

Generations

EXPANDED EDITION



The Official Publication of the National Ataxia Foundation

Volume 43, Number 4

Winter 2015-16

*The National Ataxia Foundation Board of Directors
and the Southeast Region invite you to attend the*

National Ataxia Foundation 59th Annual Ataxia Conference

**“THE MAGIC OF A CURE –
DREAM IT. HOPE IT.”**

April 1-3, 2016 – Orlando, Florida

The National Ataxia Foundation (NAF) Board of Directors and the National Ataxia Foundation Southeast Region invite you to attend the 59th Annual Ataxia Conference (AAC). Please join us at the Caribe Royal, Orlando, Florida to learn,

share, network, have fun, and enjoy the sites.

The 2016 AAC will bring together the NAF members and their families not only to meet and learn from world-leading ataxia researchers and clinicians, but also to build new friendships and reunite with old friends. Come and be part of the largest ataxia gathering in the world!

The NAF continues to strive to offer a high quality fun-filled AAC program to the ataxia community. Again this year, the General Sessions will be held only in the mornings on Friday, Saturday, and Sunday ending with a Q & A Panel, then breaking for lunch.

The 2016 AAC Birds of a Feather Sessions (BOF) are being held on both Friday (Group A) and Saturday (Group B). See page 30 for more information about these small group sessions.

Inside This Issue

- **International Ataxia Awareness Day (IAAD)** recaps begin on page 3
- Read about the upcoming **Sixth Ataxia Investigators Meeting (AIM)** on page 22
- **2016 Annual Ataxia Conference (AAC)** information, including registration forms, begins on page 23
- Several moving **Personal Stories** begin on page 44
- Ready for the new year? You'll find our **Calendar of Events** on pages 59-62

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The deadline to submit materials for the spring issue of *Generations* is February 5, 2016.

2016 AAC

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You will still only select one session to attend on either Friday or Saturday with an option to also attend the Family Planning Options on Saturday from 2-5 p.m., which will be facilitated by a neurologist and genetic counselor. Included in this session will be a presentation and discussion about Pre-implantation Genetic Determination (PGD) and In Vitro Fertilization (IVF) The TV news show "60 Minutes" aired an episode on October 26, 2014 that included a piece on PGD. Here is the link to that report: www.cbsnews.com/news/breeding-out-disease-with-reproductive-genetics/.

At the Friday evening Welcome Reception, not only will attendees have the chance to meet others attending from their region, but attendees will also have an opportunity to connect and meet other attendees that are members of the NAF's Bulletin Board and Facebook Group.

A tradition of the meeting is the Silent Auction. This year you will be able to view and bid on items on Friday from 8:30 a.m. to 5:00 p.m. and on Saturday from 8:30 a.m. to 12:30 p.m. Take your time viewing the many items available and bid early. Winning bids will be posted at 4 p.m. on Saturday. Please remember that you must pick-up and pay for your items from 4-7 p.m. on Saturday only.

Sponsors

The National Ataxia Foundation would like to thank the following Sponsors for their continued support:



The NAF is excited about the 2016 AAC and look forward to seeing you in Orlando, Florida in April. ❖

Recognitions of International Ataxia Awareness Day

— September 25, 2015 —

The National Ataxia Foundation would like to thank all the individuals, support groups, ambassadors and chapters who recognized International Ataxia Awareness Day (IAAD) through various events, proclamations, resolutions, social media and press releases throughout the United States, Canada, and Pakistan.

Individuals raised awareness about ataxia and the activities raised over \$300,000 to help support the important work of the National Ataxia Foundation.

Thank you to all who have organized and participated in an IAAD activity. Through IAAD,

we honor those who are affected by ataxia, those who we have lost, their families, friends and caregivers.

IAAD RECAPS Fundraisers

International Walk n' Roll for Ataxia

This year individuals and groups participated in the Sixth Annual International Walk n' Roll for Ataxia (previously the Global Walk n' Roll). Personal fundraising pages were available for each

Continued on page 4

International Ataxia Awareness Day *Continued from page 3*

team or individual to upload a photo, write a personal text and set their own goal. It was another great initiative to raised nearly \$4,400 to support the NAF. Congratulations to the International Ataxia Walk n' Roll Challenge winners! Thank you to all who participated and we look forward to seeing your participation at next year's event and welcome others to also join.

Atlanta Walk n' Roll

Submitted by Greg Rooks

In recognition of IAAD, the Greater Atlanta Ataxia Support Group held their annual Walk n' Roll for Ataxia on Saturday, September 19 at Shorty Howell Park in Duluth, GA.

This year's Walk n' Roll was another success. We had approximately 100 participants in attendance.



The Atlanta Ataxia Walk n' Roll for Ataxia

This year there were 10 teams participating and all doing a fantastic job. It's always exciting to see teams come out with family and friends in support. Team Jon was our top fundraising team with over \$7200. Second and third teams were Team Olivia with \$4,100 and Team Marvelous Mustaches with \$4,000. Our top fundraisers were Marcie Anthone with \$3,000 and Keri Naccarato with \$2,100.

Rudy's New York Pizza donated 20% of lunch proceeds and Will Morris and Atlanta Soundworks provided our sound system.

It's heartwarming to see so many individuals gather in support of each other. Whether you are an individual with ataxia, a caregiver, a family member or a friend, ataxia has affected all our lives.

The event raised over \$23,000.

Concord Walk n' Roll & Swim for Ataxia

Submitted by Brian Petersen

The Concord California Walk n' Roll & Swim for Ataxia was held on September 19 at Newhall Park in Concord, CA for walking or rolling around the path. After, we headed over to the Montecito pool for some swimming. The "Swim" was a great success this year.

This year I a sponsored "Hall Walkers" at the Montecito Pool and kept track of their miles and gave them to Mirna Ward, a retired nurse who was taking blood pressures, poolside. We had a sponsor who is a DJ and her radio commercials had been running for weeks. Another sponsor owns a pizza business and supplied the pizza. The local CVS supplied the drinks. The party was great. The event raised over \$2,000.

Denver Run, Walk n' Roll

Submitted by Charlotte DePew and Trish Hysong

September 13 began with a peaceful, lovely Colorado sunrise at the scenic Denver City Park Pavilion. There was a scurry of activity in preparation for the Fifth Annual Denver Run, Walk n' Roll (WRnR) for ataxia. Led by our support group leader and RWnR chairperson and with the planning committee's hard work, these wonderful volunteers put on yet another successful and fun ataxia awareness/fundraising event.

This year's event honored a passed support group member, Karen Cocquyt (1959-2014). Her husband Patrick gave a compassionate account of her life and how ataxia impacted the family. The family provided a poster-sized picture collage of precious moments in Karen's life.

Donations and participant enrollment began slower than it had in past years, a trend that seemed to be country wide this year. However, the day attracted a large group of participants ►►



The Fifth Annual Denver Run, Walk n' Roll

that had not pre-registered and over \$17,000 in additional donations. We had a good 250 people attend this year's event. There were activities for everyone from the vendor fair to partaking of the generous donations from Dunkin Donuts as well as an amazing array of items donated for our drawing and silent auction. I think it's safe to say a good time was had by all.

We, the Denver RWnR Committee, thank our gracious and dedicated members who attended, provided volunteers. Since our event does not close the park to the public, we posted two A-framed signs inviting passersby to join us and/or get ataxia information. Each year we have a few inquirers. It is each and every one of our members who helped in various ways toward ataxia research, awareness, and coping with a rare neurological progressive (I call it "nasty") disease.

To date, the Denver RWnR has raised almost \$42,000. In addition to the monies raised to fund research, this event has continually raised awareness about ataxia and the effects of ataxia on those with the condition plus their families, their significant others, friends and acquaintances.

Our group was once again thankful to have Dr. Abigail Collins give the crowd information on the frontline medical battle with Ataxia. As a prominent pediatric neurologist with additional study in movement disorders, she developed a special interest in adult as well as pediatric ataxias, much to the benefit of ataxians in the tri-state area and beyond. We look forward to seeing you next year on September 11.

Denver Run, Walk n' Roll video: https://youtu.be/BVOeT_8Yo9A?list=PLPsqd5jWwz2g7BPk_c_dG7QOs6Ca38rl5

Minnesota Walk, Stroll n' Roll

Submitted by Bill Sweeney

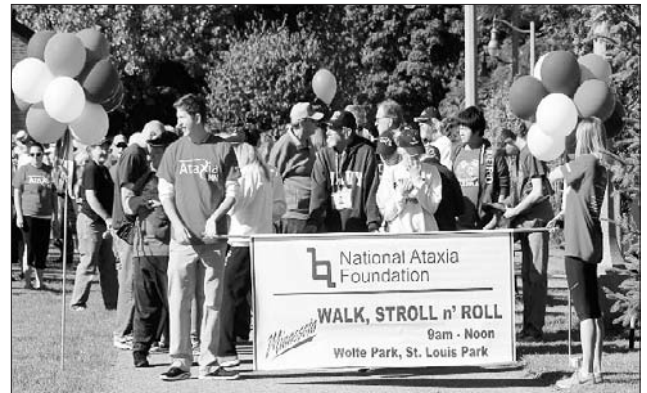
September 12 was a beautiful day in Minnesota ... And a perfect day for the Twin Cities and central Minnesota ataxia support groups to host the Sixth Annual Minnesota Walk, Stroll 'n Roll. Over 400 local supporters were joined by friends and family from Montana, Florida, Colorado, and Arizona to –

Increase awareness of ataxia

Raise money to support NAF

HAVE FUN!

A great time was had by all ... especially the Jones team from western Wisconsin, which was decked out in Hawaiian shirts, grass skirts and other Hawaiian paraphernalia! They set a new standard for "FUNd raising"!



The Sixth Annual Minnesota Walk, Stroll n' Roll

Prior to the walk, Bill Sweeney, President of the NAF, presented Harry Orr with a Governor's Proclamation declaring September 12, 2015 as Harry Orr Day in the state of Minnesota.

After the walk, the Twin Cities Trumpet Ensemble welcomed us into the Wolfe Park amphitheater stage with a program of Big Band, jazz, and patriotic music. Jim Olcott and his energetic Ensemble of brass musicians are welcome back in 2016!

Continued on page 6

International Ataxia Awareness Day *Continued from page 5*

As part of the program, Dick Jones shared his personal story of how living with ataxia has affected him and his family. Then Matt Bower, geneticist at the U of Minnesota, gave an overview of the vital role geneticists play in ataxia research and in working with ataxia patients.

Special thanks and congratulations to Terry Sweeney for co-chairing this event, and to Dawn Folger, Maryann Sweeney, Jimmy Wilson, Team captains, and Eric Pogulis and the Pogulis family for all their efforts to make this event a success.

Thanks to our donors and sponsors, over \$81,000 was raised this year to benefit the National Ataxia Foundation!!!

Minnesota Walk, Stroll n' Roll video: https://youtu.be/xCGEoI_i73Q?list=PLPsqd5jWwz2g7BPk_c_dG7QOs6Ca38rl5

You can view the photos here: <https://mmwalkstrollnroll.shutterfly.com>.

Northern California Walk n' Roll

Submitted by Joanne Loveland

NCASG held it's Walk n' Roll at a new location-Quarry Lakes Regional Park. Sixty attended. We were very pleased to share our day with Bill Sweeney, NAF President, who flew in from Minneapolis to be with us. Ataxians from Sacramento to San Jose came to enjoy the festivities, food, games and comradery. The event raised almost \$15,000.



The Northern California Walk n' Roll

New England Walk n' Roll

Submitted by John Mauro

The Northeast Ataxia Support Group's Eighth

Annual Walk n' Roll was held October 3. This year it was in memory of John Pellegrino. We had to moved it from our usual location of Lamansky Field in Auburn, MA, to the new middle school, due to the bad weather. Unfortunately, whether it was the later date or the rain, the attendance was lower than our past walks.

This year we had two new teams join us, we hope to have their continued support for years to come. Thanks to our volunteers and other area support groups, we had an abundance of raffle items donated, without their help we wouldn't be able to have such a successful walk n' roll.



Left to right: Jinny Sagorin & Joni Oh (dog), Dr. Jeremy Schmahmann, Denise Mindle, John & Dana Mauro at the New England Walk n' Roll

Over the years, as we put our walk together, we discuss the need for a stronger support system. It seems other non-profit organizations have an overwhelming amount of assistance, but yet we struggle to find people to help us. Since our cause is one that many don't understand, it's so important that we work hard to raise awareness in hopes to find a cure in the future.

Even with the obstacles we faced this year, our event was able to raise over \$18,000 for ataxia research.

OC/LA Walk n' Roll

Submitted by Cindy De Mint

On Saturday, September 26, the OC/LA chapter of the National Ataxia Foundation held their Seventh Annual Walk and Roll for Ataxia. It was the first time the event was held at scenic East Lake in Yorba Linda, where more than 500 participants walked and rolled one mile around the man-made lake while being cheered on by the Esperanza High School cheer- ►►



Theresa Gonzales's family and friends came out to support her at the walk. Left to right: Diane Weinstock (sister), Michelle Muro (cousin) and Michele Gile (friend).

leaders. The early morning event had something for everyone. Adults took part in the silent auction and purchased tickets for opportunity baskets, and children had a great time in the kids' zone with face painting, balloon animals, and super heroes.

Television anchor Michele Giele from Channel 9 News was on hand to act as the Master of Ceremonies and Dakin Tseng shared a very moving speech about his sister, Marian, losing her battle with ataxia this year. Event organizers Cindy and Gerry DeMint were supported by volunteers from the OC and LA support groups and from Western University School of Physical Therapy. Everyone worked together to create a fun morning while raising awareness and funds for ataxia. This most successful Walk and Roll to date brought in a record ... over \$81,500. Plans for next year's event are already under way. We hope to see you next year on September 17!

Western PA Walk n' Roll

Submitted by Ed Schwartz

The Western PA Ataxia Support Group held its First Annual Walk n' Roll on September 26, at South Park about 15 miles south of Pittsburgh. The event was in honor of Richard Reimond and Michael Freund, brothers of two current group members, who have passed away from ataxia.

The event was a big success and had an attendance of 75 persons. The excellent participation of two groups was a major contributor to our great attendance. Team Larry, as indicated on the shirts in the photo, was composed of 25 family members and friends of Larry Hillenbrand, who

passed in July of 2013 without really knowing the exact form of ataxia which caused his death after a 20-year battle. The other group consisted of 20 members of Triangle Fraternity from the University of Pittsburgh, who supported one of their founders who is a member of the Support Group. The event raised almost \$4,000. We look forward to seeing you next year on September 26.



The Western PA Walk n' Roll

You can see the Western PA WnR video here: https://youtu.be/QYF7Y_oJdVw?list=PLPsqd5jWwz2g7Bpk_c_dG7QOs6Ca38rl5.

The Walk followed a fundraiser at Max and Erma's Restaurant in McMurray, PA on September 14. The Support Group "earned" a designated percentage of all restaurant proceeds from meals eaten when a special coupon was presented. This fundraiser raised \$190 for one day of doing what the group does best ... eating!

Arizona "Shop 'til you Drop" Craft and Vendor Fair

Submitted by MaryFuchs, Rita Garcia & Angela Li

The Arizona Ataxia Support Group hosted its first-ever "Shop Till You Drop Craft & Vendor Fair" for International Ataxia Awareness Day at the Disability Empowerment Center in Phoenix on Saturday, October 3 from 9 a.m. to 1 p.m. The event was free to the public.

International Ataxia Awareness Day *Continued from page 7*

We welcomed families for a fun day of shopping, special guests, and raffles. Eighteen craft and health and wellness vendors displayed their products and services among a Chinese Auction with over 50 items and a 50/50 raffle. One of our most popular raffle items included a football signed by the Arizona Cardinals quarterback Carson Palmer.

Guest speaker Dr. Kamala Saha, MD, Assistant Professor of Neurology at St. Joseph's Barrow Neurological Institute, came to educate everyone about ataxia. Ralph Miller joined us to teach a popular, relaxing class of chair yoga. The children enjoyed the Kids Zone with face painting, crafts, games, and NAF tattoos. We had a special appearance by Howler the Arizona Coyote's mascot who was a big hit!



The Arizona Ataxia Support Group

We had great success in raising ataxia awareness, raising funds for the NAF, and having fun! The event raised over \$3,500.

Utah Walk n' Roll

Submitted by Jenny Durrant

Sunshine greeted the 2015 Utah Walk n'Roll, which was held on Saturday, September 26 in Layton, Utah. It was amazing to have so much support and to see so many happy faces! There were over 150 attendees who supported the Utah Ataxia Support Group by participating in many different activities including a silent auction,



The Utah Walk n' Roll

music, games, information booths, and more. The event raised over \$6,600, double what the UASG raised last year so a big THANK YOU to all those that supported the UASG in any way!

Ataxia "Spin-off-Challenge" World Spinners

This event was created by to raise awareness of ataxia. On the event website you are able to learn about "The Challenge," register, and/or start a team to share your story. In its second year, "The Challenge" has raised over \$550.

Boscov's Friends Helping Friends

Submitted by Mike Cammer

Boscov's Department Store hosted the popular "Friends Helping Friends" special shopping day on October 20 where discount passes were available for purchase of \$5.

Kathy Schmidt sold two-thirds of the passes this year, along with the Central PA Support Group, raising almost \$600.

Fitness in the Park – Zumba

Fitness in the Park was held on Saturday, September 19 at Hap McLean Park, in Park City, KS from 9 a.m. to noon. There was "Zumba" in the park and a chance to win a raffle prize to raise ataxia awareness. The event raised \$1,000.

Fort4Fitness

Submitted by Cheri Bearman

An estimated 28,000 spectators and a participants filled Parkview Field and downtown ►►



Gil and Cheri Bearman and friend Mark Kline

Fort Wayne for the Eighth Annual Fort4Fitness Fall Festival, September 25-26. The festival is a celebration of fitness and includes a fitness expo, Seniors Marathon, and Kid's Mile Run on Friday and four-mile, 10K, and half-marathon races on Saturday.

Cheri and Gil Bearman and friend Mark Kline walked the final 1.2 miles of the Seniors Marathon in 30 minutes Friday evening in recognition of IAAD. After the event, they enjoyed dinner at a Fort Wayne favorite, The Redwood Inn, to celebrate.

Through Cheri's e-mail campaign, friends and family members learned about ataxia and donated over \$1,300 to the National Ataxia Foundation!

Game Day Fundraiser

Submitted by Jim Fisher

I am a math teacher at Prep and was recently diagnosed with ataxia in July 2015. I have had symptoms since I was 14. A fundraiser was held on September 12. The event donated \$1,000 to the National Ataxia Foundation.

I would simply like to share how many generous people there are out there. My ataxia was a gift to let me know how many caring people still exist. We make sacrifices to bring out the goodness in people. I love what NAF is doing for the disease. In light of all the things that are currently going on in the world, 98% of people care for the elderly, the sick, the mal-nourished and disabled. When you see disabled person, say "Hello" or

smile at them because they are as gifted and lucky as you!

GETRAG Jeans Day

Submitted by Alana Moehlman

We had a "Jeans Day" at GETRAG Transmissions Corporation where I work located in Sterling Heights, MI on September 25. We were happy to do our small part in spreading the word about ataxia. The event raised almost \$100.

Hoedown for Ataxia Awareness

Submitted by Joe & Cathy DeCrescenzo

Joe and Cathy DeCrescenzo, with the DE Support Group, hosted a very successful Ataxia Hoedown for ataxia awareness and fundraising Saturday, September 19 in Bear, DE at the Seton Corral.



Back (left to right): Todd Gould, Kathleen and Danny Swaszowski, Cathy Decrescenzo, and Cowboy Rob Holley. Front: Karen Taylorm, Nancy Gould, and Joe Decrescenzo.

