

# Generations

**EXPANDED EDITION**



*The Official Publication of the National Ataxia Foundation*

*Volume 42, Number 4*

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*The National Ataxia Foundation Board of Directors and  
the North Central Regional Support Groups invite you to attend the*

**National Ataxia Foundation**

**58th Annual Membership Meeting**

**“Soaring Mile High for a Cure”**

**March 6-8, 2015 – Denver, Colorado**

The National Ataxia Foundation (NAF) Board of Directors and the National Ataxia Foundation North Central Region Support Groups invite you to attend the 58th Annual Membership Meeting (AMM). Please join us at the Sheraton Denver Downtown in Denver, CO to learn, share, network, have fun, and enjoy the sites.

The 2015 AMM will bring together 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!

NAF continues to strive to offer a high-quality, fun-filled AMM program to the ataxia community. To meet those objectives, NAF has made some changes and additions to the 2015 AMM program. General Sessions this year will be held only in the mornings on Friday, Saturday and Sunday ending with a Q & A Panel, then breaking for lunch. On Saturday Morning there will be a Continental Breakfast offered to all registered conference attendees through the generosity of our sponsor MetLife Center for Special Needs Planning.

Also, new for the 2015 AMM the 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. You will still only select one session to attend on either Friday or Saturday with an option to also attend the new Family Planning Options session on Saturday from 2-5

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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 that included a piece on PGD. Here is the link to the "60 Minutes" report: [www.cbsnews.com/news/breeding-out-disease-with-reproductive-genetics/](http://www.cbsnews.com/news/breeding-out-disease-with-reproductive-genetics/).

New to the activity room will be "Speed Friending," a facilitated session where attendees will meet other attendees they may want to connect with further throughout the meeting. Participants are invited to bring a friend and contact cards to exchange on Friday at 1 p.m.

At this year's Friday evening Welcome Reception, not only will attendees have the chance to meet and visit others attending from their region, but they will also have an opportunity to connect and meet other attendees that are members of 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 1:00 p.m. Take your time viewing the many items available and bid early. Winning bids will be posted at 3:30 p.m. on Saturday. Please remember that you must pick-up and pay for your items from 3:30-7 p.m. on Saturday only.

NAF is excited about the new program changes for the 2015 AMM and look forward to seeing you in Denver, CO in March. ❖

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# Recognitions of International Ataxia Awareness Day

— September 25, 2014 —

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

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**

### ***Fifth Annual Global Walk n' Roll***

Individuals and groups participated in the Fifth Annual Global Walk n' Roll for Ataxia (previously the Virtual Walk n' Roll). The Global Walk n' Roll this year raised over \$17,000, as of December 9, thanks to the teams and individuals who supported them. Top fundraisers so far this year are: Brian Petersen & PetersenTeam, Cheri Bearman & Happy Hoosiers, Sunny Prom and the Utah Ataxia Support Group.

For more information on Global Walk n' Roll, visit [www.ataxia.org/walk/virtual](http://www.ataxia.org/walk/virtual).

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*International Ataxia Awareness Day  
Continued from page 3*

**Denver Fourth Annual Run, Walk n' Roll**

*Submitted by Patricia Smith-Hysong  
and Charlotte DePew*

September 7 began with a peaceful, lovely Colorado sunrise at Denver's beautiful City Park Pavilion. There was a scurry of activity in preparation for the Fourth Annual Denver Run, Walk n' Roll (RWnR) for ataxia. Led by support group leader and RWnR chairperson Charlotte



**The Denver Fourth Annual Run, Walk n' Roll for Ataxia**

DePew and with the assistance of the planning committee, these wonderful volunteers put on yet another successful and fun ataxia awareness/fundraising event.

This year's event honored passed support group members Sharie Lindberg and Bettylou McIntosh. Husbands and families of each gave compassionate accounts of their lives and how

ataxia impacted all. The Denver Support Group-NAF table had further information of their productive lives and pictures. Society lost two inspirational and wonderful souls in 2013.

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 that had not pre-registered and nearly \$4,700 in additional donations. We had close to 225 people attend this year's event. There were activities for everyone, from the vendor fair, to hula hooping, to partaking of the generous donations from Dunkin Donuts as well as an amazing array of items donated for our drawing, and other activities. I think it's safe to say a good time was had by all.

