Greater Houston Area Support Group Leader

Dave Cantrell - Montgomery, TX

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

E-mail: dcant7358@aol.com

Facebook Group:

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

North Texas Area Support Group Leader

David Henry Jr. - Trophy Club, TX

(817) 73 9-2886 (contact by email preferred)

E-mail: chevelle@sbcglobal.net

Facebook Group: www.facebook.com/Ataxiasupport

Ambassadors

Dana LeBlanc - Orange, TX

(409) 883-5570

E-mail: tilessal@yahoo.com

Debra Whitcomb - El Paso, TX

(915) 329-0721

E-mail: debrawhitcomb@hotmail.com

Utah

Utah Support Group Leaders

Grant Beutler - Salt Lake City, UT

E-mail: grant.beutler@gmail.com

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

(801) 585-6635

E-mail: lisa.ord@hsc.utah.edu

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

Virginia

Chesapeake Chapter President

Carolyn Davis - Vienna, VA

(703) 759-2008

E-mail: ccnafpres@gmail.com

Washington

Western Washington Support Group Leader

Sherry McLaughlin

(360) 344-2445

E-mail: ccherilynmc@yahoo.com

Ambassador

Linda Jacoy - Spokane, WA

(509) 482-8501

E-mail: linda4727@hotmail.com

Wisconsin

Wisconsin Support Group Leader

Kory Macy - Madison, WI

(608) 628-2700

E-mail: kstab77@yahoo.com

Ambassador

Richard Jones - Elmwood, WI

(715) 639-2324

E-mail: Jones1957@hotmail.com

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/

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

Matching Gifts

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

Participants Needed for Research in Spinocerebellar Ataxia

CLINICAL TRIAL READINESS FOR SCA1 AND SCA3 -READISCA-

DO YOU MEET THE FOLLOWING STUDY CRITERIA?

- You have the clinical or genetic diagnosis of spinocerebellar ataxia type 1 or type 3 (SCA1 or SCA3) **OR**
- Diagnosis of SCA1 or SCA3 in one of your first degree relatives

For example

- You have early ataxia and your parent has SCA1 or SCA3
- You have no symptoms but you were tested positive for SCA1 or SCA3
- You have no symptoms and have not taken DNA testing, but your sibling or parent tested positive for SCA1 or SCA3

If so, then you may qualify for participating in this international multi-institutional study. Please note that various restrictions may apply for the eligibility.

MAIN GOALS OF THIS STUDY

- To establish the world's largest group of early stage and symptomless SCA1 and SCA3 individuals.
- To validate imaging signs in early stage and symptomless SCA1 and SCA3 individuals.
- To adapt recent findings to design clinical trials for spinocerebellar ataxias.

IRB# Pro00022607

If you are interested and would like to have further information, please contact:

Houston Methodist Research Institute
Tetsuo Ashizawa, MD - Contact PI/PD

Phone: 346-238-5021

Email: U01SCA1&3@houstonmethodist.org

Please note that there are 18 study sites across the US where you can participate in this project

- This is not a treatment trial. Rather, this study is to get ready for treatment trials we anticipate within 5 years.
- This research visit will likely take about half a day. You will be asked to return annually for the next five years.
- We will draw blood and perform DNA testing to confirm your genetic diagnosis, and if you wish to know your gene status, we will release the DNA results to your doctor or genetic counselor at no cost to you.
- You will be asked about optional spinal fluid collection by spinal tap (you can say "no" but the spinal fluid is extremely important for developing new drugs for SCAs).
- If qualified, you will be asked to participate in an imaging study using an MRI machine in Boston, Baltimore, Minneapolis or Gainesville (FL).
- There will be no cost for participation, and all expenses will be paid.