It turned out to be a family-oriented and festive occasion. Over 250 friends, family, parishioners and many of Delaware's finest country line dancing community gathered with them for a dinner of pulled pork, fried chicken, coleslaw, baked beans, vegetarian chili, regular chili, corn bread and two cakes. There was no cost for any of this. Beer, wine, soda and water were available at no charge, all we asked was for a donation to the NAF. We had DJs Steve Pistoia and Laura Stanton. Cowboy Rob Holley and his wife Susan

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International Ataxia Awareness Day

Continued from page 9

were the Masters of Ceremony and lead the dancing and festivities. We danced the evening away. There was also a “photo op” area, featuring straw bales, a western backdrop and a real saddle. Each guest was given a blue western bandana.

By the end of the evening, we had collected our goal of \$10,000.

IAAD Garage Sale

Tamra Humes had a garage sale in memory of her daughter in Baton Rouge, LA and to raise awareness of ataxia. The event raised \$500.

Liam’s Muffin Fundraiser

Submitted by Liam Ingersoll

My name is Liam Ingersoll and I am currently a junior at Northwest High School in Justin, Texas. Last year I was hospitalized with post-viral



Liam Ingersoll

ataxia and was fortunate enough to fully recover. This virus gave me insight into the life of those who have a degenerative neurological ataxia.

I very much wanted to do something to aid the National Ataxia Foundation and spread awareness. Collaboratively, my

mother and I baked muffins and I sold them to the Northwest High School marching band and drumline to raise funds on September 25th. I am proud to say that I raised \$240.

I look forward to organizing more fundraisers in the future!

PartyLite Fundraiser

Submitted by Virginia Giliberti-Paolillo and Lisa Cole

Lisa Cole of Port St. Lucie, FL, hosted a PartyLite Jar Candles fundraiser. The total amount of jars that were sold was \$558. PartyLite donated 40% of the sales to the organization

chosen by the party hostess. The event raised \$223.20 to help find a cure or assist others who have ataxia.

Tea Time for Ataxia

This year’s Tea Time for Ataxia was held in the Aubrey Rose Tea Room on October 10. We really have a lot of followers who look forward to the event making this event even more successful than last years. The event has raised over \$8,900.

Team KR Endurance

Team KR Endurance is a virtual run event organized by KR Endurance, a coaching organization for personal and individualized training to allow athletes to reach their peak. This event raised over \$1,000.

Tour de Shunk - Go on 3! for Ataxia Awareness

Submitted by Michael Cammer

I was a little nervous the night before as we had one heck of a thunderstorm come through with extremely windy conditions and heavy rains until about 11:30 p.m. I thought for sure the road would be littered with debris, but as I left my mother’s and headed over to Rocky’s Bicycle Shop from Shunk to Monroeton I knew the first 25 miles of the course was all clear. I arrived at Rocky’s as the fog was clearing and a brilliant sun was just peaking over the mountain tops. It was a little chilly, about 50 degrees, but it looked like it was going to be a great day for riding. I checked in, received my rider number and was soon on my way a little after 8 a.m. The main pack of “two-wheelers” would soon follow at 9 a.m., some of the more experience riders would catch up with me about halfway up Canton Mountain about the 23-mile mark. Canton Mountain was a “grueller,” as it was close to a 1,200 vertical climb over 2.7 miles! It was the biggest climb of the day and felt good to be done and coasting a little downhill to the first rest stop at the rides namesake at the Shunk Fire Hall. The next 15 miles was pretty uneventful, but then I hit ►►

climb two! Not as bad as the first, but it was still about a mile-and-a-half and 650 vertical feet up, but I made it to the Barbours Fire Hall rest stop with a smile and ready for lunch!

I was soon on the road again on what was turning out to be one beautiful autumn day until about 1 o'clock! The course was now on State Route 14 heading toward the 75-mile rest stop in Ralston. The storm that passed the night before and left the sunshine also brought in a headwind for the last 40 miles. Some final turns and I was finally at the "holy rollers," a 15-mile stretch of road resembling a roller coaster ride leading to the finish at Rocky's. They just never seem to end! But they did and I arrived back a Rocky's around 5 p.m. for a spaghetti dinner



Michael Cammer

and a message! I finished the 102.5 miles about an hour-and-a-half sooner than last year! I felt a hundred times better also, I learned some better cycling techniques that really improved my riding and hill climbing.

Next year's 18th annual (my 3rd) Tour de Shunk will be held on September 18, 2016.

I set my Go On 3! for Ataxia Awareness fundraising goal at \$2,500 and exceeded it by over \$1,000! I would like to thank all those who wished me well and supported me in another successful completion of the 102.5-mile Tour de Shunk. I couldn't have done it without you! This event raised over \$3,500.

Alabama Ataxia Support Group

Submitted by Becky Donnelly

The Alabama Ataxia Support Group held a special Ataxia Awareness event in Cullman, AL, on Saturday, September 19. The members wore their ataxia shirts and distributed ataxia information. The group enjoyed fellowship



The Alabama Ataxia Support Group

and a delicious meal at the famous All Steak Restaurant in Cullman. Bob and Elaine Brooks spearheaded this event. The group was overjoyed to have Becky and Ira McLain back as special guests.

Central New York Support Group Public Ceremony

Submitted by Mary Jane Damiano

Our support group hosted a public ceremony marking the 2015 IAAD at 2 p.m. Friday, September 25 at the North Syracuse Public Library. Each year, elected leaders from the community, the county, and the state bring or send proclamations recognizing the disease and the need for research. A candle was lit symbolizing hope and unity in the fight against ataxia. Light refreshments were served that were donated by Wegmans Supermarket at the program.

A press release was also sent to local radio, TV and newspapers. Although it can be challenging to attract interest from the media in our area, the local newspaper The Eagle Star-Review has run stories about ataxia: http://www.eaglestarreview.com/search/?q=ataxia&search_type=all_results. We also receive continued support year after year from our local elected officials who attend the event.

The Eagle News Star-Review printed two articles this year, one article appeared on page three

International Ataxia Awareness Day *Continued from page 11*

of the September 23 edition and said, “Ataxia Day will be observed on Friday.” The other article appeared on page five of the October 28 edition and was titled, “Annual Ceremony Keeps Ataxia in the Public Eye.”



Front (left to right): Linda Johnson, member of Central NY Ataxia Support Group and Mary Jane Damiano, chairperson of Central NY Ataxia support group. Back: Onondaga County Legislator Kathleen Rapp, Drew Davis from NYS Assemblyman Al Stirpe’s office, and Pat Gustafson, North Syracuse village trustee.

Central PA Support Group Picnic

Submitted by Chris Rakshys

The Central PA Ataxia Support Group had its Third Annual IAAD Potluck Picnic on Sunday, September 27. A small group of us gathered at Pavilion 2 of Warwick Park in Chester County and “gibby-gabbied” the afternoon away as we



The Central PA Support Group

enjoyed hamburgers, hot dogs, Mexican Cobb salad, dump cake and other goodies! We met some newbies who we will hopefully see again at our next meeting. We look forward to organizing this social event for our group each September and will continue to do so for many years to come!

Delaware Park Trophy Race *in Honor of IAAD*

Submitted by Joe Decrescenzo

On September 26, Delaware Park Race Track hosted a Trophy Race in honor of IAAD. The program for the day featured “Race 5” as the Trophy Race. After the race, Cathy, friends and myself, were in the winner’s circle to present the winning trainer and jockey a platter. The presentation was shown live on the track’s main screen. Delaware Park ran a full page letter in the program explaining ataxia and IAAD. The average Saturday attendance at the track is over 4,000.



Joe Decrescenzo with winning Jockey Tyler Conner

Former Ellison Quarterback *Eric Christian’s Battle with Ataxia* *Inspiring New Generations of Students*

The following is from an article by Jason Mason, shared with permission by the Killeen Daily Herald.

Eric Christian looks poised as he sits in front of dozens of teenage faces awaiting his next word. Eric, however, isn’t the one delivering his words, as the spinocerebellar ataxia that he has been living with for 13 years makes it hard for him to speak beyond short bursts. Instead, his childhood friend and fellow Ellison graduate, Dan Hull, delivers his speech at his side stating, “I’ve ►►



Left to right: Eric Jr., Eric Christian, and Tony Gonzales, who takes Eric to every Ellison High School game during the season

known this guy for a long time, and I've known the fight that he has for a long time. That's why I'm here today to give this message."

Eric is the Eagle's honorary captain, an honor for which he is given a white T-shirt that says, "Explosive Power" in green, which he slips on over his navy blue T-shirt that says "I am the strength behind ataxia." His friend, Fabrice Sueoka, has on the same shirt and flanks him along with Eric II. It is a theme for the night—many are touched by his story. "It brings back memories," Eric II said. But the best part for Eric isn't a memory, because Eric is still making memories with the people he's met through this game. "The main thing is that I had a good time and made good friends from football," Eric said after his speech.

You can read the complete article by following this link: <http://tinyurl.com/oxhjyxs>.

New England Events Tour

Submitted by John Mauro

This year I was able to visit several events. My first stop was in Liverpool, New York at the Walk for Dave on Saturday, August 8. Then, on



Left to right: Vincent De Jesus and John Mauro at the Boston Expo

September 18-20, along with the Central MA support group I represented the NAF in hosting a booth at the Boston Abilities Expo. On Saturday, September 26, I attended the First Annual Western PA Walk n' Roll in South Park Township, PA. And finally, I was at the New England Walk n' Roll, on Saturday, October 3.

North Texas Ataxia Support Group

Submitted by David Henry, Jr.

Again this year, our group had a picnic on Saturday, September 26 at Harmony Park in Trophy Club, TX.



The North Texas Ataxia Support Group

PCT Hike for Ataxia

Missy started her courageous Hike for Ataxia in memory of her husband, who died in 2014, to raise awareness for ataxia. She knew him since she was 14 and they were married for 36 years. She decided to reach out to people and teach them about the condition while hiking. Despite not being able to finish the hike, she continued to make several stops on her way home to bring awareness to others. The event raised nearly \$200.

San Diego Support Group Picnic

Submitted by Jane Jaffe

The San Diego Support Group planned and recognized IAAD on Saturday, September 26 by having their first Charley McLaughlin Ataxia Awareness Picnic. They met at a very popular park in San Diego and had over 50 guests. Hot dogs with all the fixings were served and guests

International Ataxia Awareness Day
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brought pot luck to share. Despite the very warm day, we had fun and enjoyed live music with a volunteer DJ.



Members of the SDSG Planning (left to right): June Wood, Jane Jaffe, Pat Ward and Joan Hay

Media Coverage

World This Morning program

*Submitted by Haji Babar Naseer
of the Bin Adam Foundation*

“World This Morning” did a program on ataxia to spread awareness about the disease on September 25. The program was telecast on the Pakistan Government TV Media PTV. Haji Babar Naseer, who has ataxia, appeared on the program to speak about his life and the disease.

The Hank Stolz Experience

Submitted by Dana Mauro

John and I have gotten to know the host of “The Hank Stolz Experience” at Charter TV 3 in Worcester, MA. In fact, he has become a good friend of ours and provided a platform to help educate our community about ataxia. Every year he promotes the New England Walk n’ Roll as well as other efforts we are involved in. This year Hank spent some time interviewing John about his recent acknowledgement by the Kraft family receiving the Myra Kraft Community MVP Award on June, 9 and also a grant for \$5,000. He spoke to me about my “Did you Know” Fact-a

Day series that I started in 2014 to promote Ataxia Awareness. Also acknowledged was the bill that passed on September 25, 2014 recognizing that day as Ataxia Awareness Day



Left to right: Hank Stolz, John and Dana Mauro in the State of MA every year. John, along with Senator Michael Moore and Representative Paul Front, were instrumental in getting the bill passed.

Interviews of the Mauros on the Hank Stolz Show can be found on the NAF’s YouTube Channel, <https://youtu.be/bmbzomqIYXE?list=FLRax0JQ0bjm90R2PSixQY0g>

Tulsa World on August 11 – Collinsville man with Friedreich’s ataxia outliving early-death predictions

The Chaffee County Times on August 19 – Widow raising ataxia awareness visits Buena Vista

Salina Journal on August 28 – Ohio woman raising awareness of disease

Sun Lakes Splash on September 1 – Ataxia Awareness Day fundraiser is October 3

SanTan Sun News on September 5-18 – October craft fair raises funds to fight the neurological disorder ataxia

Kennebec Journal/Morning Sentinel on September 6 – A little understanding goes a long way

KMEG14-Siouxland News on September 24 – Sioux City Woman Coping with Rare Disease

ABS-CBN News on September 26 – Pinoy stars come together to help Bunny Paras’ daughter

Guitar PR on September 28 – Guitarist Ian C. Bouras pushes aside ataxia with new string endorsement and upcoming gigs



KDH Pressbox.com on October 18 – Former Ellison quarterback Eric Christian’s battle with ataxia inspiring new generations of students

Proclamations/Resolutions/Citations/Bills

This year there were Proclamations or Resolutions declaring September 25 as International Ataxia Awareness Day signed in Delaware, Georgia, Iowa, Minnesota, New York, Ohio, and Pennsylvania.

On September 25, 2014, a bill was passed recognizing that day as Ataxia Awareness Day (IAAD) in the State of Massachusetts every year.

On August 28, a Proclamation was signed by Georgia’s Governor Nathan Deal proclaiming September 25, 2015 as Ataxia Awareness Day in Georgia.

On September 8, a Proclamation was signed by Governor Mark Dayton proclaiming Friday, September 25, 2015 as Ataxia Awareness Day in Minnesota.



Minnesota Proclamation

On June 26, The renewal for this Pennsylvania Senate Resolution No. 163 to recognize IAAD in June, 2016 will be presented.

On September 14, Mayoral proclamation to recognize IAAD in the City of Huber Heights, Ohio, presented to Ms. Melissa Prather by Mayor Tom McMasters. You can find the Proclamation PDF here – <http://tinyurl.com/pojxzq9> – and the City Council Meeting Agenda here – <http://tinyurl.com/ntmy9gl>.

On September 21, the renewal of the Pennsylvania House Resolution No. 434 to recognize IAAD was signed. Thanks to the newly-formed Western PA ataxia support group for their involvement with getting additional co-sponsors from their area this year!



Left to right: Eric Mosley, Joe Decrescenzo, Virginia and Wayne Hanna, and Cathy Decrescenzo with the Delaware Joint Resolution

On July 21, Wayne and Virginia Hanna were instrumental in securing Delaware Joint Resolution 39, passed and signed by both the Delaware Senate and House of Representatives declaring September 25, 2015 as IAAD in Delaware.

On September 21, The city of Sioux City, IA issued a proclamation announcing Friday, September 25 as IAAD. It was a very proud moment for Susan Shacka.

Submitted by Mary Jane Damiano

The Central New York Ataxia Support Group received four proclamations.



Drew Davis (right) presenting a proclamation to Mary Jane Damiano

Social Media/Presentation/E-mail Ataxia Awareness

Ataxia information tables were present at Combined Federal Campaign (CFC) events in Charlottesville, VA and Seattle, WA.

Dana Mauro created a “Did You Know?” Ataxia Awareness Campaign. Here is the link to the video that was released on Day 1 of the campaign: <https://youtu.be/jXNPBoI53DE?list=FLRax0JQ0bjm90R2PSixQY0g>.

International Ataxia Awareness Day
Continued from page 15

Annette Tornberg shared information about ataxia to all her FaceBook friends.

Carol Simon posted on Facebook a brief info spot about ataxia and shared a bit about how it affected her mother's family.

Claudia Serrano and her friends and family participated in the Denver Walk n' Roll to help raise funds and to spread awareness – Go Team Evan!



“Team Evan” at the Denver Walk n' Roll

Gloria Wagner had an ataxia information table in the lobby of the Lancaster School of Medicine, Lancaster, PA on September 25. She included bookmarks, leaflets, *Children with Ataxia* booklets and copies of *Generations*.

Jaqueline and Sarah Guercio had an ataxia information table at the Lakeshore Foundation in Birmingham, AL to raise awareness of ataxia.

Sean Christian took the opportunity to educate some runners and a PT about how ataxia affects him and his life. He would like to do more at next year's #March4TB!

Stephanie Sigler had all her family and friends wearing blue and posting articles on FaceBook and sharing it with all of their family and friends.

Val Warren gave a presentation on SCAs to her fellow nursing students in Pennsylvania.

Submitted by Mary Liebert

I shared portions of the NAF educational document, “What is Ataxia” on my FaceBook

page and e-mailed it to my family and friends. I tried very hard to simplify the educational document about ataxia. Hopefully when compiling it I did not leave out anything important.

Submitted by Ashim Shah

IAAD was recognized in Gujrat, Pakistan on September 25.



John Colyer Ashim Shah and family

shared a video on YouTube called “Explanation of My Disability” on October 21. You can view the video by following this link: https://youtu.be/OK6_cwVE_KY?list=FLRax0JQ0bjm90R2P6SixQY0g.

Tracy Lee Dodd posted this video on Facebook to help raise awareness. Her goal was to get 40,000 likes by October 19th in memory of her sister Jackie's 40th birthday. <https://www.facebook.com/tracy.l.dodd.7/videos/10153079843845824/?pnref=story>. The video currently has 36 likes, 20,706 views and 620 shares.

Submitted by Nickie Wettstein

Nickie Wettstein of Sioux Falls, SD created ataxia awareness in honor of her grandfather, Rolland Wettstein. She had a display which included information about ataxia, coloring sheets, cupcakes, made by her sister who works at “Oh my Cupcakes” with the NAF logo. In addition she passed out ataxia awareness bands to her clients who donated to the foundation at her salon, Ambiance. She also dropped off cupcakes and ataxia information to local businesses, Kohl's, National American University, Premier Bank, Anytime Fitness, Independent Body Works and an ophthalmology office to help spread awareness about ataxia.



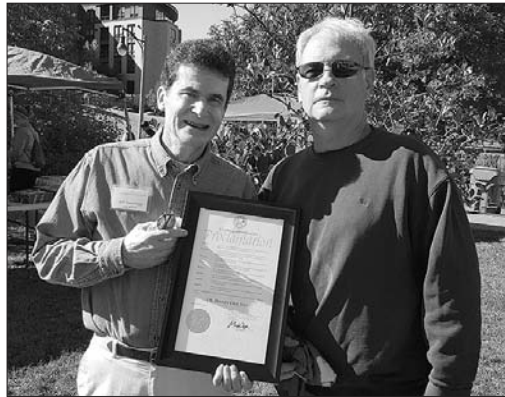
❖ **Nicke Wettstein's display**

‘Dr. Harry Orr Day’ Proclaimed in the State of Minnesota

It was an exciting day in Minnesota for the ataxia community as Governor Mark Dayton proclaimed September 12, 2015 as “Dr. Harry Orr Day.” The Governor’s proclamation was presented to Dr. Orr by the National Ataxia Foundation’s President, Bill Sweeney, at the Minnesota Walk, Stroll, n’ Roll for Ataxia with more than 400 in attendance.

Dr. Orr provides countless hours of his time and expertise to the National Ataxia Foundation as the Research Director on NAF’s Board of Directors. In that role he chairs the Medical Research Advisory Board, oversees the research grant application review process, and develops research funding programs.

Dr. Orr also serves on the Ataxia Investigators Meeting steering committee, provides the research review presentation at NAF’s Annual Ataxia Conference and so much more. The National Ataxia Foundation Board, staff and volunteers congratulate Dr. Orr on this prestigious recognition through Governor Dayton’s proclamation.



NAF President Bill Sweeney (left) and Dr. Harry Orr with the proclamation

The proclamation reads:

Whereas: Dr. Orr is the Tulloch Professor of Genetics, and directs the Institute for Translational Neuroscience at the University of Minnesota; and is a Professor of Pathology at the University of Minnesota Medical School; and

Whereas: Dr. Orr was jointly responsible for first identifying the defective gene causing a type of Spinocerebellar Ataxia in 1993; and

Whereas: Dr. Orr has authored/coauthored more than one hundred studies and medical/scientific articles relating to the genetics and pathology of ataxia; and

Whereas: Dr. Orr has overseen the work of a generation of researchers and

Ph.D. candidates who have gone on to work in ataxia research; and

Whereas: Dr. Orr is the Director of the Research Advisory Board and serves on the Board of Directors of the Minnesota-based National Ataxia Foundation; and

Whereas: Dr. Harry T. Orr has taught and performed important, award-winning research for many years at the University of Minnesota and its Medical School; and

Whereas: In 2014, Dr. Orr was elected to the prestigious Institute of Medicine of the National Academies (IOM); and

Whereas: With the potential of clinical studies looming, Dr. Orr’s contributions may accelerate progress in treating ataxia by years.