The Denver RWnR has raised over \$46,000, all of which goes to ataxia research. 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. Since our event does not close the park to the public, we posted two A-framed signs this year inviting passersby to join us and/or get ataxia information. Each year we have a few inquirers.

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 ►►



**The Concord California Walk, Roll n' Swim for Ataxia**

a special interest in adult as well as pediatric ataxias, much to the benefit of ataxians in the tri-state area and beyond.

### **Concord California Walk, Roll n' Swim for Ataxia**

The Concord California Walk, Roll n' Swim for Ataxia was held in Newhall Park in Concord, CA. Participants were able to Walk n' Roll around the path and after were able to head over to the Montecito Pool for some swimming and fun in the sun.

It was held on Saturday September 13. The event raised over \$3,000.

### **LA/OC Sixth Annual Walk n' Roll**

*By Cindy DeMint*

The Orange County Support Group and the Los Angeles Support Group hosted the Sixth Annual Walk n' Roll for Ataxia Awareness on Saturday, September 20. The event had a few changes this year ... we had a new walk route that let everybody enjoy the marina and various shops along the boardwalk. Cheerleaders from Esperanza High School lined up at the start/finish line and along the route path to cheer on the walk and rollers. Together with opportunity baskets and silent auction items, we added handmade pillow cases donated by Tina Neppel. Keeping up with tradition we had a Kids Zone with face painting, balloon animals, and well known cartoonist Ken Penders along with some of his buddies drawing for our cause. The turnout was



**Pam Ching and Nicole Tortora with the Esperanza High School Cheer Team**

smaller in numbers (around 300), but online donations doubled ... we met our goal of \$50,000.

Sherry McLaughlin, our LA Support Group leader, was presented a star award for being "Our Star" all these years, and we wish her luck on her move to Washington. Thank you to all our members for getting the word out to your family and friends and to the many sponsors, donations, and volunteers that helped make this event a huge success!

Here is the link to our video posted on YouTube: <http://youtu.be/eOKQbsnKfEM>.

### **San Diego Eighth Annual Charley McLaughlin Walk n' Roll**

San Diego Ataxia families recognized IAAD by holding their Eighth Annual Charley McLaughlin Walk n' Roll on the bay-front at Tuna Harbor Park in beautiful downtown San Diego on Saturday, September 27. Free commemorative t-shirts were given out to the first 250 participants. There was also an opportunity drawing, silent auction and entertainment.

The event was named in memory of Charley McLaughlin, who passed away from complications of Friedreich Ataxia in 2007. The weather was sunny and beautiful with plenty of walkers and rollers who helped raise awareness of ataxia and over \$15,000.

### **Atlanta Fourth Annual Walk n' Roll**

*Submitted by Greg Rooks*

In recognition of IAAD, the Greater Atlanta Ataxia Support Group held the Fourth Annual Atlanta Walk n' Roll for Ataxia on September 20 at Shorty Howell Park in Duluth, GA. The weather and occasion made it a beautiful day.

This year's Walk n' Roll was a tremendous success, exceeding previous years. We raised almost \$29,000 and had a record attendance of approximately 150.

There were 11 teams participating with all doing a fantastic job. It's always exciting to see

### *International Ataxia Awareness Day* *Continued from page 5*

teams come out with their own team shirts or other costumes. Team Jon was our top fundraising team with Team Bob coming in at a close second. Our top individual fundraiser was Marcie Anthone.

We appreciate Rudy's New York Pizza for donating 20% of lunch proceeds. After the event we gathered there and packed the house. Thanks to Will Morris and Atlanta Soundworks for providing our sound system and to Marcie Anthone for obtaining the water donation from the Coca-Cola Company.

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 our lives. We would like to thank all those that participated and donated to our event.

### ***Lowndes County Alabama Walk n' Roll***

The Lowndes County Alabama Walk n' Roll was held at Catoma Park in Montgomery, AL on Saturday September 13.