2018

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

Thursday, July 12, 2018

Tri-State Ataxia Support Group Meeting

Time: 6:30pm - 8:30pm

Location: Mount Sinai Beth Israel Medical Center, Phillips Ambulatory Care Center, Conference Room 3 10 Union Square East, New York, NY 10003

More info: Kathleen Gingerelli at 201-681-7639 or kgingerelli@msn.com

Saturday, July 14, 2018

Central Minnesota Ataxia Support Group Meeting

Time: 9:45am - 11:45am

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

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

North Texas Ataxia Support Group Meeting

Time: 10:00am - 12:00pm

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 building from the church.

More info: David Henry at chevelle@sbcglobal.net

Indiana Ataxia Support Group Meeting

Time: 11:00am - 2:00pm

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

Details: Join our 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 and enter at entrance one - follow hallway to the right) Please RSVP

More Info: Amy Draves at 765-610-2866 or amy4kids@msn.com, Teresa Coccraro at 317-439-2512 or tcoccaro12@gmail.com

St. Louis Ataxia Support Group Meeting

Time: 11:00am - 1:00pm

Location: The Center for Advanced Medicine, 4921 Parkview Place, St. Louis, MO, 63110

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

Northern CA Ataxia Support Group Meeting

Time: 11:00am – 3:00pm

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

More Info: Brian Wong at blwong7@gmail.com

Los Angeles Ataxia Support Group Meeting

Time: 2:00pm – 4:00pm

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

Sunday, July 15, 2018

Chi-Town Ataxia Friendship Group Meeting

Time: 1:00pm – 5:00pm

Location: Good Samaritan Hospital, 3801 Highland Ave, Downers Grove, IL 60515

More info: Jonas Cepkauskas at 708-381-5555 or jonas@chitownAtaxia.org

Cincinnati Area Support Group Meeting

Time: 2:00pm – 4:00pm

Location: Sharp Turn Institute, 201 E 5th St, suite 1901, Cincinnati, OH 45202

Details: We meet the third Sunday of each month at 2:00 p.m. Even numbered months will be support only meetings and odd numbered months will be programmed. Each meeting will include introductions and a show and tell time. All meetings are confidential, except for agendas and presenter materials.

We will meet at the offices of Sharp Turn Institute, 201 E. 5th St, Suite 1901, Cincinnati, OH 45202. This accessible building is downtown Cincinnati across the street from Government Square, the end point for many Cincinnati public bus routes and a transfer point for the TANK system serving Northern Kentucky. Parking is available on the

street or in a parking structure attached to the building (fee).

More Information: Julio Soriano at 513-899-1195 or asharpturn@epivision.com

Saturday, July 21, 2018

Tampa Bay Ataxia Support Group Meeting

Time: 12:30pm – 3:00pm

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

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

Sacramento Ataxia Support Group Meeting

Time: 1:00pm – 3:00pm

Location: UC Davis Medical Center Campus – The Lawrence J. Ellison Ambulatory Care Center Building, 4860 Y St, 3rd Floor, conference room 3010A, Sacramento, CA 95817

Details: We meet the third Saturday of each month. Location/Room Subject to change, please contact facilitator to confirm location.

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

Denver Ataxia Support Group Meeting

Time: 1:00pm – 4:00pm

Location: Swedish Medical Center, 501 E Hampden Ave, Englewood, CO 80113

Details: We meet in the 2nd floor conference rooms.

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

Greater Houston Ataxia Support Group Meeting

Time: 1:00pm – 3:00pm

Location: Methodist Hospital – Woodlands, 17201 Interstate 45, The Woodlands, TX 77385

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

Saturday, August 4, 2018

Florida Ataxia Support Group Meeting

Time: 10:30am – 1:30pm

Location: South West Library - Community Room,
7255 Della Dr, Orlando, FL 32819

Details: Darlene Harris at 813-431-2859 or
msdee004@yahoo.com, Jose de Castro Fernandez
at 954-864-1436 or josefernandezdecastro@ymail.com, or Lisa Cole at 772-370-3041 or
lisacoleAtaxia@gmail.com

Arizona Ataxia Support group Meeting

Time: 1:00pm - 3:00pm

Location: Ability 360, 5025 E Washington Street,
Phoenix, AZ 85034

More Info: Angela Li or Mary Fuchs at
ArizonaAtaxia@gmail.com

Saturday, August 11, 2018

Central Minnesota Ataxia Support Group Meeting

Time: 9:45am - 11:45am

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

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

North Texas Ataxia Support Group Meeting

Time: 10:00am - 12:00pm

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
building from the church.