Now, therefore, I, Mark Dayton, Governor of Minnesota, do hereby proclaim Saturday, September 12, 2015, as Dr. Harry Orr Day in the State of Minnesota. ❖

Deadline

The deadline to submit materials for the upcoming spring edition of *Generations* is Friday, February 5, 2016.

Please submit content by e-mail to joan@ataxia.org or by mail to National Ataxia Foundation, 2600 Fernbrook Lane, Suite 119, Minneapolis, MN 55447-4752.

From the Desk of the **Executive Director**

As we enter a new year, the National Ataxia Foundation is embarking on a strategic planning process that will help guide us through the next three to five years. The focus of this strategic plan is to develop a road map to help better serve the ataxia community through increased funding, greater ataxia awareness, clinical trial readiness, and an enhanced communication strategy. These enrichments will allow NAF to continue its efforts in being more responsive to the needs of the ataxia community.

Part of this process was a membership survey which focused on 20 key questions. We were pleased by the response rate of those completing the survey and the valuable input received will significantly help in this strategic planning process. Thank you!

As we look forward into 2016, NAF will be hosting the Sixth Ataxia Investigators Meeting (AIM) in late March. We anticipate 150 of the world-leading ataxia researchers attending this world-class scientific conference on ataxia.

April 1-3 will be the National Ataxia Foundation's 59th Annual Ataxia Conference being held at the Caribe Royale in Orlando, Florida. Hosted by the Southeastern Region, we foresee a great turnout and hope to see you at the world's largest gathering of the ataxia community. Come early and join us in the late afternoon of March 31st and you will have the opportunity to meet many of the world's leading ataxia researchers face-to-face and learn firsthand of their current

research efforts through a dedicated poster session during the AIM.

In reflection, in many ways 2015 was a breakthrough year in terms of awareness, events, and research. In 2015 NAF received more than 100 quality ataxia research proposals from scientists throughout the world. These important proposals focused on basic and translational research and represented many of the different forms of ataxia. Through our generous donors throughout the year and those who helped us meet the \$200,000 research match challenge, NAF was able to support many of these promising studies. Thank you and thank you to our anonymous donor!

Congratulations to all who held an International Ataxia Awareness Day event and to the organizers of Walk n' Rolls throughout the United States. These events raised the level of ataxia awareness

throughout the nation, informing tens of thousands of people across the country, and raised over \$300,000. A heartfelt thank you to the organizers, donors, sponsors, participants, and volunteers.

The National Ataxia Foundation was established in 1957 with a vision to foster research and help ataxia families. Thanks to the generous support of donors and partners, our amazing volunteers, and a dedicated Board of Directors and staff, NAF is moving forward on the vision of the original founders. Thank you. ❖



Michael Parent

Visit our website: www.ataxia.org

Like us on Facebook: www.facebook.com/ataxiafoundation/timeline/

Follow us on Twitter: https://twitter.com/NAF_Ataxia

Progress through Partnership: NINDS 9th Nonprofit Forum

Submitted by Michael Cammer

On September 8 and 9, I attended the NINDS Nonprofit Forum along with Carolyn Davis and Janean McKay from the Chesapeake Chapter of the National Ataxia Foundation and representatives from over 50 other non-profits and related agencies. There was also a very strong presence from the program directors at NINDS including the director, Dr. Walter Koroshetz, who was actively engaged with the group the entire time.

Some highlights of the forum were:

After a welcoming from Dr. Koroshetz, there was a presentation on patient registries from Dr. Joe Selby, the Executive Director of PCORI. He discussed who builds them, why we build them and the importance of building registries. Next he talked about the National Patient-Centered Clinical Research Network (PCORnet). PCORnet's goal is to improve the nation's capacity to conduct clinical research more efficiently by creating a large national patient-centered network which would allow for large-scale research to be conducted on any condition with accuracy and efficiency in real-world situations. It would increase efficiency through the use of electronic data and partnerships, shared infrastructure and common data models. Research priorities would evolve through patients, clinicians and delivery systems. PCORnet would develop Patient Powered Research Networks (PPRNs) in Phase I for common diseases and for rare diseases. Phase II would develop Clinical Data Research Networks (CDRN) for registries that have common disease cohorts. PCORnet's vision is that PPRNs must grow into the populations included within the CDRNs. He finished with PCORI's role in research awards as a source of funding for registries.

After Dr. Selby spoke there was a panel discussion called "Lessons Learned and Case Studies in Patient Registries." They discussed what kinds of data are collected for registries, who are eligible for registries and what are the key challenges facing new registries, and then discussed "ideal world" answers to those questions. They also discussed getting a registry started and building and maintaining patient registries. I was pleased that the National Ataxia Foundation has a vital patient registry available for enrollment by anyone with any form of ataxia or who is at risk to develop ataxia. (For more information, visit <https://www.ataxia.org/research/patient-registry.aspx>.)

Dr. Alan Willard from NINDS spoke on "NIH 101: Priority Setting, Decision Making and NIH Basics." He explained about the size and scope of the NIH and that there are 27 different institutes of which 24 award grants. Each institute is different and they have their own unique missions and priorities. They each have their own budget, different types of grants they support and different strategies for making funding decisions. Dr. Willard then discussed the NIH grant cycle which takes nine months to complete. There are three stages from planning and submitting, to review and to the funding and awarding of grants. He gave the NIH's website link to grants and funding to help guide and assist with the process, it is: <http://www.nih.gov/grants-funding>. After a researcher submits a grant request, it is subject to numerous reviews, from peer review to scientific and NIH in-house reviews. Reviewers evaluate what is being proposed, why it is important and whether the

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Progress through Partnership...
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applicant can complete the research, as described in the application. They review the overall impact and the “core” criteria, significance, investigators, innovation, approach and environment, all before going to the funding stage. What determines which awards are made? Scientific merit (peer review scores), program considerations and availability of funds. If the grant request makes it this far it goes to council for a second, broader review before being awarded funding based on the institutes overall goals and priorities.

During the “Overview of the NIH Strategic Plan” by Dr. Koroshetz, he discussed the goals of the NIH plan is to develop a “living document” that would guide the NIH in fulfilling its mission over the next five years, articulate approaches and opportunities that are forward-looking and identify major trans-NIH themes that will advance biomedical research. This plan will not address individual institutes or centers because they each have their own individual strategic plans. It will focus on areas of opportunity that apply across biomedicine from fundamental science to health promotion/disease prevention to treatments and cures. It will unify principles by setting priorities and enhancing stewardship.

Dr. James Kaiser, medical officer for the FDA discussed the Critical Path Innovation Meeting. The new CDER program promotes understanding of challenges in drug development and strategies to address them. It addresses emerging technologies and the new uses of existing technologies and novel clinical trial designs and methods, potential biomarkers not ready for DDT qualification program and potential clinical outcome assessments not ready for formal qualification. It is nonbinding on the FDA and other participants. Requests may come from anyone with a role in drug development: disease advocacy organizations, public/private partnerships, industry, academia or government. FDA experts participate as resources allow. The desired outcomes are to identify issues facing development of proposed innovation, identify avenues for information and exposure of the FDA to new emerging sciences. The FDA link for more information is <http://www.fda.gov/drugs/developmentapprovalprocess/druginnovation/ucm395888.htm>.

Overall, it was a very informative forum. Developing, building and maintaining registries and the NIH awarding of grants were the two main focus subjects of the forum. Beforehand, I knew the NIH was a large facility, but I was completely surprised by the size and scope of its operation and security was amazing. I think it is easier to get through airport security than it is to get on to the grounds of the NIH! ❖

CoRDS Registry

Coordination of
Rare Diseases at Sanford



 **National Ataxia
Foundation**
www.ataxia.org

Everyone who has any form of ataxia or who is at risk for ataxia is encouraged to enroll in the CoRDS/NAF ataxia patient registry.

To register in the CoRDS ataxia patient registry, go to www.ataxia.org and click on “**Ataxia Patient Registry**.” If you prefer to enroll by postal mail, please contact CoRDS personnel.

For more information on CoRDS and/or enrollment, visit www.sanfordresearch.org/cords or call (605) 312-6413. Thank you for participating in this important research tool.

Young Investigator SCA Research Award

Analysis of Transcriptional Changes in Machado-Joseph Disease Using Isogenic Patient-derived Neurons

Philipp Koch, MD

University of Bonn, Bonn, Germany

The following is a research summary of a grant funded by NAF for fiscal year 2014.

Machado-Joseph Disease (Spinocerebellar Ataxia Type 3) is an inherited and devastating neurodegenerative disorder clinically characterized by progressive ataxia. It is caused by a CAG repeat expansion mutation in the MJD1 gene, which results in an expanded stretch of the amino acid glutamine in the protein ataxin-3 (ATXN3). Currently, no effective treatment or cure is known for this disorder.

During the course of the disease, the protein ATXN3 accumulates and forms large aggregates in the nuclei of affected neurons. These aggregates are believed to induce molecular changes in the neurons, which eventually result in neurodegeneration. However, the exact mechanism for how expanded ATXN3 induces neuronal degeneration remains elusive.

In the past, researchers concentrated on the idea, that ATXN3 induces cell death via a toxic “gain of function.” Other lines of evidence suggest that the expansion of ATXN3 interferes with the physiological function of the protein. In this context, ATXN3 has been shown to bind directly to specific genes and to modify their expression.

Recently, a new technique has been described which enables the generation of patient-specific nerve cells (neurons) in cell culture by reprogramming and subsequent differentiation of skin cells derived from affected patients. This technique allows for the first time to investigate changes in gene expression directly in living

human neurons. However, considering that humans are genetically diverse with hundreds or thousands of genes varying from individual to individual, a comparative gene expression requires closely related subjects or better “so-called” isogenic controls were identical individual (such as monozygotic twins) differ just by one gene (for instance the length of the CAG repeat in the MJD1 gene). Modern genetic engineering techniques allow to generate such isogenic pairs to perform gene expression analyses.



Dr. Philipp Koch

In this project we used genetic engineering techniques (so-called CRISPR/Cas9 gene editing) to generate isogenic neurons from patients suffering from Machado-Joseph Disease. During the time course of the project more than 150 cell lines from three different MJD patients were generated. These lines did either have only the normal or only the expanded CAG repeat. As control we included lines where the MJD1 gene (Ataxn3 protein) was completely

Analysis of Transcriptional Changes...
Continued from page 21

eliminated. Neurons from in total >50 different lines were analyzed for their gene expression profile either under standard culture conditions or following initiation of ATXN3 aggregation. The direct comparison of the neuronal gene expression patterns in neurons harboring the mutation with those not harboring the mutation identified a set of 89 genes to be differentially expressed. This number increased to >150 genes following aggregation of ATXN3. Among those genes, we found several genes involved in protein quality control and homeostasis as well

as structural stability of the neurons. When ATXN3 was completely eliminated, a class of genes showed changes in gene expression, which are involved in processing and the modification of proteins. We are currently following the identified genes and will try to shed light on their role in the initiation, progression and severity of Machado Joseph Disease.

In summary, we were able to identify so far unknown changes in gene expression in isogenic neurons derived from patients suffering from Machado Joseph Disease and hope that our research will contribute to the development of potential new and effective strategies to treat the disease. ❖

Advancing Ataxia Research: The Sixth Ataxia Investigators Meeting

The National Ataxia Foundation will host The Sixth Ataxia Investigators Meeting (AIM), "AIM 2016: From Basic Science to Clinical Therapeutics" on March 29 – April 1, 2016 at the Caribe Royale in Orlando, Florida. The AIM brings together an international roster of investigators to address the diverse causes of ataxia, to better define the pathogenic basis of ataxia, and to explore routes to therapy.

AIM 2016 provides a critical mechanism to facilitate collaboration among ataxia researchers. Assembling leading ataxia scientists and clinician researchers helps accelerate world-wide ataxia research by advancing the understanding of ataxia disease mechanism and focusing on the most recent scientific advances with the ultimate goal of facilitating the push towards therapies for the ataxias.

New cutting-edge and unpublished research will focus on the meeting themes which include:

- Cerebellar circuitry and its role in ataxia
- Biological basis of cerebellar degeneration
- Genomic/genetic approaches to cerebellar function and ataxia and epigenetics
- Therapeutic strategies for ataxia: translational Research
- Therapeutic strategies for ataxia: clinical

trials, outcome measures and drug development

This meeting provides an essential forum for recruiting new investigators to the field to help establish the future leaders of ataxia research through direct interactions with senior scientists. Junior investigators will have the opportunity to meet those with ataxia and their families who will attend the Annual Ataxia Conference (AAC) which overlaps with the AIM.

On Thursday, March 31st, there will be a scientific poster session dedicated exclusively for AAC attendees. The expertise and collaborative nature of the assembled scientists, bolstered by the participation of relevant National Institutes of Health staff ensures that this meeting will create the forum for presenting the latest developments in basic, translational and clinical research. Attendance is intended for scientists and physicians who are actively involved in ataxia research.

The National Ataxia Foundation is grateful to the AIM co-leaders David Lynch, MD, PhD and Gülin Öz, PhD and steering committee members Alexandra Durr, MD, Albert La Spada, MD, PhD, and Harry Orr, PhD.

For more information about the AIM, contact Sue Hagen at susan@ataxia.org.

2016 NAF Annual Ataxia Conference Agenda & Overview

Please Note: Due to circumstances beyond our control, this conference agenda is subject to change. The most current version of the schedule can be found at http://www.ataxia.org/events/2016_AAC/2016_AAC_Schedule.pdf.

The National Ataxia Foundation (NAF) Board of Directors and the National Ataxia Foundation Southeast Region invite you to attend the 59th Annual Ataxia Conference (AAC). Please join us at the Caribe Royal, Orlando, Florida to learn, share, network, have fun, and enjoy the sites.

The 2016 AAC will bring together the NAF members and their families not only to meet and learn from world-leading ataxia researchers and clinicians, but also to build new friendships and reunite with old friends. Come and be part of the largest ataxia gathering in the world!

THURSDAY, MARCH 31ST

EVENT	LOCATION	TIMES
NAF Registration	South Registration	9:00 a.m. – 5:00 p.m.
Come by and get your conference program, name badge, Saturday banquet tickets, and welcome bag. Check in your Silent Auction items and say, “Hi” to the NAF Staff and volunteers.		
Silent Auction Item Drop Off	Grand Sierra ABC	9:00 a.m. – 5:00 p.m.
All items being donated for the Silent Auction are due in the Silent Auction room by Friday, April 1 at 4 p.m. Auction items range from something that represents your state or country, art work, sports memorabilia, theme baskets, hand-crafted items, hotel stays and weekend getaways. Bring an item to donate and then have fun bidding on the items of your choice. Thank you for supporting this event and sharing items from your local area.		
Exhibitor Set-Up	Grand Sierra ABC	10 a.m.
Exhibitors	Grand Sierra ABC	Noon – 5:00 p.m.
Exhibitors will be present as their schedules permit. If you would like to recommend a company or service provider to be an exhibitor at the conference, please contact the NAF at joan@ataxia.org . If you are interested in information about exhibiting, you will find more detailed exhibitor information and an application form on the NAF’s website.		
Leadership Meeting	Curacao 3 & 4	1:00 – 3:00 p.m.
Designed to provide information and support to the NAF’s Chapter Presidents, Support Group Leaders and Ambassadors. The meeting is a valuable resource for volunteers who serve in these appreciated positions. If you are interested in becoming a NAF Support Group Leader or Ambassador, contact Lori Shogren at lori@ataxia.org prior to the meeting.		
Fundraising Meeting	Curacao 3 & 4	4:00 – 5:00 p.m.
Anyone who is interested in learning more about organizing a fundraising event or getting involved in an ataxia event to support the important work of the National Ataxia Foundation is encouraged to attend.		
AIM Poster Session	Grand Sierra F & G	5:15 – 6:15 p.m.
A great opportunity for you to view the research posters that are being presented at the Sixth NAF Ataxia Investigators Meeting (AIM). Ataxia investigators will be present to answer questions about their posters and ataxia research projects. Don’t miss this opportunity to meet face-to-face with the ataxia researchers from around the world.		

FRIDAY, APRIL 1ST

EVENT	LOCATION	TIMES
NAF Registration	South Registration	8:00 a.m. – 5:00 p.m.
Exhibitors	Grand Sierra ABC	8:00 a.m. – 5:00 p.m.
Silent Auction Item Drop Off	Grand Sierra ABC	8:30 a.m. – 4:00 p.m.
All items being donated for the Silent Auction are due in the Silent Auction room by 4 p.m.		

Silent Auction Item Bidding Grand Sierra ABC 8:30 a.m. – 5:00 p.m.

General Sessions Grand Sierra D & E 9:00 a.m. – 12:30 p.m.

Friday morning will start the General Sessions in the Grand Sierra D & E. They will incorporate practical aspects in addition to the research and medical topics of ataxia. A 30-minute Question and Answer session will follow the morning General Sessions with a panel of the morning speakers.

Activity Room Antigua 3 & 4 10:00 a.m. – 5:00 p.m.

The activity room is open to all ages. Persons under the age of 12 must be accompanied by a parent or guardian who is age 18 or older. Scheduled activities coming soon on the NAF's website, www.ataxia.org.

Lunch On Your Own 12:30 p.m.

Birds of a Feather (BOF) Group A* See Page 25 2:00 – 5:00 p.m.

Attendees will have the opportunity to attend small group sessions. See page 30 for more information about these small group sessions.

Meet & Greet Reception Grand Sierra D & E 5:00 p.m. (NEW TIME)

Please join us for the Welcome Reception. All registered conference attendees are welcome to attend. Admittance to this event and the snacks that will be served are included with your registration fee. A cash bar will be available. This event will begin with attendees gathering in the seating area designated for their region. Your region will be printed on your name badge. After meeting others in your region, attendees will then have the opportunity to meet with other NAF Bulletin Board and Facebook users in that designated seating area. You are encouraged to prepare contact cards to distribute at this event. Contact cards should only include information you wish to distribute. Information on contact cards can include your name, e-mail address, state, and diagnosis/affiliation. Repeat attendees are encouraged to welcome a First-Time Attendee. First-Time Attendees are identified with a First-Timer Ribbon on their name badge.

FRIDAY GENERAL SESSIONS

<i>TIME</i>	<i>TOPIC</i>	<i>SPEAKER</i>
9:00 a.m.	Welcome & Announcements	Camille Daglio, AAC Co-Chair & Dave Zilles, Southeast Region Representative
9:30 a.m.	NAF: Past, Present, Future	Michael Parent, NAF Executive Director NAF – Minneapolis, MN
10:00 a.m.	Update on FDRA Research.....	David Lynch, MD, PhD Children’s Hospital of Philadelphia (CHOP), Philadelphia, PA
10:30 a.m.	Physical Therapy	Jennifer Keller, PT Motion Analysis Lab, Kennedy Krieger Institute – Baltimore, MD
11:00 a.m.	Disability Decisions and Applying for SSDI	Jon Rodis & Kathleen Kane, Esq. Winthrop, MA
11:30 a.m.	The Ataxia Rollercoaster: How to Have a Smooth Ride with the Ups, Down and Loop-the-Loops of Life	Ellen Sichel, BS CEO of Custom Calm, LLS – Atlanta, GA
Noon	Q&A	Panel
12:30 p.m.	Lunch	

Birds of a Feather (BOF) Group A*

Attention Parents: Birds of a Feather Sessions for attendees under 30 years old are facilitated by experienced clinicians. Mature subject matter may be discussed. These sessions are not intended for those who are under 12 years old. Children under 12 years old should not attend a BOF session. Questions regarding these sessions may be directed to Sue Hagen, NAF Patient Services Director at susan@ataxia.org or (763) 553-0020.