**The Lowndes County Alabama Walk 'n Roll**

### ***Michigan Sixth Annual Ataxia Symposium and Walk n' Roll***

*Submitted by Elizabeth Sullivan, Clinical Research Coordinator, University of Michigan*

The day was cold, cloudy and wet, but even though we were in an all-glass building it did not dampen the warmth, enthusiasm, smiles and

spirit that abounded at the Michigan Ataxia Symposium and Walk n' Roll. While this was the first Ataxia Symposium sponsored by the University of Michigan Ataxia Clinic for patients and families, it was the Sixth Annual Walk n' Roll hosted by the Detroit Ataxia Support Group. It turned out to be a fun and informative pairing. There were patients and families from both Michigan and Ohio. This event was for any patient with ataxia and his/her family, not just UM ataxia patients. All were welcome. We even had Michigan State fans attend!

The morning started with coffee, juice and donuts while UM staff made presentations. There was a great question and answer period afterwards.

Lunch was held in the airy atrium of the Biomedical Sciences Research Building with pizza, breadsticks, fruit and vegetable trays, and cupcakes.

Thanks to Laura Masserant of Papa John's in Sterling Heights, MI, and Jeff Jordan of Papa John's in Ann Arbor, MI, for providing the pizza and breadstick. Vicki Smouthers of Cakery Chicks donated cakes and cupcakes. Water and drinks were provided by Laura Masserant, Tanya Tunstall, Madge Holland, and Elaine and Eddie Fields. Activities for children were provided by Candy Walters while my granddaughters, Jenna and Brianna Vago, and their friend Steve Dawson, corralled the children for fun and games. Laughter was the language of the day from the children's area. Two of my fellow UM research coordinators, Joanne Lord and Patty Johnson, volunteered their Saturday to help make the event a success and their efforts were greatly appreciated by all.

Randy Dombrowski created memories with great photos. Kirt Trumbla of Corporate Security Systems donated a Life Alert System.

Hank Paulson, MD, donated the event T-shirts that were a big hit and we quickly ran out! Superior Screen Printing of Detroit made the T-shirts and donated the artwork. ►►

And a special shout out to all those members of the Detroit Ataxia Support Group who provided information and advice for this event and especially to Tanya Tunstull. Her help and support for this year were immeasurable.

Our fundraising goal was \$2,000 and we have raised more than \$8,000. To all those who participated and/or donated, a heartfelt thank you from the UM Ataxia Clinic, from the research labs of Drs. Paulson and Shakkottai, from the Detroit Ataxia Support Group and from all those who care about patients and families dealing with ataxia. This event was a success all around!

### **Minnesota Fifth Annual Walk, Stroll n' Roll**

*Submitted by Bill Sweeney*

The Twin Cities and Central Minnesota Ataxia Support Groups celebrated the Fifth Annual Minnesota Walk, Stroll 'n Roll on September 13. Over 425 friends, neighbors and family members joined us to support our members and the National Ataxia Foundation. We must have connections to those in high places – for the third year in a row our walk was favored with a sunny, warm fall morning! We accomplished all goals of the Minnesota Walk: raise awareness of and educate people about ataxia, raise money to support the National Ataxia Foundation, and HAVE FUN!

The Wolfe Park location serves as a great backdrop for our event – which contains a variety of flat trails meandering through the wooded park, a small pond, and a stream which always draws several families of ducks to the MN Walk! Upon finishing the Walk, participants gathered in the Park amphitheater for a program and a drawing for a variety of gifts donated by friends and local businesses.

As part of the program, Mike, Joe and Tom Sweeney each shared their personal stories of how living with ataxia has affected them and their families. Also, Harry Orr from the University of Minnesota updated the gathering on ataxia research projects being conducted world-



### **The Minnesota Fifth Annual Walk, Stoll n' Roll**

wide and answered many questions from the audience about ataxia and the prospects for research breakthroughs.

A special thanks and congratulations to Terry Sweeney for co-chairing this year's efforts; he received extraordinary help from Dawn Folger, Maryann Sweeney, Don Folger, Jimmy Wilson, John and Kathleen Schnobrich, and Eric Pogulis and the Pogulis family.

More than 650 donors and fifteen business sponsors helped us raise over \$80,000 to support the work of NAF. Thanks for the hard work and support of all who continue to make the MN Walk a greater success each year. We look forward to seeing all participants next year and hope they all bring a friend!