More Information: David Henry at [chevelle@
sbcglobal.net](mailto:chevelle@sbcglobal.net)

St. Louis Ataxia Support Group Meeting

Time: 11:00am - 1:00pm

Location: The Center for Advanced Medicine, 4921
Parkview Place, St. Louis, MO, 63110

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

Kansas City Ataxia Support Group Meeting

Time: 12:00pm - 2:00pm

Location: KC Public Library - Trails West Branch,
11401 E 23rd St, Independence, MO 64052

More info: Stephanie Wilkins at 816-623-3318 or
sfwilkins@yahoo.com

Saturday, August 18, 2018

Twin Cities Ataxia Social Group Meeting

Time: 10:00am - 12:00pm

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

Details: The Twin Cities Ataxia Support Group
meets once a month. Family and Friends of an
afflicted individual are always welcome! We meet
on the third Saturday of every month at 10:00am
for 2 hours in a meeting room at Langton Place
which is located on the south side of the road on
Country Road D roughly for tenths of a mile east
of I35W in Roseville. We wanted to provide a
central location that is easy to access which is why
we picked this place. 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: 1:00pm - 3:00pm

Location: UC Davis Medical Center Campus -
The Lawrence J. Ellison Ambulatory Care Center
Building, 4860 Y St, 3rd Floor, conference room
3010A, Sacramento, CA 95817

Details: We meet the third Saturday of each month.
Location/Room Subject to change, please contact
facilitator to confirm location.

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

Orange County Ataxia Support Group Meeting

Time: 2:00pm - 4:00pm

Location: Orange Coast Memorial Hospital Medical
Center, 18035 Brookhurst St, Fountain Valley, CA
92708

More info: Cindy DeMint at cindyocAtaxia@gmail.com

Western Wisconsin Ataxia Support Group Meeting

Time: 2:00pm - 4:00pm

Location: Milestone Senior Living Center, 5512 Renee Dr, Eau Claire, WI 54703, 1st floor community room.

Details: Join us for our first meeting where along with getting to know each other we will discuss topic and date for future meetings. For more information or to be added to the group's mailing list please contact Richard Jones at (715) 639-2324 or jones1957@hotmail.com We look forward to meeting you!

Saturday, August 19, 2018

Cincinnati Area Support Group Meeting

Time: 2:00pm - 4:00pm

Location: Sharp Turn Institute, 201 E 5th St, suite 1901, Cincinnati, OH 45202

Details: We meet the third Sunday of each month at 2:00 p.m. Even numbered months will be support only meetings and odd numbered months will be programmed. Each meeting will include introductions and a show and tell time. All meetings are confidential, except for agendas and presenter materials.

We will meet at the offices of Sharp Turn Institute, 201 E. 5th St, Suite 1901, Cincinnati, OH 45202. This accessible building is downtown Cincinnati across the street from Government Square, the end point for many Cincinnati public bus routes and a transfer point for the TANK system serving Northern Kentucky. Parking is available on the street or in a parking structure attached to the building (fee).

More info: Julio Soriano at 513-899-1195 or asharpturn@epivision.com.

Saturday, September 8, 2018

Central Minnesota Ataxia Support Group Meeting

Time: 9:45am - 11:45am

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

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

North Texas Ataxia Support Group Meeting

Time: 10:00am - 12:00pm

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 building from the church.

More info: David Henry at cheve11e@sbcglobal.net

Indiana Ataxia Support Group Meeting

Time: 11:00am - 2:00pm

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

Details: Join our 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 and enter at entrance one - follow hallway to the right) Please RSVP.