Birds of a Feather Informal Groups will meet from 2 – 5 p.m. in various meeting rooms. Please check the hall signs for your specific group’s location. *Tentative room assignments* are listed below. Paid PCAs are welcome to attend the BOF session with their client, but not required unless client requires it.

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

SCA1 Birds of a Feather 2 – 5 p.m.Bonaire 4
Facilitators: Dr. Orr & Dr. Day

SCA2 Birds of a Feather 2 – 5 p.m. Bonaire 5
Facilitators: Dr. Oz & Dr. Wilmot

SCA3 Birds of a Feather 2 – 5 p.m. Curacao 1 & 2
Facilitators: Dr. Paulson & Lauren Moore, MS

SCA6 Birds of a Feather 2 – 5 p.m. Curacao 6
Facilitator: Dr. Shakkottai

All Other SCAs (Including SCA 5, SCA7 and SCA 8) & DRPLA Birds of a Feather 2 – 5 p.m.Curacao 3 & 4
Facilitators: Dr. Ranum & Dr. La Spada

Over Age 30 Friedreich Birds of a Feather 2 – 5 p.m. Antigua 1 & 2
Facilitators: Dr. Wilson (2-5 p.m.) & Dr. Lynch (2-4 p.m.)

Unknown Without Family History – MSA, Sporadic & Gluten Birds of a Feather 2 – 5 p.m. Bonaire 1, 2 & 3
Facilitators: Dr. Khurana (2-5 p.m.) & Dr. Perlman (2-4 p.m.)

*The following groups have been designed for parents of children who are **affected with ataxia**:

Parents (Friedreich) Birds of a Feather 2 – 5 p.m. Bonaire 6, 7 & 8
Facilitators: David Zilles (2-5 p.m.), Dr. Perlman (4-5 p.m.) & Dr. Lynch (4-5 p.m.)

SATURDAY, APRIL 2ND

<i>EVENT</i>	<i>LOCATION</i>	<i>TIMES</i>
NAF Registration	South Registration	8:00 a.m. – 5:00 p.m.
Exhibitors	Grand Sierra ABC	8:00 a.m. – 5:00 p.m.
Silent Auction Bidding	Grand Sierra ABC	8:30 a.m. – 12:30 p.m.
It’s a fun way to help raise funds for NAF and for you to bid on wonderful items. Good luck! The winning bids will be posted by 3:30 p.m. Winners must pick up and pay for their items from 4 – 7 p.m. on Saturday.		
General Sessions	Grand Sierra D & E	9:00 a.m. – Noon
Continue Saturday Morning in Grand Sierra D & E. A 30-minute Question and Answer session will follow the morning General Sessions with a panel of the speakers who presented during those sessions.		
Activity Room	Antigua 1 & 2	10:00 a.m. – 5:00 p.m.
The activity room is open to all ages. Persons under the age of 12 must be accompanied by a parent or guardian who is age 18 or older. Scheduled activities coming soon on the NAF’s website, www.ataxia.org .		
Lunch	On Your Own	Noon
Birds of a Feather (BOF) Group B*	See Pages 26-27	2:00 – 5:00 p.m.
Attendees will have the opportunity to attend small group sessions. See page 30 for more information about these small group sessions.		
Banquet	Grand Sierra D & E	7:00 p.m.
The cost of the banquet is included in your registration fee. Beverages will be available at a cash bar. The banquet includes a plated dinner entrée that you will select when you register for the conference. When you arrive at the conference please reserve your seating and verify your entrée selection prior to the banquet.		

Volunteers will be at the banquet ticket tables near the NAF registration to assist you as you obtain your banquet tickets, select your seating, and confirm your entrée selection. This is a ticketed event. Your banquet ticket will be required to enter this event. We look forward to a wonderful dinner together and a fun evening of socializing.

SATURDAY GENERAL SESSIONS

TIME	TOPIC	SPEAKER
9:00 a.m.	Stem Cell: Fact-Fiction-Future	Henry Paulson, MD, PhD & Lauren Moore, MS University of Michigan – Ann Arbor, MI
9:30 a.m.	Update on NAF Supported Research	Harry Orr, PhD University of Minnesota – Minneapolis, MN
10:00 a.m.	Detours Ahead: Life with Ataxia	Nygel Lenz, NAF Support Group Leader Clearwater, FL
10:30 a.m.	Genetics 101 and Whole Genome Sequencing	Vikram Shakkottai, MBBS, PhD University of Michigan – Ann Arbor, MI
11:00 a.m.	Sporadic Ataxia and MSA	Vikram Khurana, MBBS, PhD Brigham and Women's Hospital/ Harvard Medical School – Boston, MS
11:30 a.m.	Q&A	Panel
Noon	Lunch	

Birds of a Feather (BOF) Group B*

Attention Parents: Birds of a Feather Sessions for attendees under 30 years old are facilitated by experienced clinicians. Mature subject matter may be discussed. These sessions are not intended for those who are under 12 years old. Children under 12 years old should not attend a BOF session. Questions regarding these sessions may be directed to Sue Hagen, NAF Patient Services Director at susan@ataxia.org or (763) 553-0020.

Birds of a Feather Informal Groups will meet from 2 – 5 p.m. in various meeting rooms. Please check the hall signs for your specific group's location. Tentative room assignments are listed below. Paid PCAs are welcome to attend the BOF session with their client, but not required unless client requires it.

*The following groups are for those who are **affected with ataxia**:

Unknown With Family History Birds of a Feather 2 – 5 p.m. Bonaire 1 & 2
Facilitator: Dr. Wilmot

AOA, Episodic & Other Recessive Ataxias Birds of a Feather 2 – 5 p.m. Bonaire 3
Facilitator: Dr. Perlman

Under Age 30 With Ataxia Birds of a Feather 2 – 5 p.m. Antigua 3 & 4
Facilitators: Nygel Lenz & Jennifer Keller, PT

*The following groups have been designed for parents of children who are **affected with ataxia**:

Parents (Non-Friedreich) Birds of a Feather 2 – 5 p.m. Bonaire 5 & 6
Facilitator: Dr. Day

*The following groups are for those who are **non-affected family members**:

Family Members (Over 30) Without Ataxia (other than parents, spouses, or partners) Birds of a Feather 2 – 5 p.m. Bonaire 4
Facilitator: Camille Daglio

Family Members (Under 30) Without Ataxia

(other than parents, spouses, or partners) Birds of a Feather 2 – 5 p.m. Curacao 1
 Facilitators: Bailey Vernon, MPH, CHES & Jennifer Millar, PT

Spouses & Partners Without Ataxia Birds of a Feather 2 – 5 p.m. Curacao 2, 3 & 4
 Facilitators: Ellen Sichel, BS & Amanda Gallagher, MA, CCC-SLP

The following session is for both those who are **affected or non-affected with ataxia:

Family Planning Options Session 2 – 5 p.m. Bonaire 7 & 8
 This facilitated session will provide information on family planning options that are available to prevent passing the ataxia gene to the next generation.

SUNDAY, APRIL 3RD

EVENT	LOCATION	TIMES
NAF Registration	South Registration	9:00 – 11:00 a.m.
Exhibitors	Grand Sierra ABC	9:00 – 11:00 a.m.
General Sessions	Grand Sierra D & E	9:00 a.m – 12:45 p.m.

Sunday morning wraps up the 2016 Annual Ataxia Conference with the NAF Business Meeting and final round of General Sessions in the Grand Sierra D & E, followed by a Question and Answer Session with a panel of the speakers who presented during this time. Don't miss this general session which includes a wrap-up of all the presentations, so if you missed any during the weekend, you will hear the highlights of each speaker's presentation.

SUNDAY GENERAL SESSIONS

TIME	TOPIC	SPEAKER
9:00 a.m.	NAF Business Meeting.....	William Sweeney, NAF President NAF – Minneapolis, MN
9:30 a.m.	Management of Ataxia: Soup to Nuts	Susan Perlman, MD University of California – Los Angeles, CA
10:15 a.m.	Update on SCA Research	George “Chip” Wilmot, MD, PhD Emory University – Atlanta, GA
10:45 a.m.	Using an iPad for Aided Communication: Augmentative and Alternative Communication Options	Nancy Harrington, MS, CCC-SLP Florida Alliance for Assistive Services and Technology, University of Florida – Orlando, FL
11:15 a.m.	Ataxia Investigators Meeting:..... Worldwide Research Updates	Gülin Öz, PhD University of Minnesota – Minneapolis, MN
11:45 a.m.	Wrap-up: What We Have Learned	John Day, MD, PhD Stanford University School of Medicine – Stanford, CA
12:15 p.m.	Q&A	Panel
12:45 p.m.	Closing Remarks	Camille Daglio, AAC Co-Chair NAF – Hattiesburg, MS

VOLUNTEER INFORMATION

Volunteers donating their time contribute greatly to the success of each National Ataxia Foundation Annual Ataxia Conference. We need volunteers for the 2016 AAC. To sign up as a volunteer at the 2016 AAC or to get more information about the volunteer opportunities, please contact Dianne Williamson at diannebw@aol.com or (256) 520-4858. ❖

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- Upon your arrival at Orlando International Airport, proceed to one of the Mears Motor Shuttle ticket counters located on LEVEL 1 and present this coupon to receive your ticket. You **MUST** present a hard copy of this coupon or the online confirmation upon check-in at the Mears ticket counter.
- After redeeming your coupon for a roundtrip ticket, present your ticket to the Mears Customer Service Representative located on LEVEL 1 curbside next to the crosswalk.
- For questions, please call our toll free number at **1-800-759-5219** or locally at **407-423-5566**.
- To schedule your return transfer to the Orlando International Airport please call at least 24 hours prior to your scheduled flight time.
- Plan to allow three hours prior to your flight time for your transfer to the airport.

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National Ataxia Foundation – Annual Meeting 2016



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“THE MAGIC OF A CURE. DREAM IT. HOPE IT.”

Conference Registration Instructions

Dates: April 1 – 3, 2016

Location: The Caribe Royal Orlando
81181 World Center Drive
Orlando, FL 32821
1-800-823-8300 or (407) 238-8000

Conference Registration: The Registration Fee includes entrance to all General Sessions, “Birds of a Feather,” exhibitor area, as well as breaks, the Welcome Reception, and the Saturday Evening Banquet. NAF members enjoy a reduced ataxia conference registration fee.

Individuals eligible for the member rate include current:

- Individual Members (*Individual members may also register their spouse or caregiver at the member rate*)
- Household Members (*Household members include all the individuals living at the same address*)
- Patron Members (*Patron members include all the individuals living at the same address*)
- Lifetime Members (*Lifetime members include all the individuals living at the same address*)
- Professional Members
- Recurring Gift Members

Early Registration Fee (*includes registrations received or postmarked by February 12, 2016*):

- Members: \$125/person • Non-Members: \$180/person

Registration Fee February 13 – March 25, 2016 – You are strongly encouraged to register before Feb. 12 (*includes registrations postmarked after February 12, 2016*):

- Members: \$150/person • Non-Members: \$205/person

Registration Fee after March 25, 2016 – You are strongly encouraged to register before Feb. 12 (*All registrations after March 25th will be at the door*):

- Members: \$200/person • Non-Members: \$255/person

NOTE: The Conference Registration Fees DO NOT include hotel or transportation costs.

Instructions for Registration:

- 1. Please fill out the registration form completely** and mail with your payment to the NAF office. The requested information is necessary to complete preparations for the conference.
- 2. Registration Fees.** Whether you plan to attend the entire conference or just the General Sessions or just the banquet and/or reception, the full per person registration fee will be charged. Children attending the conference will be charged the following registration fees: children two years and under are free; children three years and over will be charged the full conference registration fee.
- 3.** Childcare services are not provided by NAF staff, volunteers or local volunteers.
- 4.** Complete and return all pages of the registration form by March 25, 2016. Please fill out the name portion of the registration form as you would like it to appear on your name badge.

NOTE: You may register for the meeting online at the NAF website: www.ataxia.org

Early Registration Deadline is February 12, 2016

Please complete all pages of the registration form and return to the following address:
National Ataxia Foundation, 2600 Fernbrook Lane, Suite 119, Minneapolis, MN 55447-4752
(763) 553-0020 Fax: (763) 553-0167 E-mail: joan@ataxia.org

“Birds of a Feather” Frequently Asked Questions

What are “Birds of a Feather (BOF)” sessions?

“Birds of a Feather” sessions are small break-out groups facilitated by medical professionals and/or trained small group leaders. The groups are organized by the type of ataxia that the participant has been diagnosed with or the role that person has, such as parent, spouse/partner, or other family member.

What is presented at the BOF sessions?

Information about research, clinical care, management of symptoms and questions from the group will be addressed. BOF sessions also provide a time for attendees to meet others and share similar concerns and issues that are relevant to being affected by ataxia.

When do the BOF sessions meet?

BOF *Group A* sessions meet on Friday from 2 – 5 p.m. BOF *Group B* sessions meet on Saturday from 2 – 5 p.m. You will select only one session from either *Group A* or *Group B* to attend.

Can anyone attend a Birds of a Feather session?

Yes, anyone over age 12 who has registered and paid the meeting registration fee can attend a session.

Do I have to attend a BOF session?

No, attendance (as with all events at the annual conference is optional to the attendee. However, many attendees in the past have said that BOF sessions were the most valuable part of the annual conference for them.

Do I have to decide when I register for the annual conference which session I plan to attend?

It is not necessary, however, indicating your BOF selection when you register helps NAF in conference and room planning purposes

I am a family member without ataxia. May I attend the Birds of a Feather session that is specific to my family member’s diagnosed type of ataxia?

We encourage you to select a group that fits the role you have in your diagnosed family member’s life, however we understand each person’s need may be different and the goal of these sessions is to be a valuable experience for all conference attendees. You may attend the session that will be most helpful for you, but keep in mind the specific focus of the group.

Share Your Story in *Generations*

Generations is published quarterly by the National Ataxia Foundation and reports on research, chapters and support group activities, events and other topics related to ataxia.

Personal stories from those affected by ataxia are an important part of the publication. Stories submitted should be no longer than 1,200 words. If possible, tell how NAF has made an impact in your life or situation.

Submit stories to naf@ataxia.org or to the address on the inside front cover to be considered for publication.

iSearchiGive Is Good for NAF

iSearchiGive.com is a search engine powered by Yahoo! Search and *iGive.com*. It is the Internet’s first online shopping mall where a portion of each purchase is donated to a charity of your choice. Use it to search the web, and your favorite cause automatically receives money for every qualified search.

iSearchiGive.com is totally free, with no hidden fees. Please sign up today and indicate that the National Ataxia Foundation is your favorite cause to support for the important work of the Foundation.

I am a non-family member Personal Care Assistant (PCA). May I attend a BOF session?

PCAs are welcome to attend the session with their client, however it is not required unless the client needs assistance.

How do I select which Birds of a Feather Session to attend?

Your selection will be based on whether you are diagnosed with ataxia or if you are a family member or a caregiver of a person who is diagnosed with ataxia. Some BOF groups are also divided by the age of the attendee.

The following sessions (Group A) will meet on Friday afternoon:

- **SCA1** for those who are over 12 years old and have been diagnosed with SCA1
- **SCA2** for those who are over 12 years old and have been diagnosed with SCA2
- **SCA3** for those who are over 12 years old and have been diagnosed with SCA3
- **SCA6** for those who are over 12 years old and have been diagnosed with SCA6
- **All other SCAs and DRPLA** (including SCA 5, 7, 8) for those who are over 12 years old and have a diagnosis of SCA other than SCA 1, 2, 3, or 6
- **Unknown without a family history, MSA, Sporadic and Gluten Ataxia** for those who are over 12 years old and have been diagnosed with MSA, Sporadic, or Gluten Ataxia and where there is no family history of ataxia.
- **Over Age 30 Friedreich** for those diagnosed with Friedreich ataxia who are over the age of 30.
- **Parents (Friedreich)** for parents of a child(ren) who is/are affected by Friedreich ataxia.

The following sessions (Group B) will meet on Saturday afternoon:

- **Unknown with Family History** for those who are over 12 years old and have been diagnosed with an Unknown Type of Ataxia and where there is a history of ataxia in their family.
- **AOA, Episodic, and other Rare Recessive Ataxias** for those who are over 12 years old and have been diagnosed with AOA, Episodic, or other rare recessive ataxias other than Friedreich ataxia.
- **Under age 30 with Ataxia** for those diagnosed with any type of ataxia who are 12-30 years old.
- **Spouses and Partners without Ataxia** for spouses and partners who are not diagnosed with ataxia.
- **Parents (Non-Friedreich)** for parents of a child(ren) who is/are affected by any form of ataxia other than Friedreich ataxia.
- **Family Members Over 30 without Ataxia** for family members such as siblings, children, grandparents, etc. other than parents, spouses, or partners.
- **Family Members Under 30 without Ataxia** who are 12-30 years old such as siblings, cousins, children, grandchildren, etc.

Are there any other small-group sessions?

Yes, the National Ataxia Foundation will be offering a facilitated session on Family Planning Options on Saturday from 2 – 5 p.m. This session is for prospective parents or others who are interested in learning about options such as pre-implantation genetic diagnosis, genetic counseling, adoption, as well as other choices which may prevent the passage of the ataxia gene to their children. For those who plan to attend a Birds of a Feather session on Friday, you are welcome to register for this Saturday session as well. Please arrive promptly at 2 p.m. for this session. For the continuity of this group's presentation, joining the group after 2 p.m. is discouraged.

I have more questions. Is there someone I can email or speak with?

Yes, you may contact Lori Shogren at lori@ataxia.org or Sue Hagen at susan@ataxia.org or call (763) 553-0020 and ask to speak with Sue or Lori. ❖

2016 NAF Annual Ataxia Conference Registration

Online registration available at www.ataxia.org. Instructions can be found on page 29.

The NAF will send out all conference materials and handouts through e-mail.
For those who do not have access to e-mail, materials will be mailed out.

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

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

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

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

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

*Indicates required information. PCA = Personal Care Attendant.

2016 NAF Annual Ataxia Conference Registration

**Please indicate the Birds of a Feather (BOF) session you plan to attend in question 6 below.
Select ONE SESSION ONLY in Group A (Friday) or Group B (Saturday):**

— Group A on Friday (A-H) —

A: SCA1 **B:** SCA2 **C:** SCA3 **D:** SCA6 **E:** All other SCAs (including 5, 7, 8) & DRPLA
F: Unknown w/out Family History – MSA, Sporadic & Gluten **G:** Over 30 (Friedreich Ataxia)
H: Parents (Friedreich Ataxia)

— Group B on Saturday (I-O) —

I: Unknown w/ Family History **J:** Spouses/Partners w/out Ataxia
K: Under 30 w/ Ataxia **L:** Family Members (under 30) w/out Ataxia
M: Parents (non-Friedreich Ataxia) **N:** Family Members (over 30) w/out Ataxia
O: AOA, Episodic & Other Rare Recessive Ataxias (does not include Friedreich Ataxia)

Please complete the following for each person (continued from page 32):	#1	#2	#3	#4
6. Please indicate the Birds of a Feather session you plan to attend from Group A Friday (A-H) or Group B Saturday (I-O) Select one session only				
7. Do you plan on attending the Family Planning Options session on Saturday from 2–5 p.m.? Y or N				

TRAVEL INFORMATION

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

For parking arrangements at the hotel, we need to know if you will be driving a van with a lift: Yes No

Air Carrier: _____ Flight Number: _____

Arrival Date/Time: _____ Hotel Check-in Date: _____

Departure Date/Time: _____ Hotel Check-out Date: _____

VOLUNTEER INFORMATION

Volunteers donating their time contribute greatly to the success of each National Ataxia Foundation Annual Ataxia Conference. We need volunteers for the 2016 AAC to be held in Orlando, FL on April 1–3. To sign up as a volunteer at the 2016 AAC or to get more information about the volunteer opportunities, please contact Dianne Williamson at (256) 520-4858 or diannebw@aol.com to sign up.