2014 MN Walk, Stroll 'n Roll team and event pictures can be viewed on Dropbox at the following link: <https://www.dropbox.com/sc/fwb8dlmlqq6weak/AAC3YCEFIGAcxg32gZzytKiYa?n=342300904>.

### **Central Massachusetts Seventh Annual Walk n' Roll**

*Submitted by John Mauro*

The New England Ataxia Group Walk n' Roll, sponsored by The Ride For John, was the best year to date. It was held on Saturday, September 20, at Lamanski Park in Auburn, MA.

Thank you to the New Hampshire, Rhode Island and Central Massachusetts Support Groups

## International Ataxia Awareness Day Continued from page 7

and friends from New York, Connecticut and Maine that participated in the walk. We had 250 people at the walk and raised over \$26,000. Thank you to the New England passage for bringing 30 trikes for people with disabilities to try out, Abilities Plus who brought different adaptive skiing equipment for display, Health Source for offering free chair massages, and Mary Knight from WXLO for being the MC for the event.

Senator Michael Moore presented John Mauro a proclamation from the state of Massachusetts



### The Central Massachusetts Seventh Annual Walk n' Roll

for all of his efforts in creating awareness on ataxia. Special guests Dr. Schmahmann from Massachusetts General Hospital Ataxia Unit was one of the speakers and supporters as well as Lori Shogren from the National Ataxia Foundation. Lori helped organize the registration tables and was able to meet personally many people she has only talked to on the phone over the years. It was nice for the members to meet Lori in person.

### Seattle Fourth Walk n' Roll

Submitted by Milly Lewendon & Barb Andrews

The Seattle Ataxia Support Group last held a Walk N' Roll event in 2014. What an absolutely beautiful day it was for our fourth Walk n' Roll event on September 27th. Alki Beach was perfect in every way – sunny, dry, and little wind. We started our morning with coffee, courtesy of

Tully's Coffee Company, and delicious muffins. Our group was a good size with great support from JoAnne Wolff-Howell in raising a team of 17 individuals from Boeing. As in past years, members of First Baptist Church of Kirkland supported this event with an opening prayer, face painting, shirt distribution, and great participation with walkers and cyclers. With our new ataxia T-shirts on, it looked like a moving sea of bright, lively green!

The course was all paved and flat near the Puget Sound waters. We had a view of waves, boats, and even a few folks swimming! Landmarks along the route included: an authentic giant anchor used long ago, bronze life-size harbor seal mother and baby, and a miniature replica of the Statue of Liberty. Surrounded by people and dogs galore, there was still plenty of room for our "green parade," beginning with the huge NAF banner.

When we rallied again after the Walk n' Roll, it was time for the goody bags and prize drawings. We received some great donations this year. Thank you to our corporate sponsors: Maxx Nutrition, Vickie Bergquist Insurance, Bed Bath and Beyond, Ivar's Fish and Chips, and Starbucks. Seattle NAF group members were generous with contributed items as well. Thanks to you, also. (You know who you are!).

Thank you to volunteers who helped everything run so smoothly: Pastor Vince Armfield, Eldean Montgomery, Kaitlynn Eason, Chase ►►



Face painting and food were highlights of at the Seattle Fourth Walk n' Roll

Armfield, Caitie Simpson, Steve Barbouletos, Cindi and Mike Bates, Emily Bonkowski, Dave and Sandra Parker and Jori Acacio. Special thanks to the Outdoors for All Foundation for sharing their information about providing outdoor activities for people with disabilities.

Our fund-raising goal was \$10,000. We estimate, with the matching funds, to be over \$10,000! Thank you to everyone who participated and contributed to our event.

**Utah First Walk n' Roll**

*Submitted by Jenny Durrant*



**Utah First Walk n' Roll**

The Utah Ataxia Support Group held its first Walk n' Roll at Layton Common Park on Saturday September 27. It was a great success with over 100 attendees, some of who have been fighting ataxia for years and others who came long distances to participate. Even though it rained, everyone was excited to walk for themselves or for a loved one. It was a fun day to learn more about ataxia and to visit with friends. Thousands of dollars were raised! So a BIG THANK YOU to all those who helped do an activity, donate and/or buy an auction item, the attendees and the generous donors! Our first Walk n' Roll event was a success because of you!