More Information: Amy Draves at 765-610-2866 or amy4kids@msn.com, Teresa Coccraro at 317-439-2512 or tcoccaro12@gmail.com

St. Louis Ataxia Support Group Meeting

Time: 11:00am - 1:00pm

Location: The Center for Advanced Medicine, 4921 Parkview Place, St. Louis, MO, 63110

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

More Information: Shannon Dunphy Lazo at 202-306-2738 or shand@hotmail.com

Thursday, September 13, 2018

Tri-State Ataxia Support Group Meeting

Time: 6:30pm - 8:30pm

Location: Mount Sinai Beth Israel Medical Center, Phillips Ambulatory Care Center, Conference Room 3 10 Union Square East, New York, NY 10003

Details: Kathleen Gingerelli at 201-681-7639 or kgingerelli@msn.com

Saturday, September 15, 2018

Tampa Bay Ataxia Support Group Meeting

Time: 12:30pm - 3:00pm

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

Details: Darlene Harris at 813-431-2859 or
Msdee004@gmail.com

Sunday, September 16, 2018

Chi-Town Ataxia Friendship Group Meeting

Time: 1:00pm - 5:00pm

Location: Good Samaritan Hospital, 3801 Highland Ave,
Downers Grove, IL 60515

Details: Jonas Cepkauskas at 708-381-5555 or
jonas@chitownAtaxia.org

Greater Houston Ataxia Support Group Meeting

Time: 1:00pm - 3:00pm

Location: Methodist Hospital - Woodlands, 17201
Interstate 45, The Woodlands, TX 7385

Details: Dave Cantrell at Home: 936-588-5179, Cell:
936-206-1504, E-Mail: dcantr7358@aol.com

Cincinnati Area Support Group Meeting

Time: 2:00pm - 4:00pm

Location: Sharp Turn Institute, 201 E 5th St, suite 1901,
Cincinnati, OH 45202

Details: We meet the third Sunday of each month at 2:00 p.m. Even numbered months will be support only meetings and odd numbered months will be programmed. Each meeting will include introductions and a show and tell time. All meetings are confidential, except for agendas and presenter materials.

We will meet at the offices of Sharp Turn Institute, 201 E. 5th St, Suite 1901, Cincinnati, OH 45202. This accessible building is downtown Cincinnati across the street from Government Square, the end point for many Cincinnati public bus routes and a transfer point for the TANK system serving Northern Kentucky. Parking is available on the street or in a parking structure attached to the building (fee).

More information: Julio Soriano at 513-899-1195 or
asharpturn@epivision.com.

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Disability Resources

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

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 March 2018 – June 2018. 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.

Anthony La Spada	Jacqueline DeVito	Patricia Rymut
Barry Washburn	JoAnn Evans	Robert A. Keiter
Bob Keiter	Joel Leventhal	Santa Croce Family
Brad Sherrod	John Louis Weir	Sharon Baggett
Bradley Lower	Karla Ann Owen	Summer B. Little
Buddy W. Madden Jr.	Kate & Judy Loftin	Susan Hochberg
Cheryl Martin	Krista Humes	Teri Kemper
Claire J. (Mackey) Conway	Leona A. Johnson	Tom Schramm
Danny Cook	Manuel Cardoza	Vickie Balogh
Debra Griffin Cutten	Melvin Goodman	Wanda Sue States
Ellen Moetsch	Michael Hensley and the Kansas City Ataxia Support Group (KC Wobblers)	William Kingery
Gay Coakley		
Gordon Ballinger	Mrs. Barbara Engler	

Upcoming Informational, Awareness Events, and Fundraisers

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

Saturday July 14, 2018

Dart Tournament Fundraiser

Time: 4:00pm - 7:00pm

Location: Booger Reds, 6125 SE 15th St, Midwest City, OK 73110

Details: 501/Cricket Tournament. \$10 entry fee per contestant at the door. Cash prizes. Half of the entry fee is donated to NAF and matched by Booger Reds. Non-dart players are welcome. 50/50 raffle and prizes, light snacks will be served. All proceeds benefit the National Ataxia Foundation.