IMAGE CONSENT POLICY

By attending the 2016 NAF Annual Ataxia Conference you give your consent, unless you notify us otherwise, to use your image captured during the conference through video, photographs, or digital imagery, to be used by the National Ataxia Foundation in promotional materials, publications, and web site and waive any and all rights to these images.

VIDEOTAPING/FILMING/RECORDING POLICY

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

SOLICITATION POLICY

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

— AAC Registration continues on page 34 —

2016 NAF Annual Ataxia Conference Registration

Not sure if your membership is current?

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

Take advantage of the MEMBER RATE and JOIN TODAY!	Quantity	Total
<p>Yes, I would like to be a member of NAF! Please add an ADDITIONAL</p> <p> <input type="checkbox"/> \$35 (Annual Individual) <input type="checkbox"/> \$55 (Annual Household) <input type="checkbox"/> \$100+ (Annual Patron) <input type="checkbox"/> \$500 (Lifetime) <input type="checkbox"/> \$55 (Annual Professional) <input type="checkbox"/> \$50 (Individual Outside U.S.) <input type="checkbox"/> \$70 (Household and Professional Outside U.S.) <input type="checkbox"/> Recurring membership \$_____ /month (for more information, please call NAF) </p> <p>You may register for the conference as a member if you sign up today!</p> <p><i>*Household, Patron and Lifetime memberships include all individuals who share the same residence.</i></p>		
<p>Yes, I'd like to support the Annual Ataxia Conference Fund (provides travel grants, offsets registration fees, helps cover costs associated with the meeting)</p> <p>Here is my sponsorship contribution!</p> <p> <input type="checkbox"/> \$125 (Offset of Registration) <input type="checkbox"/> \$400 (Travel Grant) <input type="checkbox"/> Other: \$_____ (Any amount is helpful!) </p>		

REGISTRATION FEES (includes all General Sessions, reception, and banquet)	On or Before 2-12-2016	From 2-13 to 3-25-2016	After 3-25-2016 at door	Quantity	Total
<input type="checkbox"/> NAF Member* (applies to NAF members who have an Individual, Household, Patron, Recurring or Lifetime membership <i>(member rate is applied to one caregiver per individual member with ataxia)</i>)	\$125	\$150	\$200		
<input type="checkbox"/> Non-Member*	\$180	\$205	\$255		

*No registration refunds will be made after March 14th

TOTAL CHARGES:

PAYMENT INFORMATION: Visa MasterCard Discover AMEX Check enclosed

Name of Card Holder: _____

Address: _____

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

Phone Number: _____ E-mail: _____

Credit Card Number: _____ Expiration Date: _____

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

Early Registration Deadline is February 12, 2016

Please complete all pages of the registration form and return to the following address:
 National Ataxia Foundation, 2600 Fernbrook Lane, Suite 119, Minneapolis, MN 55447-4752
 (763) 553-0020 Fax: (763) 553-0167 E-mail: joan@ataxia.org

Conference Information and Resources

Conference Registration

Registration is open and you are encouraged to register before **February 12, 2016** to receive the discounted early registration rate. General registration rates apply after **February 12, 2016**. Registrations after **March 25th** will only be accepted on-site at the conference. (Additional “on-site” registration fee will apply.) If you are bringing an attendant, please register together on the same registration form. Each person who is planning on attending daily sessions, the reception, or banquet needs to register. Event entry will be allowed only with properly registered name badges.

The conference registration fee includes attendance at all the sessions, light appetizers at the Friday evening Meet & Greet Reception and a plated meal at the Saturday evening Banquet. Thanks to the hard work of the conference planning committee and hosting groups the NAF did not have to raise registration fees this year!

The conference registration form is also available on the NAF’s website, www.ataxia.org. Please fill out the registration form completely, including your travel information, as we need all the information to finalize plans.

Please note: *There will be no refunds of registration fees for cancellations received after March 14. Registration at the door is not recommended.*

Member Registration Discount

Being a member of the National Ataxia Foundation has its benefits – one benefit is paying a lower registration fee for the Annual Ataxia Conference. If you are not currently a member of the Foundation or if your membership renewal is coming soon or if you are uncertain of your membership status, please consider this a great opportunity to contact the office at (763) 553-0020 or joan@ataxia.org. Visit www.ataxia.org to

become a member or renew your membership online. This will prevent unnecessary extra fees or errors in your membership status when you register for the 2016 Annual Ataxia Conference. Thank you for taking the time to renew or become a member of the National Ataxia Foundation.

Conference Deductions by Attendees

<http://www.irs.gov/pub/irs-irbs/irb00-19.pdf>

Rev. Rul. 2000–24, page 963 (In part)

Medical expenses.

Amounts paid by an individual for expenses of admission and transportation to a medical conference relating to the chronic disease of the individual’s dependent are deductible as medical expenses under section 213 of the Code (subject to the limitations of that section), if the costs are primarily for and essential to the medical care of the dependent. The cost of meals and lodging while attending the conference are not deductible as medical expenses under Code section 213.

Travel Grant Program

Please see page 40 for more information on how to support the Travel Grant program or how to apply.

About Orlando

A world-renowned destination, Orlando is the place to make all of your vacation dreams come true. Of course, it is beloved for its theme parks: Walt Disney World, Universal Orlando® Resort, SeaWorld Orlando and many others. With seven of the world’s top 20 theme parks in one destination, not to mention nearly 100 other attractions, Orlando certainly knows how to entertain. Discounted Disney theme park

Continued on page 36

Conference Information and Resources
Continued from page 35

tickets can be found at <http://www.mydisneymeetings.com/59aac/>.

Orlando also beckons with world-class resorts, shopping opportunities for every budget, all-season golf courses, and some of the most enticing dining opportunities on the planet. Less known but equally inviting are the downtown sections of Orlando itself and many nearby towns in Central Florida – places that celebrate public art and take pride in offering a myriad of cultural opportunities.

Transportation – Mears Transportation Group runs lift-equipped shuttle service between hotels, attractions and Orlando International Airport, but **24-hour advance reservations are required**. To receive a \$4-off Mears Hotel/Airport Roundtrip Online Discount, go to www.mears.com, click on the “Book Orlando Shuttle Now” box and enter the code 512326050 in the “promo Code” box provided in the lower left hand corner. You **MUST** present a copy of your online confirmation upon check-in at the Mears ticket counter upon arrival at the airport. The I-Ride Trolley is the best way to see International Drive. The trolleys, featuring lifts and lock-downs, operate daily from 8 a.m. to 10:30 p.m. with service every 20 minutes.

Weather – The month of April is characterized by rising daily high temperatures, with daily highs increasing from 80°F to 85°F over the course of the month. Daily low temperatures range from 59°F to 64°F.

Consumer Alert (Source: Trip Advisor) – While theme parks such as Walt Disney World, Universal and Sea World may seem pricey, travelers should be cautious when looking for discounted tickets. While some legitimate companies run deals and discounts for Orlando theme parks, some offers may be deceiving and even illegal. Tourists should be aware of which companies are legitimate operations and which may not be. Tourists should be especially careful

of companies advertising discount theme park tickets at booths in tourist areas in Florida. Many of these are run by timeshare sales companies offering the discount as part of a sales pitch. Some booths are selling tickets that have been acquired secondhand and illegally from other tourists. Some tourists may be approached about selling their tickets, but travelers are advised to refuse, since the buying and selling of used tickets is illegal in the state of Florida. Some theme parks, such as Walt Disney World, have introduced security measures such as finger scans to eliminate the use of illegal tickets, so it is possible that a ticket bought through an illegitimate company will be of no use. In addition, attempting to use an illegal ticket may have legal repercussions. Many of the booths that sell the tickets open up and disappear very quickly, so it can be difficult to track down those responsible for any crime. If it looks too good to be true, it probably is.

Travel Advisory – The NAF Annual Ataxia Conference is being held during a busy time in Orlando. The airport, conference hotel, theme parks, restaurants, and roadways will be busy. Please plan accordingly.

Please visit www.visitorlando.com for a complete list of attractions, planning, and transportation information.

Caribe Royale

The Caribe Royale is the official conference hotel of the 2016 NAF Annual Ataxia Conference. The Caribe Royale is located on World Center Drive and is located 15.5 miles from the Orlando International Airport at 8101 World Center Drive, Orlando, FL 32821.

For your stay and planning purposes at the Caribe, the following information is provided.

- The meeting space being held for the NAF is in the Grand Sierra Ballroom area of the Grand Caribe Convention Center. Golf Cart transportation to and from your guest room, the convention center, and/or the main reception building can be requested if required by dialing 4903 from any house phone or calling ►►

(407) 239-8000 if a house phone is not available.

- Standard room reservations at the Caribe Royale can be made online at <https://bookings.ihotelier.com/bookings.jsp?groupID=1477001&hotelID=5636>. For guests who prefer to phone in their reservation call Hotel Reservations at 1-800-823-8300 and ask for the National Ataxia Foundation's group rate which is under the group name "National Ataxia Foundation." Reservations at group rate will be available until **February 27, 2016**. The NAF group rate starts at only \$149 + tax for Standard Rooms. The \$19.95 per night resort fee is waived for attendees booked inside the NAF room block. See the Room Type Guide for additional details.

- All ADA rooms must be reserved through the NAF office. ADA rooms cannot be reserved through the hotel. Availability of ADA room types are limited. Please have alternative room types in mind when requesting a reservation for an ADA room. For more detailed information about the room types available, please refer to the Room Type Guide on pages 42-43. To inquire about the availability of an ADA room at the Caribe, please contact Lori Shogren at (763) 553-0020 or lori@ataxia.org.

- If you need ADA equipment you are encouraged to bring those items with you or make arrangements to rent equipment locally. Resources to rent equipment can be found in the Orlando Services and Resources section of this article. The NAF is unable to provide ADA equipment however the Caribe Royale may have a limited number of shower chairs, grab bars, or detachable shower heads available. **Be sure and request these items when making your reservation if needed.**

- Parking at the Caribe Royale – Self Parking is complimentary. Valet Parking is available at Caribe Royale. Valet Parking for those with disabilities is complimentary. Please identify that you are with the National Ataxia Foundation

Group if you require this service. The costs are as follows: \$9 + tax Day Guest Valet (per day) and \$12 + tax Overnight Valet (per night). Visit their restaurant/bar and get your ticket validated (three-hour max). There is ample parking available in the open lot surrounding the resort and convention center. If you are planning on using a handicap parking space bring your out-of-state or international disabled parking permit with you. It should be prominently displayed in the windshield of the car when you are parked in designated public handicapped parking spots. Temporary permits are not available.

- Service Dog Information – The service dog relief area at the Caribe Royale will be designated near the Convention Center and Tower II.



The Caribe Royale in Orlando, Florida will be the site of the 2016 NAF Annual Ataxia Conference.

Transportation Options – Guests staying at Caribe Royale and Buena Vista Suites can easily enjoy much that Orlando has to offer with a variety of discounted and complimentary transportation options. Complimentary scheduled shuttle transportation to all four Walt Disney Parks as well as Disney Springs (formally known as Downtown Disney) in the evening for dining and entertainment options, is available. Shuttle reservations can be made up to 30 days in advance. Lift-equipped shuttle service reservations are required at least 24-hours in advance. All other reservations must be made at least one hour prior to departure, first come, first served.

Conference Information and Resources

Continued from page 37

It is requested that attendees be at the bus stop 10 minutes early. Shuttle reservations can be made by contacting at Guest Services at (407) 238-8010 prior to arrival or in the main lobby 7 days a week 7 a.m. to 10 p.m. or at Ext. 8010 when you are on-site. Please note there are some shuttle service changes, see the Caribe Royale website at <http://www.thecaribehotelsorlando.com/transportation> for additional information.

Standard WiFi package (Basic Plan) for up to two devices is complimentary in guest rooms for AAC attendees. The price is currently \$4.99 per day to upgrade your plan to four devices per suite. Upon check in you can access the Internet by entering the suite number and last name of the individual listed on the room reservation.

- Visit the Caribe Royale website <http://www.cariberoyale.com/> for more information.

The following information can be used as a guide as you plan your **transportation needs** in Orlando. The National Ataxia Foundation does not endorse products, services, or manufacturers. Those mentioned below are included for your information only. The NAF assumes no liability for the use or contents of any product or service mentioned.

Transportation and Getting There

To help you with planning, NAF encourages you to access the links to important websites that will inform you of your rights and your responsibilities when traveling by air. Go to NAF's website at www.ataxia.org and select the Links tab at the top of the home page. You will be directed to a list of links. Select the category Accessible Travel to find websites such as Transportation Security Administration and the U.S. Department of Transportation.

Passengers requiring any in-flight assistance should contact their airline before traveling. Airlines will generally work with passengers to

try to meet their particular in-flight needs. Also, visit the TSA Cares website, <https://www.tsa.gov/travel/passenger-support>, for contact information to request screening assistance, scooter assistance, service animal assistance, and any other accessible services that you may need at the airports you utilize during your travels.

Orlando International Airport Ground Transportation – Information Booths are located throughout the airport including on Level 3 (Departures) of the “A” Terminal at the West end (gates 1-59) near Sea World and at the East end (gates 70-129) near Sea World. Note: Information Booths are open from 6:00 a.m. to 8:00 p.m.

Visit http://www.orlandoairports.net/transport/local_transport.htm or <http://www.orlandoairports.net/ops/disabled.htm> or call (407) 825-8463 for a complete listing of accessible services and ground transportation options to and from the Orlando International Airport.

Shuttle Vans

Approximate Rates to the Caribe Royale per person are one-way \$20, or round trip \$32.

Located in Terminal A, on the Ground Transportation Level (Level 1), at the Commercial Lane parking spaces: A9-A10 and A36-A37.

Located in Terminal B, on the Ground Transportation Level (Level 1), at the Commercial Lane parking spaces: B9-B10 and B40-B41.

Mears Transportation Group – (407) 423-5566
<https://www.mearstransportation.com/>

Mears Transportation Group runs lift-equipped shuttle service between hotels, attractions and Orlando International Airport, but 24-hour advance reservations are required. To receive a \$4-off Mears Hotel/Airport Roundtrip Online Discount, go to www.mears.com, click on the “Book Orlando Shuttle Now” box, and enter the code 512326050 in the “promo Code” box provided in the lower left-hand corner. You MUST present a copy of your online confirmation upon check-in at the Mears ticket counter upon arrival at the airport. ▶▶

Super Shuttle – (800) 258-3829

<http://groups.supershuttle.com/nationalataxia-foundationannualmeeting2016.html>

SuperShuttle is providing a group discount for shuttle service from the Orlando International Airport to the Caribe Royale All-Suite Hotel and Conference center. To receive the group discount use the group reservation website or phone number that is provided. 24-hour advance reservations are required. If you require a van with a lift please select that option when making your reservation.

Taxi Cabs

Approximate rates to the Caribe Royale are \$43-\$52.

Located in Terminal A, on the Ground Transportation Level (Level) 1, at Commercial Lane parking spaces: A5-A8 and A22-A25.

Located in Terminal B, on the Ground Transportation Level (Level) 1, at Commercial Lane parking spaces: B5-B8 and B30-B34.

Ace Metro/Luxury Cab – (407) 855-1111

Diamond Cab Company – (407) 523-3333

Quick Cab – (407) 447-1444

Star Taxi – (407) 857-9999

Town & Country Transport – (407) 828-3035

Yellow/City Cab – (407) 422-2222

Rental Cars

If you are planning to rent a car in Orlando, be sure to call ahead to reserve vehicles with hand controls. Several rental companies – including Alamo, Avis, Dollar, Hertz and Enterprise – have these models available for rent.

Orlando Area Services and Resources**Personal Care Attendants (PCA)**

If you need a personal care attendant, please make arrangements prior to attending the meeting to have someone accompany you or have a PCA hired before you arrive in Orlando. Please note that NAF is unable to provide attendant care services. Due to liabilities and

health concerns, NAF staff or volunteers and hotel employees are not able to provide PCA services.

Firstlight Home Care – (407) 434-0675

<http://www.firstlighthomecare.com/home-health-care-winter-park-orlando/>

Sunshine In Home Care, LLC – (407) 992-6670

<http://www.sunshineinhomecare.com/>

Childcare

If you need childcare, please make arrangements prior to attending the meeting. Please note that the NAF is unable to provide childcare services. Due to liabilities and health concerns, NAF staff or volunteers and hotel employees are not able to provide childcare services.

Super Sitters, Inc. – (407) 382-2558

<http://super-sitters.com/>

Accessible Equipment, Wheelchair, and Scooter Rentals

K&M Rentals – (407) 363-7388

<http://www.km-rentals.com/>

ScootaRama – (407) 897-6839

<http://www.scootarama.com/>

ScooterBug – 800-726-8284

<http://www.scooterbug.com/>

Walker Mobility – (407) 518-6000

1-888-SCOOTER

<http://www.walkermobility.com/>

Scootaround Inc. – 888-441-7575

<http://scootaround.com/>



Research Match Challenge

Thank you to those who helped us reach the \$200,000 research match challenge. Because of your generosity, the National Ataxia Foundation will be able to support many promising research studies. Thank you!

NAF AAC Travel Grant Program Needs Your Support

“Being around other people with ataxia at the meeting helps me feel less alone.”

The National Ataxia Foundation’s Annual Ataxia Conference (AAC) connects the ataxia community. The meeting program is designed to foster learning and understanding by providing informative presentations about ataxia research and on living with ataxia. Connecting with those who understand and face the same challenges is also an important component in which individuals with ataxia, their family members, and caregivers have the opportunity to share and network.

Traveling to an Annual Ataxia Conference can be financially difficult. To help those with ataxia who are unable to financially attend the AAC, the NAF established an AAC Travel Grant Program to help with some of the costs associated with attending the AAC.

You can help someone with ataxia attend the AAC by making a donation to the NAF AAC Travel Grant Program. Your gift to the AAC

Travel Grant Fund will make an huge difference in someone’s life. Thank you for your support and for making the AAC experience possible for an individual affected by ataxia who would not have been able to attend without your help.

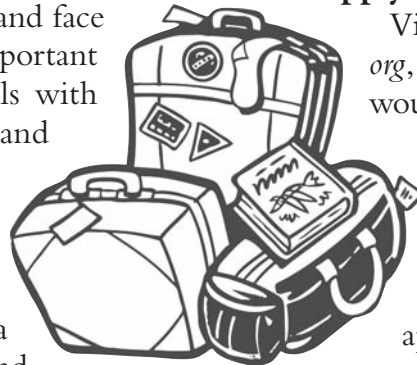
Applying for an AAC Travel Grant

Visit the NAF website, www.ataxia.org, to download the application. If you would like an application sent to you in the mail, contact Lori Shogren at (763) 553-0020 or by e-mail at lori@ataxia.org to request one.

Applications will be accepted until January 15, 2016. Travel Grant applicants will be notified of the status of their application after the application deadline and after all applications have been reviewed.

You can also download the forms by following these links:

- Adult – <http://tinyurl.com/qeb4gtl>
- Children – <http://tinyurl.com/oszfy4v> ❖



Silent Auction

The Silent Auction held during the National Ataxia Foundation Annual Ataxia Conference (AAC) is a fun way to support the NAF and for you to bid on quality items from various states and countries. This long-standing NAF tradition begins Friday, April 1 at 8:30 a.m., with final bidding ending on Saturday at 12:30 p.m. Winners must pick up and pay for their items from 4-7 p.m. on Saturday.

Auction items should range from something that represents your state or country, art work, sports memorabilia, theme baskets, hand-

crafted items, hotel stays and weekend get-aways. Items being donated should be dropped off at the registration area on Friday, April 1 at 4 p.m. Please complete and include the form at left with your items.

If you are not able to attend the conference, but have a quality item that you would like to donate, please call (763) 553-0020 or e-mail Joan at joan@ataxia.org for details on where to ship your item. Donate an item and then have fun bidding on the items of your choice!

Thank you for supporting this event.