**Arizona Bowl n' Roll**

The Arizona Ataxia Support group held a Bowl n' Roll in recognition of IAAD to raise awareness in the Phoenix community on September 21. The event was held at Lucky Strike Bowling Lanes in Phoenix. It was a great



**Arizona Bowl n' Roll** (photo by David Garcia)

success with support and attendance from our support group members, their family and friends. We had a fun time bowling and even won some raffle prizes. The event raised over \$1,200 and a good time was had by all.

**New Jersey Ataxia Support Group Bowling Fundraiser**



**New Jersey Bowling Fundraiser**

The New Jersey Ataxia Support Group held a bowling fund raiser on September 28 in recognition of IAAD. It was held at the AMF Strike n Spare Lanes in Green Brook Township. Bowling was \$10 per person with \$5 of the admission fee being donated to NAF. Members of the support group attended with their family and friends and there were approximately 35 people. We ordered pizza and soda, mingled and everyone had a good time. The event raised \$1,500.

**Fourth Annual Bingo for Ataxia**

The Fourth Annual Ataxia Awareness Bingo was held in Berlin, MD on Saturday, September 27. The event went well and we raised over \$3,000.

*International Ataxia Awareness Day*  
Continued from page 9

### **Tea Time for Ataxia**

Tea Time for Ataxia was held in the Aubrey Rose Tea Room on October 11. We really have a lot of followers that look forward to the event every year. This year we had a tea basket raffle for each sitting that we sell tickets for \$5 each. The baskets are filled from the Aubrey Tea Room Boutique plus a \$50 gift certificate. This year our event raised over \$7,000.

### **Tour de Shunk Go on 3**

*Submitted by Mike Cammer*

On September 14, I participated on my trike in the 16th Annual Tour de Shunk, a 102.5-mile bike ride in north eastern Pennsylvania. My slogan was “Go On 3” for Ataxia Awareness to mark IAAD. I started the day with every intention of just doing the 50-mile option, but when I got to the 25-mile rest stop in Shunk I



**Mike Cammer at the 16th Annual Tour de Shunk**

was feeling pretty good even after the two-and-a-half mile hill climb to get there. It was a beautiful day for riding so instead of turning around, I made the decision to move on. I went down through the valleys, up another long climb before descending to the 50-mile rest stop and lunch. Back on the road again through some more valleys before my last major hill climb and down to the 75-mile rest stop. Still feeling pretty good at this point! The next 10 miles were a very welcomed flat stretch on Route 14 but that would all soon change. I start to hear a little voice in my head say, “What were you thinking?” The last 18 miles or so were the grueling “20 holy rollers,” a long stretch of

hilly road heading back to the finish at Rocky’s Bike Shop in Monroeton. But I moved on finally getting into Rocky’s a little after 6:00 p.m. to enjoy a nice massage and then a spaghetti dinner!

I definitely spread awareness to many people in NE PA who have never heard of ataxia. It was definitely the “buzz word” of the day! I also raised just under \$1,900 for the National Ataxia Foundation and an additional \$300 for the Geisinger ThinkBIG Pediatric Cancer Fund! The ride was a great success and very rewarding knowing I helped two great organizations! I am Already looking forward for the 2015 Go On 3 ride! Thanks everyone for your support!

**Fort4Fitness**  
*Submitted by Cheri Bearman*

### **Fort4Fitness**

*Submitted by Cheri Bearman*

Lives are changing as a result of Fort4Fitness in Fort Wayne, IN. On September 26- 27 the Seventh Annual Fort4Fitness Fall Festival was held in downtown Fort Wayne.

On Saturday, September 28, I participated in the Fort4Fitness event, walking the four-mile race with my husband Gil, grandson Abram (in his stroller), daughter Cara and her husband Brent, and sister Deb and friend Ron in recognition of IAAD. We went very slowly, but we finished the course.