More information: Christopher DeHaven at (936) 223-0795 or photoman94@gmail.com

Saturday, July 28, 2018

Wisconsin Disability Pride Festival

Time: 12:00pm - 5:00pm

Location: Tenney Park, Madison WI

Details: Come join the WI Ataxia Support Group at the Disability Pride Festival at Tenney Park in Madison. We will have a table and information about Ataxia, NAF and the support group in WI. There will be live entertainment by people with disabilities, food, and adaptive activities. There will also be information about resources for people with disabilities. Come join us for a great time. All proceeds benefit the National Ataxia Foundation.

More info: More Information: Kory Macy at 608-628-2700 or kstab77@yahoo.com

Thursday, August 3, 2018 - Sunday, August 5, 2018

Abilities Expo Houston

Time: Friday & Saturday 11-5, Sunday 11-4

Location: NRG Center, One NRG Park, Houston, TX 77054

Details: For nearly 40 years, Abilities Expo has been the go-to source for the Community of people with disabilities, their families, seniors, veterans and healthcare professionals. Every event opens your eyes to new technologies, new possibilities, new solutions and new opportunities to change your life.

More info: <https://www.abilities.com/houston/>

Saturday, August 4, 2018

Crab Feast to Cure Ataxia

Time: 2:00pm - 6:00pm

Location: Boulevard Heights, Volunteer Fire & Rescue Department, 4101 Alton Street, Capitol Heights, MD 20743

Details: Join us for an evening of crabs, crabs and more crabs! Fried chicken, pulled BBQ pork, corn on the cob, watermelon, Chesapeake chips, and more. This event is not recommended for children under 13. This is an all you can eat affair with silent auction to raise funds to help fight Ataxia. Visit the event website to donate in support for this event, purchase tickets for this event, start or join a team, set a goal, and begin raising money in support of NAF! All proceeds benefit the National Ataxia Foundation.

More info: Letitia Diggs at 202-386-8289 or

letitia.diggs@icloud.com

<https://ataxia.donorpages.com/2018CrabFeast/>

Saturday, August 25, 2018



Tri-State Walk n' Roll to Cure Ataxia

Time: 8:00am - 11:00am

Location: Liberty State Park, 1 Audrey Zapp Drive, Jersey City, NJ 07305

Details: No registration fee - donations gladly accepted, all proceeds benefit the National Ataxia Foundation. To volunteer or for more information contact Kathy Gingerelli at kgingerelli@msn.org Event website: www.Ataxia.org/walk/tristate Event Website: www.Ataxia.org/walk/tristate

Rockin' for Ataxia

Time: 1:00pm - 5:00pm

Location: Cheers (formerly Sullivan's Pub), 660 147th St, Midlothian, IL 60445

Details: Come and have a rockin' good time raising fund to help end Ataxia! This event will include live entertainment, raffle, auction, cash bar, and pizza appetizers. Admission is \$30 advance/\$35 at the door. Join the Rockin for Ataxia Team to raise donations and begin getting the word out about your fundraising efforts to fight Ataxia! Visit the Rockin For Ataxia team page: <https://Ataxia.donorpages.com/2018IAAD/RockinForAtaxia/> to start fundraising today! To order event tickets or raffle tickets online visit: <http://www.fightAtaxia.org/rockin.html> All proceeds benefit the National Ataxia Foundation.