Ataxia Research through Brain Tissue Donation

The National Ataxia Foundation thanks all of the donors and families who have generously donated brain tissue in the past. Brain tissue research provides hope for those who are affected with ataxia and their family members. However donating tissue for medical research is an important and deeply personal decision.

Planning for brain tissue donation well in advance will ensure that the wishes of you or your loved one are honored at the time of passing. Although enrollment may take place at the time of death, advanced planning will help the process go smoothly and family members will not be burdened with additional details and stress at the time of the loved one's passing. Brain tissue donation should be made within 12 to 24 hours after the death occurs.

If you are affected with Friedreich Ataxia and wish to be a donor, please contact Dr. Arnulf Koeppen at (518) 626-6377 or arnulf.koeppen@va.gov.

If you are affected with any other form of ataxia and wish to be a donor, please contact Sue Hagen at the National Ataxia Foundation at (763) 553-0020 or susan@ataxia.org. The National Ataxia Foundation acts as a liaison between the donor and the researcher who will be receiving the brain and any other related tissue for ataxia research. Once the introduction has been made by NAF, the details of planning for the tissue donation will be between the donor or donor's family and that research institution.

If an individual does not have a plan in place prior to death and the person dies unexpectedly or in the evening or on a weekend, a family member may contact the Brain Endowment Bank™ immediately following the death at 1-800-UM-BRAIN or (305) 243-6219. The Brain Endowment Bank™ staff will respond to the call 24 hours a day, seven days a week.

Thank you for your interest in the Ataxia Brain Tissue Donation program. ❖

Don't forget about your SILENT AUCTION item Donation!!

Please have card filled out and attached to your item prior to bringing it into the registration room. Thank you!

Item Description _____

Minimum bid (if Any) \$ _____

Name _____

Name of Group _____

Address _____

City _____ *State* _____ *Zip* _____

Phone Number _____ 2016

Email Address _____

Item Number _____
Office Use only

2016 Annual Ataxia Conference Room Type Guide

Caribe Royale Orlando

The Caribe Royale is a resort property on 53 acres just minutes from Orlando's world famous theme parks and attractions at 1818 World Center Dr, Orlando, FL 32821. The Caribe Royale has 1,218



spacious, well-appointed one-bedroom suites, 120 luxurious two-bedroom lakeside villas, and expansive state-of-the-art meeting and event facilities, along with a variety of dining options.

All rooms come with a pull-out sofa bed. The bed height in all rooms is 27". Self-parking and in-room Internet are both complimentary for NAF attendees at the Caribe Royale.

Buena Vista Suites Orlando

On the Caribe Royale property is their sister property the Buena Vista Suites. Both properties will provide attendees easy access to the Caribe Convention Center also located on the property. Parking



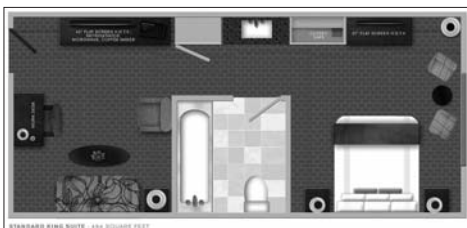
and in-room Internet are both complimentary for NAF attendees at the Buena Vista Suites. The Buena Vista Suites has 279 one-bedroom suites.

All rooms come with a pull-out sofa bed. The bed height in all rooms is 27". Standard Suite layouts at the Buena Vista Suites is the same as the Standard Suite layout at the Caribe Royale.

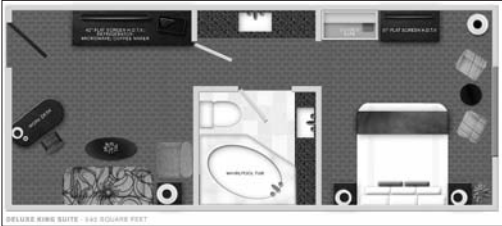
Room Type Chart

Visit the Caribe Royale website for additional details: www.cariberoyale.com.

Room Type	Rate	Description
Caribe Standard Suites King/Double Queen – 494 sq. ft.	\$149 + tax	A limited number of ADA rooms with Roll-in Showers or Step-in Tubs are available in the Standard King One-Bedroom Suites. These room types are located within the three towers on the resort property. The bathroom door width in ADA Suites is 33 7/8". The step-in tub height is 13.5". The bathroom door width in non-accessible Suites is 29 7/8".

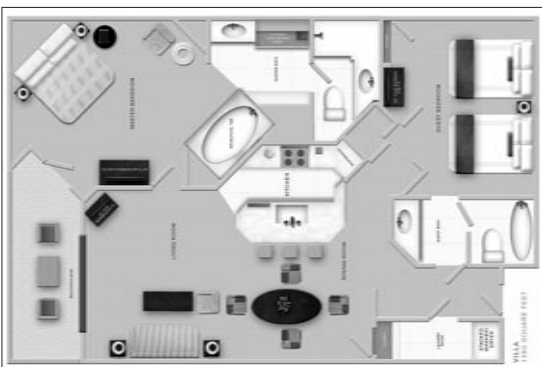


<i>Room Type</i>	<i>Rate</i>	<i>Description</i>
Caribe Deluxe King Suites – 592 sq. ft.	\$169 + tax	A limited number of ADA rooms with Step-in Tubs are available in the larger Deluxe King One-Bedroom Suite format. These room types are located within the three towers on the resort property. The bathroom door width in ADA Suites is 33 7/8". The step-in tub height is 13.5". The bathroom door width in non-accessible Suites is 29 7/8".



<i>Room Type</i>	<i>Rate</i>	<i>Description</i>
Caribe Executive Suites	\$299 + tax	A limited number of ADA rooms with Step-in Tubs are available in the Two Bedroom Executive Suite format. These room types are located within the three towers on the resort property. The bathroom door width in ADA Suites is 33 7/8". The Step-in Tub height is 13.5". The bathroom door width in non-accessible Suites is 29 7/8".

<i>Room Type</i>	<i>Rate</i>	<i>Description</i>
Caribe Villas – 1,260 sq. ft.	\$229 + tax	A limited number of ADA rooms with Roll-in Showers or Step-in Tubs are available in the two-bedroom villa (smoking and non-smoking) format. Villas are located in four, four-story towers surrounding a private villa pool and set slightly apart from the rest of the hotel. However, you're just a short stroll away from dining options located in the main reception building and central area of the hotel. All villas come with a queen-sized, pull-out sofa bed in addition to the king master bedroom and double queen bedroom. The bathroom door width in all villas is 33". The Step-in Tub height is 13.5".



<i>Room Type</i>	<i>Rate</i>	<i>Description</i>
Buena Vista Standard King Suites – 460 sq. ft.	\$149 + tax	A limited number of ADA rooms with Roll-in Showers and Step-in Showers are available in the King Suite (smoking and non-smoking) formats. The step-in tub height is 13.5". Standard Suite layout at the Buena Vista Suites is the same as at the at the Caribe Royale. ❖

My Ataxia Story

By Cheryl (Cheri) Lou (Kukelhan-Hoffman) Bearman

The type of ataxia that runs in my family is Spinocerebellar Ataxia Type 3 (SCA3), aka Machado-Joseph Disease (MJD). My mother had the condition and passed it on to three of her six living children. I, my oldest brother, and my oldest sister inherited it. Two sisters and one brother did not inherit the condition. My mother was pretty sure she inherited the condition from her mother, though it was not diagnosed in my grandmother's time. Doctors thought my grandmother had arthritis and thus walked with a walker and fell often. My grandmother had five children – three boys and two girls. My mother, her only sister, and her youngest brother inherited the condition. Her two older brothers did not inherit it. On average, each child (male or female) of an affected parent (mother or father) has a 50% chance of inheriting the condition.

In my family, those of us who are afflicted with SCA3 started showing symptoms in our early 50's. Neither of my siblings who have SCA3, nor I, know if any of our children have inherited the condition from us, as none of our children have reached age 50 yet. There is a genetic test for SCA3, but it is recommended to forego the test, as a positive result may negatively affect the ability to get insurance.

I will be 59 this year. I am still able to walk unassisted for the most part, but I am becoming more and more unstable. I have always been very active, athletic, coordinated, and agile. As the condition progresses, it is becoming more and more difficult for me to do the things I have always enjoyed. I was a runner but am no longer

able to run, so I walk with trekking poles for stability. I have been a student of yoga for many years, but I can no longer do all of the poses without a bar or the wall to assist me. In spite of this, I continue to practice yoga as always. I still am able to ride my bicycle, but I am aware of my balance becoming more precarious. In addition to my yoga practice and riding my bicycle on a regular basis, I maintain my fitness level by walking two miles almost daily (with trekking poles), and I do 30 minutes of muscle strengthening exercises and stretching most mornings.

Another symptom of SCA3 is double vision, due to lack of ability to coordinate the muscles of the eyes. Fortunately, glasses with prisms mostly correct this issue. I also have severe neuropathy in my feet and lower legs and have not found anything to help. I have tried chiropractic, acupuncture, medications, and massage. The ataxia has not yet affected my speech or

ability to swallow. Both handwriting and keyboarding have become somewhat more difficult for me. I find myself backspacing repeatedly to correct errors (for every 10 letters I type correctly, I backspace five). It is very frustrating for someone who was once an avid typist!

Since my walking skills are deteriorating, my husband and I traveled out West this past summer, rather than postponing the trip until he retires in two years. This trip had been on my "bucket list" for some years, so we decided to do it while I was still able! We flew to Denver, rented a car, and drove almost 4,000 miles to Seattle and back to Denver, visiting five ►►



Gil and Cheri Bearman

national parks on our journey – Glacier, North Cascades, Yellowstone, Grand Teton, and Rocky Mountain. Each park was unique and spectacular! We also spent a wonderful weekend in Seattle visiting with our son!

On the final day of our 15-day adventure, we ventured up Mt. Evans, just west of Denver. We traveled by car all the way to the summit, 14,130 feet, and then hiked the final quarter mile up a windy, narrow, steep, rocky path to the very top. Every step up for me was a treacherous, scary experience, while toddlers and mothers carrying infants literally skipped up the path around me! I was the **ONLY** one on the path with trekking poles, but I **MADE IT TO THE TOP!** Though the trip was very taxing and tiring for me (getting in and out of the car, in and out of hotels, slow

and steady walking to see the sights), overall we had a most excellent “Wild West Adventure”!

I have found the best way to live with ataxia is to maintain a positive attitude, remain physically active – move every day! – and rely on the support of faith, family and friends.

Many different types of ataxia, both hereditary and non-hereditary, have been discovered. Some types can be identified with genetic testing, but many cannot. The hereditary ataxias are often diagnosed by family history and symptoms. There is no treatment or cure for any of the ataxias. The National Ataxia Foundation (NAF) funds many research projects around the world and much work is being done to find cures and treatments. To learn more about ataxia, go to www.ataxia.org. ❖

Pre-K Ataxia Awareness

By Megan Hardigree

My son, Raylan, age four, has cerebellar atrophy with ataxia. As his mom, I spoke to his class at Lee County Pre-K in Leesburg, Georgia about ataxia ... what a fun and interesting job. Ataxia is sometimes difficult to explain to adults let alone children.

This is a little of how my time went with 22-four year olds:

We started off making sure everyone knew where the brain is located. Then we talked about how the brain helps you balance. Raylan has trouble balancing and that’s why he uses his walker. Then we played a game, each child spun in Mrs. Musgrove’s chair 15 times and tried to walk a straight line. We talked about how it was hard, but how if you put your hands out to help your balance, it was easier.

Then we explained how using a walker requires both hands. Using hula-hoops, the children walked around the classroom and had



Raylan Hardigree

to navigate certain areas without dropping their “walkers.” Also, with their hands occupied holding their “walkers” we discussed how they were supposed to hold toys or get their lunchbox to the lunch room, common challenges Raylan faces every day.

We finished our time talking about how everyone is different. Whether you have a walker, glasses, black hair, or blue eyes, everyone is different and that makes everyone special.

It was a great day.

If you would like to contact Megan, please do so by e-mail at mkhardigree@gmail.com. ❖

Making a Difference through Music

By Ian C. Bouras

Many people saw the wonderful write-up in the Utica paper – “Club Scene” and came to see me play. One of the people I met read the article and wanted to see what I was doing. He also plays guitar, has a different neurological issue, and was curious how I dealt with it. It was great to meet him.

All of my performances were great. Tuesday, October 13, I played at the Boulder Coffee Co., Friday the 16th at Utica Brews and Saturday the 17th at Starry Nites Café, all in Rochester, NY. I am able to tell people about ataxia during my performances. I have CD’s available at the shows and ask that a donation be made to the NAF in lieu of payment. I play for almost two hours, usually playing about one hour, taking a short break, and then playing for another 45-50 minutes. There are times when I lose track of time and don’t stop! I have so much fun playing.

I recently was offered a new string endorsement with StringJoy (www.stringjoy.com), who is

very supportive and totally behind me. This endorsement will allow me to reach more of the guitar enthusiasts with my music and to also bring some attention and support to ataxia.

I feel like I am really making a difference, even with life setting up a roadblock, I have found “my” way around it. I am very happy to feel like I am making a difference and also to share people’s reactions to what I am doing. I will be doing many more in the near future! I have another CD I would like to finish and I have been invited back already to play again at the venues, but will continue to perform in new areas so I have a greater reach spreading information and bring awareness about ataxia. I hope to also perform in other states as well in the future. The reaction and feedback I have been getting about my live looping is great, and that makes me excited to do more.

If you would like to hear some of Ian’s songs, here is a link for some free downloads: http://www.sdmprecords.com/free_downloads.html. ❖



Ian C. Bouras performing at the Boulder Coffee Co.

Study of Cardiomyopathy in Friedreich’s Ataxia Patients

A new IRB-approved study at Weill Cornell Medical College on Friedreich’s Ataxia is recruiting patients between 18 to 30 years old. The purpose of the study is to compare different tests and procedures and to evaluate their use-

fulness in assessing the cardiac manifestations of FRDA. The study requires a two-day, overnight stay in New York City. For more information contact Aileen Orpilla at (646) 962-4537 or aio2001@med.cornell.edu.

The Day My Life Changed Forever

Submitted by Mary Ornstein on behalf of Eric Christian

I remember it like it was yesterday. It was a typical day spending quality time with my son at the gym. We decided to pick up some fast food for dinner at a drive-thru, and while ordering my speech began to slur, sounding muffled and distorted. I remember my son and I laughing at each other and didn't think much more about it. Little did I know this was the start where my life would be changed forever. I was experiencing, from a mysterious illness, double vision and balance issues. After several visits, to several different doctors and specialists, my testing and bloodwork coming back "normal," they all came up the same conclusion. I was given the diagnosis of SCA on April 26, 2002. Over the past 12 years I have gone from a cane to a walker and now I am in a wheelchair.

I believe that growing up playing team sports has prepared me to deal with my new life. I was a popular kid and a gifted athlete. Fabrice Sueoka, a longtime friend, has been with me since my darkest hour and has stuck by my side. I've accepted my fate and vowed to never complain or give up on living. Somebody else can always have it worse and I have chosen not to be bitter about having this disease. It has allowed me to meet people throughout my life that I may have never met otherwise.

I haven't worked for 12 years. I had a successful career as a hairstylist for 22 years and a successful career as a senior associate for a well-know company for 20 years as a platform artist/educator. I have kept a positive attitude and

remained focused on things I still could do independently. I set short term goals and stick to them. Stretch to stay flexible and exercise, exercise, exercise!

Throughout my journey I have really learned a lot about my family and true friends. I have also learned a lot about my character and my will to fight my disease, my faith and the things that are important! **DON'T SWEAT THE SMALL STUFF!** The past years of living with this unfor-

giving disease, I wouldn't wish this on my worst enemy!

I hope that if my children or grandchildren inherit the disease, they will see me as a pillar of hope and strength and continue to live no matter what. My disability doesn't define me as a person. It's just slowed me down a little bit and caused some frustration in

my life. I did make the decision to give up my driver's license for safety reasons. Losing the last little bit of independence and freedom made it a very tough decision.

It can be very easy to become depressed, because you don't want to be looked at as a burden to others. I admit that sitting around the house all day, every day, I often find myself trying to find things to do to stay positive. I love my family members deeply but I wish they would step back and put themselves in my shoes. I'm not asking for any special treatment, or pity. I just want them to see the struggles I live with every day and just have a little more patience as

“
**Over the past 12 years
I have gone from a
cane to a walker
and now I am in
a wheelchair.**
”

The Day My Life Changed Forever
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frustrating as it may be for everyone involved.

Things seemed to be going as well as to be expected until December of 2013, when my ataxia progressed and I noticed my health was declining. I have been depressed and felt alone dealing with this horrible disease. You either have high highs or low lows. Without support from family and friends I couldn't imagine living with this disease.

Living with the struggles of ataxia, it is really becoming harder to get around these days. I was very fortunate to spend some bonding time with my son and his girlfriend. The timing of our bonding experience could not have come at a better time for both of us. The week we spent together has really recharged my focus and reminded me of the reason I love my kids, grandchildren, family and friends and zest for life.

Things have really have sped up which has greatly affected my speech. For the past 13 years I've had to deal with some form of dizziness or nausea every day! I can also tell my balance and being upright is starting to become difficult. I'm starting to find myself question what my purpose in this life is. I'm not angry or bitter, I'm just in pain and having a hard time understanding. But, no matter what the situation, I will continue to stand up for myself with pride, dignity and respect. At the end of the day my mind is at peace. I am not feeling sorry for myself but I am complaining about my disease. Paying attention to my body and recognizing the many changes I've gone through I realize I've been brave and vigilant, but for the first time I'm concerned about my future. I really find peacefulness and

joy in simple things in life that others may take for granted.

At this point I feel like, I've experienced life and I'm very much at peace. You've heard me say, "It's your turn to live" a million times and "It's all good!" We all are going to leave this place at some point! As sad and tough as it may be to carry on, just know I'm always with you. Life goes on.

I have been blessed in my young adult life with two wonderful kids and two beautiful grandkids! I am very fortunate to have a very good support system when it comes down to family and friends! Never take that special gift for granted! I attribute a lot of my strength to move forward to growing up with two loving parents. My mom

dealt with a lot of stuff in her own life which has allowed me to better understand why she is who she is today! She is the glue that has kept our family together!

A dear childhood friend, Mary Hernandez Ornstein, unknowingly made a long-time dream happen for me. She talked about having a "Celebration of Life." A true celebration of my simple life, bring awareness to

my disease, to celebrate my life while I could enjoy everyone's encouragement and kind words. This was the greatest gift anyone could have given me. This dream became a reality on October 3, 2015 and it was more than I could have imagined! I was concerned about how people would respond to my disease, but they know now what this brutal diagnosis is and what it does to your body. I say celebrate your life with those that you love and value, and with those that love you! It was a highlight of my life hearing friends sharing old stories and what I mean to them. This was humbling, but an encouragement of a lifetime for me and my mother as well, who is my main caregiver. She was in awe of ►►



Celebration of Life – Eric Christian and childhood friend Mary Ornstein

all the love and support we both received. "It's all good."

Currently I am averaging 7,400 push-ups a month, 525 plank sit-ups a day and 240 miles a month on a recumbent bike. A little extreme for most people, but as former athlete I like to test my limits! While I am unable to speak or walk, I still get on the floor and raise my body up to a push-up position, and will continue to do everything I can to continue fighting and win my body over. I believe that this rigorous workout has kept my body and mind strong and why I am still alive today. It is my hope that somehow I can inspire others who have ataxia to work day after

day and not give in and to move their bodies with this debilitating disease.

My ultimate goal is to achieve awareness. To speak for those who have been silent. This has given me a reason to live again and not give up. I am very humbled by all the e-mails I have received from many different people that have been inspired, motivated, and want to learn more about my story and ataxia. A simple dream I had back in 2005, my dear friend Mary and I have brought the NAF and ataxia awareness to Killeen, Texas!

If you would like to contact Eric, please e-mail him at ebchristian@yahoo.com. ❖

Speaking Opportunity at Oregon State

By Jason Wolfer

In the early summer I was contacted by a Professor from the Oregon State University. She teaches a class titled "Psychology of Disabilities," and had come into contact with a few of the blogs that I had written concerning my life and struggles with Spinocerebellar Ataxia. She asked if I would consider coming to her class in the fall and speak to her students.

This seemed like an excellent opportunity, and so on the afternoon of October 27, I spoke to 27 students about my neurological disease known as SCA. Most of them, just like most of society, had never heard of my disease, and I gave them a quick outline of the physical layout and connection between the brain, the cerebellum, and the spinal column.

The students were very receptive and after my talk was over, spent about 40 minutes asking me questions. It was a great experience, and there are now 27 more people who have been educated about ataxia.

Two of those students then asked me if I would be willing to be interviewed by them for a class paper. They called me two days later and we did a 45-minute interview. If you would like to listen to the talk I gave, and the question and answer time, the two segments can be found on YouTube. Here are the links: <https://youtu.be/wTt8XGoT2C0> and https://youtu.be/BP-Mbgmd_64.



❖ Jason Wolfer at OSU

Carolyn's Story: My Journey with Ataxia

By Carolyn J. Allen

In 2004, I began experiencing unexplained symptoms, such as walking difficulty, falling frequently and severe balance issues. Over the next few years my symptoms began to worsen. Soon I began to experience vision and speech issues as well – however, I just attributed this to getting older. For several years, I was misdiagnosed with anxiety and depression disorders.

I continued my long and active career with the University of Minnesota until I retired in 2006. After that, I really began looking for a solution to my symptoms. I had many tests, saw numerous doctors and even sought out respected specialists – with no answers.

Finally, in 2010, I was diagnosed with ataxia by my neurologist, Dr. Moen Masood. My neurologist suggested I go to the U of M for a second opinion. It was the first time I was told that I would not get any better. I am currently in a wheelchair, but I remain positive. The great news is that I have slow-progressing ataxia and can still enjoy time with my loved ones. I will be forever indebted to Dr. Masood for solving this puzzle.

In 2014, my husband Dan and I made the decision to begin home care with Comfort Keepers in Blaine, MN. Previously I had a negative experience with my caregivers and caregiving agencies. I am thankful to report that I now have several great Comfort Keepers with whom I have developed special bonds. Most of the time I work with my weekday caregiver, Rhonda. Instead of using the term “clumsy,” we use the words “Happy Feet” and “Happy

Hands.” That has had a positive impact for me. Nothing holds me back – I use my Rifton Pacer, a device similar to a walker that holds me upright, to go on walks at local parks and in the mall with my caregivers. My Uncle donated his handicap-accessible van to me after he passed away – this gives me the freedom to travel out of my home easily. There is no time for daytime TV here! We are too busy exercising at the local gym, shopping, going to the movies, going out to eat and going downtown for special events.

Another Comfort Keeper caregiver, Sam, works with me evenings and weekends. We enjoy scrapbooking, computer projects, outdoor activities, going on my scooter (that was given to me by my Mom) on the local trails, etc. Sam and I also came up with an idea to make t-shirts to help spread ataxia awareness. I have traveled with my caregivers to visit family out of state ... Rhonda



Carolyn J. Allen

fits in just like another sister!

My husband and I currently live in a one-level detached town home, which was custom designed to fit my needs. We have experienced many ups and downs that have made our love for each other stronger. We participate in the Minnesota Walk, Stroll, n' Roll each fall in St. Louis Park. In the future we plan on traveling to the NAF Annual Ataxia Conference. I am an active member of a local support group for those affected by ataxia. Recently I joined the NAF as a life-time member. I believe that I am a part of God's plan to spread ataxia awareness. ❖

Chapter and Support Group News
from Around the Country

Mississippi and Louisiana Chapters

Submitted by Camille Daglio

The Mississippi Chapter and Louisiana Chapter of the National Ataxia Foundation enjoyed a day of fun, good food, and visiting with friends on September 13. It was the first time an event of this type has been held and we are hoping to plan one annually in future years.

Tampa Bay Ataxia Support Group

Submitted by Linda Farrow

Saturday, October 10 there was a meeting of the Tampa Bay Ataxia Support Group led by our president, Nygel Lenz. The meeting was held at Marsoni Hall on the USF campus and was catered by Jason’s Deli.

While we were enjoying the delicious food we went around the table and each person attending introduced themselves. Some new people were there and we were very glad to have them there.

One of the members husband raised the question about some “sleep” problems that may be associated with ataxia. A lively discussion followed with some suggestions as to where one might find some further information on the subject, as well as suggestions as to where adaptive help might be obtained.

Next, we were introduced to our new vice president, Darlene Harris, who will be leading our next meeting to be held in January 2016. She will have information on self reliance, vocational rehabilitation, community care for disabled adults and Hillsborough Co. Disabled Liaison. It sounds like an very good meeting and we will set the dates for our 2016 meetings.

There was a discussion about who will be attending the Annual Ataxia Convention to be held in Orlando in April 2016, our entries for the Silent Auction and some fundraising to support the Convention.

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Members of the Mississippi and Louisiana Chapters

Chapter and Support Group News
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Northern California Ataxia Support Group

Submitted by Joanne Loveland

Our final support group meeting was held on October 17. Twenty-three attended. We welcomed two new people. Our program was "Canine Companions." Six puppies came with their trainers. The dogs live with their volunteer trainers for 16 months before they are interviewed to be a companion for a disabled person. We enjoyed watching the dogs follow commands. One trainer shared that his last dog went to a young girl with Friedreich Ataxia.

Alabama Ataxia Support Group

Submitted by Becky Donnelly

The Alabama Ataxia Group held their meeting on October 24 in Birmingham at Covenant Presbyterian Church. Our guest speaker was retired Judge Debra Goldstein, who covered criteria for obtaining disability. She gave the "Medicare 5 Points" and explained many of the finer points associated with gaining approval. This topic was of great interest to the group, and the judge answered many questions from the group.



Left to right: Judge Debra Goldstein, Becky Donnelly and Susan Mason at the Alabama Ataxia Support Group meeting

Members enjoyed a delicious brunch, and later a luncheon, catered and donated by member Susan Mason. A brief business meeting followed with reports from the different Cell Group leaders.

Central PA Ataxia Support Group

Submitted by Michael Cammer

We had our quarterly support group meeting on October 24 and had the pleasure of have Dr. Pedro Gonzalez from Penn Medicine and Children's Hospital of Philadelphia (CHOP). He gave one of the most engaging presentations on the developments in ataxia research and RNAi that I have heard since becoming involved with the National Ataxia Foundation. This "sneak peak" into RNAi therapy for the SCAs was so very exciting, and having Dr. Gonzalez share it with our small group was such a treat for us. We only heard the basics and I'm sure much more from definitive sources will be coming out in the near future!

Twin Cities Ataxia Social Group

Submitted by Tom Sweeney

The Twin Cities Ataxia Social Group experienced a busy summer and early fall, capped off with our Walk, Stroll n' Roll for Ataxia. Our event has raised over \$80,000 for the second consecutive year. There were over 450 people that attended. The day of the walk, September 12, also was proclaimed "Dr. Harry Orr Day" by Minnesota Governor Mark Dayton. The proclamation recognizes Dr. Orr's groundbreaking research in Ataxia.

Our group is growing. About 25-30 members regularly attend the monthly meetings with even more attending special events like the annual Christmas party. Group members also have instituted an annual summer picnic in July, bi-monthly month break out groups of caregivers and persons with Ataxia, and a guest speakers program. ▶▶

At our October meeting, psychologist June Meyerhoff discussed strategies to help deal with the emotional aspects of ataxia. June is the daughter of Pete Meyerhoff, the originator of “Pearls of Wisdom.”

Denver Area Ataxia Support Group

Submitted by Charlotte DePew and Trish Hysong

At our last meeting, we had a warm and interactive social time together with a new couple attending plus some of our long-term members as well. Donna and Tom Sathre, previous Denver Ataxia Support Group Leaders (1998-2009), were present along with our ageless author, Ben Price. Tom brought his normal wit and lively eyes despite his debilitating ataxia. Benetta Price is the same: a soul filled with life, beautiful as ever, and brought us the “best-ever” chocolate chip cookies by Chef, her soul-mate.

Over 150 pictures taken at the September 13 Run, Walk ‘n Roll for (RWnR) Ataxia in Honor of Karen Cocquyt were viewed in a slide show of nearly everyone attending the



Left to right: Karl Herman, Charlotte DePew, Corey Banks, Trish Hysong, and Debbie Crystal from the Denver Area Ataxia Support Group’s RWnR Planning Committee. All of the businesses on the sign contributed in some small to significant way.

RWnR. These pictures are available to anyone on a DVD/CD by contacting Karl Herman at karl832@earthlink.com.

Also, we have members who moved from Denver and still have our group in their thoughts and send us their greetings and best wishes: Keri Naccarato in Georgia and Amy Cantrell in Texas. ❖

GoodSearch Is Good for NAF

Did you know that donating money to the National Ataxia Foundation is as easy as changing your Internet search engine?

GoodSearch.com donates 50 percent of its revenue to the charities and schools designated by its users. Simply go to the site’s home page and follow the easy steps to make NAF your charity of choice.

Then use GoodSearch as you would any other search engine. You’ll make a difference in the lives of those with ataxia!

Donate a Vehicle to Benefit NAF

Do you have a spare car or truck sitting unused, or know someone who does?

Donating a vehicle to the National Ataxia Foundation helps support the important work that is being done on behalf of all who are affected by ataxia and their families.

To donate your car, truck or motor home, call the NAF office at (763) 553-0020. Your vehicle will be picked up at the location you designate. Please have the certificate of title with the vehicle.

NAF 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 family member or friend 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 at lori@ataxia.org or (763) 553-0020.

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

Social Networks

NAF BULLETIN BOARD

Moderator – Atilla and Bear

www.ataxia.org/forum/toast.asp

NAF CHAT ROOM

Moderator – Della (ddpokernut@yahoo.com)

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

NAF FACEBOOK GROUP

www.facebook.com/group.php?gid=93226257641

NAF FACEBOOK FANS

www.facebook.com/lshogren?ref=profile#!/pages/National-Ataxia-Foundation/227766109304

NAF YOUTUBE CHANNEL

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

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

Chapters, Support Groups and Ambassadors

– ALABAMA –

ALABAMA SUPPORT GROUP LEADER

Becky Donnelly – Hoover, AL

(205) 987-2883

E-mail: donnelly6132b@aol.com

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

AMBASSADOR

Dianne Blain Williamson – Huntsville, AL

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

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

– ARIZONA –

PHOENIX AREA SUPPORT GROUP LEADERS

Angela Li – Peoria, AZ

(847) 505-4325

E-mail: angelali1010@gmail.com

Mary Fuchs – Sun Lakes, AZ

(480) 212-6425

E-mail: mary11115@msn.com **Facebook Group:**

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

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

AMBASSADOR

Bart Beck – Tucson, AZ

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E-mail: bbeck15@cox.net

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

– ARKANSAS –

AMBASSADORS

Judy and David King – Hot Springs Village, AR

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

– CALIFORNIA –

LOS ANGELES AREA SUPPORT GROUP LEADERS

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Lora Morn – Santa Monica, CA

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Sacramento Area Location Representatives

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Donna Hoag – Lincoln, CA

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Teresa Bredberg – Sacramento, CA

E-mail: tbredberg@sbcglobal.net

S.G. Website: <https://norcalataxia.org>

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

ORANGE COUNTY AREA SUPPORT GROUP LEADER

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PALO ALTO SUPPORT GROUP LEADERS

Victoria Tanoury, RN, CNRN – Stanford, CA

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Sarah Kahn – Stanford, CA

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

– COLORADO –

DENVER AREA SUPPORT GROUP LEADER

Charlotte DePew – Aurora, CO

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Facebook Group:

<https://www.facebook.com/groups/denverataxia2011/>

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

– CONNECTICUT –

TRI-STATE SUPPORT GROUP LEADERS

Kathy Gingerelli – Parsippany, NY

(973) 334-2242

E-mail: kgingerelli@msn.com

Denise Mitchell – Bronxville, NY

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www.ataxia.org/chapters/Tri-State/default.aspx

– DELAWARE –

DELAWARE SUPPORT GROUP LEADER

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

– FLORIDA –

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

AMBASSADORS

Debra Hass – Fort Lauderdale, FL

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

Meghan McBrearty – Tallahassee, FL

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

– GEORGIA –

GREATER ATLANTA SUPPORT GROUP LEADERS

Dave Zilles – Atlanta, GA

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E-mail: dzilles@earthlink.net

Greg Rooks – Atlanta, GA

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Lealan Sims – Hilton Head Island, SC

(678) 234-6600

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S.G. E-mail: atlantaataxia@yahoo.com **Facebook Group:**

<https://www.facebook.com/groups/317380459539/>

<http://www.ataxia.org/chapters/Atlanta/default.aspx>

AMBASSADOR

Kristie Adams – Savannah, GA

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

– ILLINOIS –

CHI-TOWN FRIENDSHIP GROUP LEADER

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

CHICAGO METRO AREA SUPPORT GROUP LEADER

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Elaine Darte – Coffeen, IL

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

– INDIANA –

HAPPY HOOSIERS INDIANA SUPPORT GROUP LEADER

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

– IOWA –

IOWA SUPPORT GROUP LEADER

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

– KANSAS –

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– KENTUCKY –

AMBASSADOR

Janice Johnson – Brownsville, KY

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

– MAINE –

MAINE SUPPORT GROUP LEADER

Alan and Paula Nadeau – Belgrade, ME

*NAF Directory**Continued from page 55*

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— MARYLAND —**CHESAPEAKE CHAPTER PRESIDENT**

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— MASSACHUSETTS —**BOSTON AREA SUPPORT GROUP LEADERS**

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 S.G. E-mail: ngataxia@outlook.com
www.ataxia.org/chapters/Boston/default.aspx

CENTRAL MA SUPPORT GROUP LEADER

John and Dana Mauro – Auburn, MA
 (508) 736-6084
 E-mail: john@ataxia.org
 E-mail: danamauro63@msn.com

Facebook Group:

www.facebook.com/ataxiadidyouknow?ref=hl
www.ataxia.org/chapters/CentralMA/default.aspx

— MICHIGAN —**DETROIT AREA SUPPORT GROUP LEADER**

Tanya Tunstull-Marshall – Detroit, MI
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 E-mail: tinyt48221@gmail.com
www.ataxia.org/chapters/Detroit/default.aspx

WESTERN MICHIGAN SUPPORT GROUP LEADER

Lynn K. Ball – Grand Rapids, MI
 (616) 735-2303
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www.ataxia.org/chapters/LynnBall/default.aspx

— MINNESOTA —**CENTRAL MN SUPPORT GROUP LEADER**

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 E-mail: mbinnebose@hotmail.com
www.ataxia.org/chapters/StCloud/default.aspx

TWIN CITIES SOCIAL GROUP

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

Maryann Sweeney – Minneapolis, MN
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 E-mail: maryann.sween@gmail.com
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Lori Goetzman – Rochester, MN
 (507) 282-7127
 E-mail: logoetz@gmail.com
www.ataxia.org/chapters/LoriGoetzman/default.aspx

— MISSISSIPPI —**MISSISSIPPI CHAPTER PRESIDENT**

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

— MISSOURI —**KANSAS CITY SUPPORT GROUP LEADERS**

Jim Clark – Gladstone, MO
 (816) 468-7260
Lois Goodman – Independence, MO
 (816) 257-2428
www.ataxia.org/chapters/KansasCity/default.aspx

ST. LOUIS AREA SUPPORT GROUP LEADER

Sarah “Janeen” Rheinecker – St. Louis, MO
 (417) 379-3799
 Email: sjrheinecker@gmail.com
www.ataxia.org/chapters/StLouis/default.aspx

AMBASSADOR

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

— NEW HAMPSHIRE —**NEW HAMPSHIRE SUPPORT GROUP LEADER**

Jill Porter – Manchester, NH
 (603) 626-0129
 E-mail: jilleporter@comcast.net
www.ataxia.org/chapters/Bedford/default.aspx

— NEW JERSEY —**NEW JERSEY SUPPORT GROUP LEADER**

Priya Mansukhani – Bridgewater, NJ
 (908) 685-8805
 E-mail: priyamans@gmail.com
www.ataxia.org/chapters/NewJersey/default.aspx

TRI-STATE SUPPORT GROUP LEADERS

Kathy Gingerelli – Parsippany, NJ
 (973) 334-2242
 E-mail: kgingerelli@msn.com
Denise Mitchell – Bronxville, NY
 E-mail: markmeghan2@gmail.com
www.ataxia.org/chapters/Tri-State/default.aspx

– NEW YORK –**CENTRAL NEW YORK SUPPORT GROUP LEADER****Mary Jane Damiano** – N. Syracuse, NY**Judy Tarrants** – Fabius, NY

(315) 683-9486

E-mail: jtarrants@aol.com

www.ataxia.org/chapters/CentralNewYork/default.aspx**TRI-STATE SUPPORT GROUP LEADERS****Kathy Gingerelli** – Parsippany, NJ

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Denise Mitchell – Bronxville, NY

E-mail: markmeghan2@gmail.com

www.ataxia.org/chapters/Tri-State/default.aspx**– NORTH CAROLINA –****TARHEEL SUPPORT GROUP LEADERS****Ron and Donna Smith** – Garner, NC

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E-mail: rsmith@sacherokee.com

E-mail: dsmith@sa-pr.com

Jerry and Tammy Hauser – Advance, NC

(336) 998-2942

E-mail: deaconwfu@msn.com

www.ataxia.org/chapters/Tarheel/default.aspx**– OHIO –****GREATER CINCINNATI AREA SUPPORT GROUP LEADERS****Jennifer Mueller** – Lexington, KY

(513) 284-2865

E-mail: jenmu@yahoo.com

Julia Soriano – Cincinnati, OH

(513) 899-1195

E-mail: julia@epivision.com

Group Blog: <http://ataxiafoundationcleveland.blogspot.com/>www.ataxia.org/chapters/Cincinnati/default.aspx**CLEVELAND AREA SUPPORT GROUP LEADER****Carmen Pieragastini** – Willowick, OH

(216) 272-5588

E-mail: willowpier@roadrunner.com

www.ataxia.org/chapters/Cleveland/default.aspx**– OREGON –****WILLAMETTE VALLEY SUPPORT GROUP LEADER****Jason Wolfer** – Gervais, OR

(503) 502-2633

E-mail: wolfer.jason@gmail.com

Facebook Group:<https://www.facebook.com/groups/388993597939205/>www.ataxia.org/chapters/Willamette/default.aspx**– PENNSYLVANIA –****CENTRAL PA SUPPORT GROUP LEADER****Michael Cammer** – Downingtown, PA

(610) 873-1852

E-mail: michael.cammer62@hotmail.com

Facebook Group:<https://www.facebook.com/groups/1475283086068548/>www.ataxia.org/chapters/CentralPA/default.aspx**WESTERN PA SUPPORT GROUP LEADER****Donna Eiben** – South Park, PA

(412) 655-4091

E-mail: dawn.eiben@verizon.net

Ed Schwartz – Venetia, PA

(724) 941-2210

E-mail: eds@ataxia.org

SG Website:

<http://nafwesternpasupportchapter.weebly.com/>**Facebook Group:** <https://www.facebook.com/wpaataxia>www.ataxia.org/chapters/SouthPark/default.aspx**– RHODE ISLAND –****RHODE ISLAND SUPPORT GROUP LEADER****Anabela Azevedo** – Bristol, RI

(401) 297-8627

E-mail: azevedo70anabela@gmail.com

www.ataxia.org/chapters/Rhodelsland/default.aspx**– TENNESSEE –****MIDDLE TN AREA SUPPORT GROUP LEADER****Alex Cohn** – Nashville, TN

(256) 504-0240

E-mail: alex.j.cohn@us.pwc.com

www.ataxia.org/chapters/TN/default.aspx**– TEXAS –****GREATER HOUSTON AREA SUPPORT GROUP LEADER****Ashley Grayson** – Houston, TX