More info: Jonas Cepkauskas 708-381-5555 or

jonas@fightAtaxia.org

Sunday, August 26, 2018



Northeast Ohio Walk n' Roll to Cure Ataxia

Time: 10:00am Registration, 11:30 am Walk n' Roll

Location: Lakewood Park Women's Pavilion, 14532 Lake Ave., Lakewood, OH 44107

Details: Upper Edgewater West reserved shelter, located off Route 6/Memorial Shoreway. All proceeds benefit the National Ataxia Foundation. To volunteer or for more information contact Julie Clarich at julieplus3@gmail.com. Event website: www.Ataxia.org/walk/NEOWalk



Minnesota Walk n' Roll to Cure Ataxia

Time: 8:00am - 11:00am

Location: Wolf Park, 3700 Monterey Drive, St. Louis Park, MN

Details: No registration fee - donations only. All proceeds benefit the National Ataxia Foundation.

To volunteer or for more information contact Wendy Sweeney at wendysweeney1@comcast.net. Event Website: www.Ataxia.org/walk/minnesota

Saturday, September 8, 2018

New England Walk n' Roll to Cure Ataxia



Time: 9:00am Registration; 10:00am Walk n' Roll

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

Details: No registration fee - donations only. Come and learn about Ataxia while having fun raising funds for NAF. Free, Family, Fun! Entertainment

and raffle following Walk n' Roll. All proceeds benefit the National Ataxia Foundation. To volunteer contact Anabela Azevedo at azevedo70anabela@gmail.com. For more information contact Jeannette Viveiros at (508) 837-3565 or jeannette@Ataxia.org. Event Website: www.Ataxia.org/walk/newengland

Sunday, September 9, 2018



Denver Run, Walk n' Roll to Cure Ataxia

Time: 8:00am - 10:30am

Location: Denver City Park Pavilion, between Colorado Blvd & 17th St

Details: No registration fee - donations only. Come and learn about Ataxia while having fun raising funds for NAF. All proceeds benefit the National Ataxia Foundation. To volunteer or for more information please contact Charlotte DePaw at cldepew77@comcast.net or (253) 720-8132. Event Website: www.Ataxia.org/walk/denver

Saturday, September 15, 2018



Orange County Walk n' Roll to Cure Ataxia

Time: 8:00am - 1:00pm

Location: Yorba Linda, CA

Details: No registration fee - donations only. We will have a DJ, opportunity drawing for participants, vendors showing their products/services, children's activities including face painting, balloon animals, and game. Plus a chance to untie with other's affected by Ataxia. All proceeds benefit the National Ataxia Foundation. To volunteer or for more information please contact Cindy DeMint at cindyocAtaxia@gmail.com or (714) 329-4437. Event website: www.Ataxia.org/walk/oc



Sacramento Stride N' Riders

Time: 10:00am - 2:00pm

Location: Howe Park, 2201 Cottage Way, Sacramento, CA 95825

Details: Please join the *Sacramento Stride N' Riders* as we Go the Extra Mile 2 Cure Ataxia! All proceeds benefit the National Ataxia Foundation. More information: Teresa Bredberg at 916-215-2686 or tbredberg@sbcglobal.net

Thursday, September 20, 2018 - Sunday, September 23, 2018

Abilities Expo - Boston

Time: 10:00am - 2:00pm

Location: Boston Convention & Exhibition Center - Hall C, 415 Summer Street, Boston, MA 02210

Details: For nearly 40 years, Abilities Expo has been the go-to source for the Community of people with disabilities, their families, seniors, veterans and healthcare professionals. Every event opens your eyes to new technologies, new possibilities, new solutions and new opportunities to change your life

Event Website: <https://www.abilities.com/boston/>

Saturday, September 22, 2018



Atlanta Walk n' Roll to Cure Ataxia

Time: 8:00am - 11:00am

Location: Shorty Howell Park, 2750 Pleasant Hill Rd, Duluth, GA 30096

Details: No registration fee - donations only. Come and learn about Ataxia while having fun raising funds for NAF. The event is a 1.25 mile Walk or Roll around Shorty Howell Park. The event is followed by refreshments, Ataxia information, and team recognition for the most dollars raised. All proceeds benefit the National Ataxia Foundation. To volunteer or for more information please contact Greg Rooks at atlantaAtaxia@gmail.com. Event Website: www.Ataxia.org/walk/atlanta

Sunday, September 23, 2018

Kansas City Family & Friends Ataxia Awareness Fundraiser & Picnic

Time: 12:00pm - 3:00pm

Location: Macken Park - Festival Shelter, 1000 Clark Ferguson Dr, North Kansas City, MO 64116

Details: There will be Food, Games, Caricature Artist, Massage Therapist, Raffle and a Bake Sale! Donations to support the National Ataxia Foundation will be gladly accepted. Visit the event website to donate online or to join us in fundraising. "We may wobble but we will never fail" Please join us in supporting this great cause! All proceeds benefit the National Ataxia Foundation.