(832) 530-0866

E-mail: ashleygrayson90@gmail.com

Facebook Group:<https://www.facebook.com/groups/ataxia.houston/>www.ataxia.org/chapters/Houston/default.aspx**NORTH TEXAS AREA SUPPORT GROUP LEADER****David Henry Jr.** – Trophy Club, TX

(817) 739-2886 (contact by e-mail preferred)

E-mail: cheve11e@sbcglobal.net

Facebook Group:<https://www.facebook.com/Ataxiasupport>www.ataxia.org/chapters/NorthTexas/default.aspx**AMBASSADORS****Dana LeBlanc** – Orange, TX

(409) 883-5570

E-mail: tilessal@yahoo.com

www.ataxia.org/chapters/GoldenTriangle/default.aspx**Debra Whitcomb** – El Paso, TX

(915) 329-0721

E-mail: debrawhitcomb@hotmail.com

www.ataxia.org/chapters/Whitcomb/default.aspx**– UTAH –****UTAH SUPPORT GROUP LEADERS****Grant Beutler** – Salt Lake City, UT

E-mail: grant.beutler@gmail.com

Jenny Durrant – North Ogden, UT

E-mail: jenny@utahataxia.org

Lisa Ord, PhD, LCSW – Salt Lake City, UT

(801) 587-3020

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

Facebook Page: www.facebook.com/utahataxiaS.G. Website: www.utahataxia.org

NAF Directory

Continued from page 57

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

– VIRGINIA –

CHESAPEAKE CHAPTER PRESIDENT

Carolyn Davis – Vienna, VA

(703) 759-2008

E-mail: ccnafpres@gmail.comwww.ataxia.org/chapters/Chesapeake/default.aspx

– WASHINGTON –

OLYMPIC AREA SUPPORT GROUP LEADER

Sherry McLaughlin

(360) 344-2445

E-mail: ccherilynmc@yahoo.comwww.ataxia.org/chapters/Olympic/default.aspx

SEATTLE AREA SUPPORT GROUP LEADER

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AMBASSADOR

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(509) 482-8501

E-mail: linda4727@hotmail.comwww.ataxia.org/chapters/Spokane/default.aspx

– WISCONSIN –

WISCONSIN SUPPORT GROUP LEADER

Jenny Mathison – Madison, WI

(608) 285-5285

E-mail: mjmathison@att.netwww.ataxia.org/chapters/Wisconsin/default.aspx

International Support Groups & Ambassadors

– CANADA –

OTTAWA SUPPORT GROUP LEADER

Prentis Clairmont – Ottawa, Ontario

(613) 864-8545

E-mail: prentis.clairmont@gmail.com **Facebook Group:**<https://www.facebook.com/groups/1468963499991380/>www.ataxia.org/chapters/Ottawa/default.aspx

– INDIA –

INDIA SUPPORT GROUP LEADER

“Seek a Miracle Ataxia Group” (SAMAG)

Chandu Prasad George

Hyderabad, Secunderabad, India

Mobile: 0091-9989899919, 0091-9885199918

E-mail: sam_ataxiaindia@yahoo.comS.G. E-mail: india.ataxiagroup@gmail.com**Facebook Group:** <https://www.facebook.com/ataxiain>S.G. Website: www.ataxia.inwww.ataxia.org/chapters/Chandu/default.aspx

– PAKISTAN –

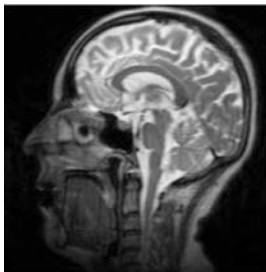
AMBASSADOR

Sajjad Jaider – Sindh, Pakistan

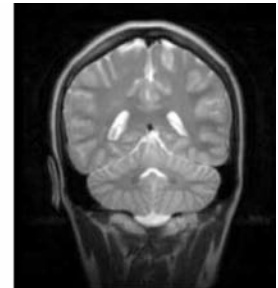
0092-(300) 8221850

E-mail: sajjadhaiderb@hotmail.com

Thank You NAF Chapters, Support Group Leaders, and Ambassadors!

Please submit your meetings and event listings to lori@ataxia.org.

PATIENTS with
MSA-C
needed for an MRI study
at the University of Minnesota,
Minneapolis



Travel expenses reimbursed.

Contact: Diane Hutter

(612) 625-2350

hutte019@umn.edu

Calendar of Events

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

SUPPORT GROUP MEETINGS

Saturday, January 2, 2016

New Hampshire Ataxia Support Group New Year's Luncheon

Time: 11:30 a.m.

Location: Fratello's Italian Grill, 155 Dow St., Manchester, NH

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

Saturday, January 9, 2016

Central Minnesota Ataxia Support Group Meeting

Time: 9:45 – 11:45 a.m.

Location: Harvest Bank Branch, 24952 County Road 7, St. Augusta, MN 56301

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

North Texas Ataxia Support Group Meeting

Time: 10 a.m. – noon

Location: Ben Washington Baptist Church, 615 Davis St., Irving, TX 75061

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

Wednesday, January 13, 2016

Willamette Valley Ataxia Support Group Meeting – Albany

Time: 11:30 a.m. – 1 p.m. on the second Wednesday of every month

Location: 400 NW Hickory, Albany, OR 97321

Details: For more information contact Jason Wolfer at (503) 502-2633 or wolfer.jason@gmail.com.

Thursday, January 14, 2016

St. Louis Area Ataxia Support Group Meeting

Time: 5:30 – 7:30 p.m. on the second Thursday of every month.

Location: Washington University Medical Center, 4444 Forest Park Ave., Rm. 509, St. Louis, MO 63108

Details: For additional information contact Janeen Rheinecker at (417) 379-3799 or stlataxia@gmail.com.

Tri-State Ataxia Support Group Meeting

Time: 6:30 – 8:30 p.m.

Location: Bethel Israel Medical Center, Phillips Ambulatory Care Center (PACC), Second Floor Conference Room, 10 Union Square East, New York, NY

Details: For more information contact Kathy GINGERELLI at kgingerelli@msn.com or Denise Mitchell at markmeghan2@gmail.com.

Saturday, January 16, 2016

Denver Area Ataxia Support Group Meeting

Time: 1 – 4 p.m.

Location: Swedish Medical Center, Second Floor Conference Center (meeting room TBD), 501 E. Hampden Ave., Englewood, CO 80113.

Details: For more information contact Charlotte DePew at (720) 379-6887 or cldepwe77@comcast.net.

Northern California Ataxia Support Group Meeting

Time: 11:30 a.m. – 2 p.m.

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

Details: For more information or to RSVP contact Joanne Loveland at (952) 323-6895 or joaneloveland@gmail.com.

Twin Cities Ataxia Social Group Meeting

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

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

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

Sunday, January 17, 2016

Willamette Valley Ataxia Support Group Meeting – Portland Area Location

Time: 3 – 4:30 p.m.

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

Details: To RSVP or for more information contact Jason Wolfer at (503) 502-2633 or wolfer.jason@gmail.com.

Saturday, January 23, 2016

New Hampshire Ataxia Support Group Meeting

Time: 10 a.m. – noon

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

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

Sunday, January 31, 2016

Greater Houston Area Support Group Meeting

Time: Noon – 1 p.m.

Location: Women's Hospital of Texas, 7600 Fannin St., Houston, TX 77054

Details: For more information contact Ashely Grayson at (832) 530-0866 or ashleygrayson90@gmail.com.

Saturday, February 6, 2016

Rhode Island Ataxia Support Group Meeting

Time: 11 a.m. – 2 p.m.

Location: Bristol Pocket and Recreation, 101 Asylum Rd., Bristol, RI 02809

Details: To RSVP or for more information contact Anabela Azevedo at (401) 297-8627 or azevedo70anabela@gmail.com.

Tuesday, February 9, 2016

Utah Ataxia Support Group Meeting

Time: 7 p.m.

Location: John A. Moran Eye Center, 65 Mario Capecchi Dr., Salt Lake City, UT 84132

Details: For more information contact Dr. Lisa Ord, PhD, LCW at (801) 585-6635 or lisa.ord@hsc.utah.edu.

Wednesday, February 10, 2016

Willamette Valley Ataxia Support Group Meeting – Albany

Time: 11:30 a.m. – 1 p.m. on the second Wednesday of every month

Location: 400 NW Hickory, Albany, OR 97321

Details: For more information contact Jason Wolfer at (503) 502-2633 or wolfer.jason@gmail.com.

Thursday, February 11, 2016

St. Louis Area Ataxia Support Group Meeting

Time: 5:30 – 7:30 p.m. on the second Thursday of every month.

Location: Washington University Medical Center, 4444 Forest Park Ave., Rm. 509, St. Louis, MO 63108

Details: For additional information contact Janeen Rheinecker at (417) 379-3799 or stlataxia@gmail.com.

Saturday, February 13, 2016

Central Minnesota Ataxia Support Group Meeting

Time: 9:45 – 11:45 a.m.

Location: Harvest Bank Branch, 24952 County Road 7, St. Augusta, MN 56301

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

Kansas City Ataxia Support Group Meeting

Time: 2 – 4 p.m.

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

Details: For more information contact Lois Goodman at (816) 257-2428 or Jim Clark at (816) 468-7260

North Texas Ataxia Support Group Meeting

Time: 10 a.m. – 12 p.m.

Location: Ben Washington Baptist Church, 615 Davis St., Irving, TX 75061

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

Saturday, February 20, 2016

Mid-Atlantic Ataxia Social Group Meeting

Time: 1 – 3 p.m.

Location: St. Thomas Episcopal Church, 1108 Providence Rd., Towson, MD 21286

Details: To register for this meeting please visit <http://tinyurl.com/ataxia-feb2016>. This meeting is free to attend and lunch is included.

Orange County Ataxia Support Group Meeting

Time: 2 – 4 p.m.

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

Details: For more information contact Cindy DeMint at cindyocataxia@gmail.com.

Twin Cities Ataxia Social Group Meeting

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

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

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



Saturday, February 27, 2016**New Hampshire Ataxia Support Group Meeting****Time:** 10 a.m. – noon**Location:** Villa Crest Nursing and Retirement Home, 1276 Hanover St., Manchester, NH**Details:** For more information or to RSVP contact Jill Porter at (603) 626-0129 or jilleporter@comcast.net.**Wednesday, March 9, 2016****Willamette Valley Ataxia Support Group Meeting – Albany****Time:** 11:30 a.m. – 1 p.m. on the second Wednesday of every month**Location:** 400 NW Hickory, Albany, OR 97321**Details:** For more information contact Jason Wolfer at (503) 502-2633 or wolfer.jason@gmail.com.**Thursday, March 10, 2016****St. Louis Area Ataxia Support Group Meeting****Time:** 5:30 – 7:30 p.m. on the second Thursday of every month.**Location:** Washington University Medical Center, 4444 Forest Park Ave., Rm. 509, St. Louis, MO 63108**Details:** For additional information contact Janeen Rheinecker at (417) 379-3799 or stlataxia@gmail.com.**Tri-State Ataxia Support Group Meeting****Time:** 6:30 – 8:30 p.m.**Location:** Bethel Israel Medical Center, Phillips Ambulatory Care Center (PACC), Second Floor Conference Room, 10 Union Square East, New York, NY**Details:** For more information contact Kathy Gingerelli at kgingerelli@msn.com or Denise Mitchell at markmeghan2@gmail.com.**Saturday, March 12, 2016****Central Minnesota Ataxia Support Group Meeting****Time:** 9:45 – 11:45 a.m.**Location:** Harvest Bank Branch, 24952 County Road 7, St. Augusta, MN 56301**Details:** For additional information contact Marsha Binnebose at (320) 248-9851 or mbinnebose@hotmail.com.**North Texas Ataxia Support Group Meeting****Time:** 10 a.m. – noon**Location:** Ben Washington Baptist Church, 615 Davis St., Irving, TX 75061**Details:** The meeting room is in a separate bldg. from the church. For more information contactDavid Henry at cheve11e@sbcglobal.net.**Friday, March 18, 2016****Palo Alto Ataxia Support Group Meeting****Time:** 1 – 2:30 p.m.**Location:** Herbert Hoover Memorial Building, 211 Quarry Rd, Palo Alto, CA 94304**Details:** For additional information contact Victoria Tanoury at (650) 736-1399 or vtanoury@stanfordhealthcare.org or Sarah Kahn at skahn@stanfordhealthcare.org.**Saturday, March 19, 2016****Twin Cities Ataxia Social Group Meeting****Time:** 10 a.m. on the third Saturday of every month (approximately two hours)**Location:** Langton Place in Roseville at 1910 W. County Rd. D, Roseville, MN 55112**Details:** For additional information contact Lenore Healey Schultz at (612) 724-3784 or schultz.lenore@yahoo.com.**Utah Ataxia Support Group Meeting****Time:** 7 p.m.**Location:** TBD**Details:** For more information contact Dr. Lisa Ord, PhD, LCW at (801) 585-6635 or lisa.ord@hsc.utah.edu.**Saturday, April 9, 2016****Central Minnesota Ataxia Support Group Meeting****Time:** 9:45 – 11:45 a.m.**Location:** Harvest Bank Branch, 24952 County Road 7, St. Augusta, MN 56301**Details:** For additional information contact Marsha Binnebose at (320) 248-9851 or mbinnebose@hotmail.com.**Kansas City Ataxia Support Group Meeting****Time:** 2 – 4 p.m.**Location:** Northeast Library, 6000 Wilson Rd., Kansas City, MO**Details:** For more information contact Lois Goodman at (816) 257-2428 or Jim Clark at (816) 468-7260.**Mid-Atlantic Ataxia Social Group Meeting****Time:** 1 – 3 p.m.**Location:** St. Thomas Episcopal Church, 1108 Providence Rd., Towson, MD 21286**Details:** To register for this meeting please visit <http://tinyurl.com/ataxia-april2016>. This meeting is free to attend and lunch is included.

Calendar of Events
Continued from page 61

North Texas Ataxia Support Group Meeting

Time: 10 a.m. – noon

Location: Ben Washington Baptist Church, 615 Davis St., Irving, TX 75061

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

**INFORMATIONAL, AWARENESS,
AND IAAD EVENTS
AND FUNDRAISERS**

Friday, February 5-7, 2016

Los Angeles Abilities Expo

Time: Friday 11 a.m. – 5 p.m., Saturday 10 a.m. – 6 p.m., Sunday 10 a.m. – 2 p.m.

Location: Los Angeles Convention Center, West Hall A

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

Monday, February 29, 2016

Rare Disease Day

Details: Each year, Rare Disease Day is observed on the last day of February. This year is will be observed on the rarest day! The goal is to draw attention to rare diseases as an important public health issue that cannot be ignored. To learn more about the global initiatives supported through rare disease day, please visit www.rarediseaseday.org. Celebrate #RDD2016!

Thursday, March 31, 2016

AIM Poster Session

Time: 5:15 – 6:15 p.m.

Location: Caribe Royale, Orlando, FL

Details: Registration fee required to attend. See page 22 for more information or visit our website, www.ataxia.org. Registered AAC attendees are welcome to engage in this opportunity to interact with ataxia researchers.

Friday, April 1-3, 2016

59th Annual NAF Annual Ataxia Conference

Location: Caribe Royale, Orlando, FL

Details: Registration fee required to attend. See page 29 for more information or visit our website, www.ataxia.org.

Friday, April 15, 2016

Brain Health Fair

Location: Vancouver Convention Centre, Vancouver, BC, Canada

Details: The Brain Fair is a free, daylong event connecting hundreds of neurology patients, families and caregivers affected by a brain disease, as well as students interested in brain science and the general public interested in brain health. For more information please visit <http://patients.aan.com/go/activities/brainhealthfair>.

Friday, April 29 – May 1, 2016

NY Metro Abilities Expo

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

Location: New Jersey Convention & Expo Center

Details: Admission is free. www.abilitiesexpo.com/newyork/ ❖

Remembering NAF in Your Will

There have been a number of heroes over the years that have quietly made a significant impact on the National Ataxia Foundation and the ataxia families it serves. These are people who named NAF as a beneficiary in their will.

Most of the time the Foundation is unaware of the kind acts of these champions until after they are gone, but each time we are deeply touched and honored by their selfless commitment in helping others.

Over the years these individuals, who have

chosen NAF as a beneficiary, have given anywhere from a few thousand dollars to nearly one million dollars. Their forethought and benevolence has enabled the Foundation to support promising ataxia research and to provide meaningful programs and services to ataxia families across the country.

Perhaps this is the time to consider adding the National Ataxia Foundation in your will For more information, please call NAF at (763) 553-0020 or e-mail mike@ataxia.org.

Memorials and In Your Honor

The National Ataxia Foundation is grateful to those who have made contributions in memory or in honor of their friends and families whose names are listed below. This list reflects contributions made in September through October 2015. 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 let us know if the contribution is a memorial or in honor of their friend or family member.

Jason Aiello	Dan Eustache	David Kalamas	Barb Pogulis
David Alessi	Rick Eustache	Carole Karlenzig	Barbara Pogulis
Crystal Allsopp	James Fagg Jr.	Aghdas Kaviani	Scott Quinn
Diane Anderson	Linda Farrow	Anne Killan	Debbi Radke
Cheri Bearman	Matt Farrow	Donna Klotz	Kay Reese
Carole Brown	Jeffrey Fields	Jamie Kosieraki	Amanda Renneberg
Bob Burman	Vaughn Freedman	Marcella Kukulhan	Norma Rice
Edward Burman	Debi George	Sharon Lamunion	Jim Richards
Jim Burman	Duane Graner	Fred Liebert	Janet Riley
Barbara Bynum	Robert Hall	Eileen Lyle	Margaret Russo
Mike Cammer	David Hankins	Howard Lyle	Don Santa Croce
Abie Cavazos	Carol Haukos	Brent Masserant	Edward Scheffler
Eric Christian	Jeffrey Helman	David Matley	Derek Semler
Eugene Clark	Jeannie Hernandez	Angelo Matrisciano	Cheryl Serge
Terry Curto	Craig Hindley	Charley McLaughlin	John Surabian
Linda Dahlager	Dale Hines	Jeanne Morris	Linda Swinkola
Cathy DeCrescenzo	Edythe Hines	Gordon Musilli	Marlea Waddell
Joe DeCrescenzo	Patricia Hogan	Peter Ostrowski	Barry Washburn
Dawn Dizon	Jordan Hubbard	Richard Ostrowski	David Westrick
Dorothy Drelick	Sydney Hubbard	Antonio Pimentel	Karen Wills
John Ebron Jr.	Krista Humes	Ruth Platts	Virgie Wince



HAPPY NEW YEAR

from Everyone at the NAF Office

Julie Braun

Sue Hagen

Jan Jensen



Michael Jensen

Liz Hogan

Jan Stewart



National Ataxia Foundation

2600 Fernbrook Lane, Suite 119
Minneapolis, MN 55447-4752
(763) 553-0020

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Visit our store at
www.ataxia.org!**

GIFT – HONOR – MEMORIAL

A contribution given in memory of a friend or relative is a thoughtful and lasting tribute, as are gifts to honor your friends or family. A Gift Membership is a wonderful gift to a friend or relative for special occasions like birthdays, graduations, anniversaries, and holidays. NAF will acknowledge your gift without reference to the amount.

Simply fill out this form and mail with your check or credit card information to the National Ataxia Foundation.

Honor/Memorial envelopes are available free of charge by writing or calling NAF.

My contribution is:

In Memory In Honor Gift Membership

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Occasion _____

Send Acknowledgment Card to:

Name _____

Address _____

City/State/Zip _____

From:

Name _____

Address _____

City/State/Zip _____

Is your address correct? Are you receiving more than one issue of *Generations*? If there are any changes that need to be made, please call NAF at (763) 553-0020 or e-mail joan@ataxia.org.

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 – \$55

Individual – \$35 Household – \$55

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 \$ _____

Credit Card: Visa MasterCard Discover

Name on Card _____

Card # _____

Exp. Date _____ CVV # _____

Signature _____

Phone Number _____