More Information: Laurie Colby at Home; 816-429-6456, Cell: 816-745-4549,

E-Mail: Lcolby61@gmail.com

Event website: <https://ataxia.donorpages.com/2018IAAD/KCWobblers/>

Tuesday, September 25, 2018

International Ataxia Awareness Day (IAAD)

International Ataxia Awareness Day (IAAD) is on September 25 of each year. It is a coordinated effort from individuals and Ataxia organizations around the world to help shed light on this rare disease. What better way to get involved in the fight against Ataxia than IAAD? For more info visit: <https://ataxia.org/international-ataxia-awareness-day/>

Saturday, September 29, 2018



Utah Walk n' Roll to Cure Ataxia

Time: 12:30pm - 3:00pm

Location: Chapel Park, 152 Chapel St, Layton, Ut 84041

Details: Join us for this year's Walk n' Roll which will include a silent auction and raffle to support our efforts to fight Ataxia! Visit the event website to make a donation online or join us in raising funds for this important cause. All proceeds benefit the National Ataxia Foundation.

More Information: Lisa Ord, PhD, LCSW at (801) 585-6635 or lisa.ord@hsc.utah.edu, For sponsorship information or to donate a raffle or silent auction item contact: Andrea Bair at benanddex@gmail.com
www.Ataxia.com/donorpages.com/2018IAAD/UtahAADFundraiser



Western PA Run, Walk n' Roll to Cure Ataxia

Time: 9:00 am Registration, 10 am

Walk n' Roll

Location: Millvale Riverfront Park Pavillion Millvale, PA, 15209

Details: No registration fee - donations only. All proceeds benefit the National Ataxia Foundation. To volunteer or for more information please contact Madalyn Gottschalk at (412) 926-8579 or samgotts32@gmail.com

Saturday, September 29, 2018



Tennessee Attacks Ataxia Walk n' Roll to Cure Ataxia

Time: 9:00 am

Location: Content to come

Details: No registration fee - donations only. All proceeds benefit the National Ataxia Foundation. To volunteer or for more information please contact Ondie Mitchell at 3mitchells@bellsouth.net

Event Website: <https://ataxia.org/event/tennessee-attacks-ataxia-walk-n-roll-to-cure-ataxia/>

Saturday, October 6, 2018



New Hampshire Walk n' Roll to Cure Ataxia

Time: 9:00am registration, 10:00am

Walk n' Roll

Location: Aviation Museum of New Hampshire, 27 Navigator Rd, Londonderry, NH 03053

Details: No registration fee - donations only. All proceeds benefit the National Ataxia Foundation. To volunteer or for more information please contact Douglas Place at Douglas.place@comcast.net



Fort Wayne Walk n' Roll to Cure Ataxia

Time: 9:00 am Registration, 10:00am

Walk n' Roll

Location: Foster Park, 3900 Old Mill Road, Ft. Wayne, IN 46807

Details: No registration fee - donations only. All proceeds benefit the National Ataxia Foundation. To volunteer or for more information please contact Jessica Lebrato at jclebrato711@gmail.com

**We want to hear your
personal stories!
Send them to
naf@Ataxia.org**

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T-SHIRTS INCLUDE:

I Am An Ataxia Fighter • I Am the Strength Behind Ataxia
Ataxia Is Not a Foreign Cab • Walk N' Roll to Cure Ataxia

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 _____