With the help of family and friends, we raised over \$1,800 for NAF. ▶▶



**Left to right (back): Gil, Cheri, Brent, Cara, Deb, Ron and Abram (in stroller) at the Seventh Annual Fort4Fitness Fall Festival**

## **The Lou Coletti Memorial Golf Tournament**

*Submitted by Rachel Coletti*

The Annual Lou Coletti Ataxia Golf Tournament was held on October 11 and did very well this year. The event raised over \$1,600 in memory of Louis John Coletti. We would like to thank everyone for getting the tournament on the right foot. It was greatly appreciated by myself, and Lou's sons, Brian, Scott and Daniel Coletti.



## **Johannesburg, South Africa**

*Submitted by Shana Figueiredo Scholtz*

We decided to get involved and raise some awareness for IAAD. I baked 250 muffins and packaged them with an information pamphlet and attached ribbons to them. The amount of support and help I received was phenomenal and I'm happy to report I raised \$180 US in donations for the National Ataxia Foundation.

## **Chloe and Isabel Jewelry Fundraiser**

*Submitted by Freya Chapman*

I donated my commission from an online fundraiser from September 25-30 in recognition of IAAD and my mother-in-law. I was able to raise \$150.

## **Third Annual "Zumba in the Park"**

A "Zumba in the Park" event raised over \$400 on Saturday, September 13.

## **Butler Area School District Jeans Day**

*Submitted by Dena Erkens*

I am very happy with the outcome of the "Jeans Day" in honor of my two brother-in-laws, John and David Erken, and a young lady named

Erin Kiernan. Our event raised \$950 for ataxia research. My hopes are to one day, in the near future, find a cure or something that will stop ataxia from progressing any further.

## **Jack's Run**

*Submitted by Ann Nuese*

I participated in the Medtronic Marathon in October. I was able to raise over \$2,500 in memory of my dad, Jack Moore.



**Ann Nuese**

## **Boscov's "Friends Helping Friends"**

*Submitted by Cathy and Joe DeCrescenzo*

Friends Helping Friends special Boscov's shopping day pass raised \$135. Shopping passes provided a 25% discount were available for \$5 each. Although we had a lot of competition from other non-profits, every little bit helps!

*Submitted by Mike Cammer*

Mike Cammer and the Central Pennsylvania Ataxia Support Group also sold Boscov shopping passes and raised \$561.

## **Ataxia "Spin-off" Challenge**

Pamela and Robert Bryant started the "Ataxia Spin-off" Challenge by creating a video of a person spinning around in a chair and then taking a few steps with a glass of water to give people an idea of what it is like to have ataxia or to be unbalanced. Other people were "Challenged" to create their own spinning video, donate to NAF, and/or to "Challenge" others.

#Ataxiaspinchallenge/ #Ataxiaspinoffchallenge.  
<http://ataxia.kintera.org/faf/search/searchTeamPart.asp?ievent=1104992&lis=1&kntae1104992=63ABC9A33DE4425C81EC2761650EB22&team=6066322>.

The event has raised almost \$1,500.

*International Ataxia Awareness Day*  
Continued from page 11

### **Kiss Away SCA: Ataxia Lipstick Challenge**

Submitted by Sunny Prom

The Ataxia Lipstick Challenge, held September 10 to October 28, has raised over \$1,200. Visit [www.kissawayzca.org](http://www.kissawayzca.org) and <https://plus.google.com/photos/104537070211478069938/albums/6057609693320166497>.

### **Ataxia Boot Camp**

The Ataxia Boot Camp was held Saturday, September 13 in Renton, WA with John Vigor Ground as organizer. The event had raised over \$400 so far. <http://ataxia.kintera.org/faf/search/searchTeamPart.asp?ievent=1104992&lis=1&kntae1104992=63ABC9A33DE4425C81EC2761650EB22B&team=6140625>

### **Proclamations/Resolutions/Citations**

Proclamations or Resolutions declaring September 25 as International Ataxia Awareness were signed in Georgia, Maryland, Massachusetts, New York, and Pennsylvania.

On June 23, a new resolution No. 413 was prepared and introduced by Senator Patrick M. Browne and adopted by the Senate of the Commonwealth of Pennsylvania and signed in the Senate: "Resolved, That the Senate designate September 25, 2014, as 'International Ataxia Awareness Day' in Pennsylvania and urge all citizens to honor and support those individuals with ataxia and their caregivers, in the hope that a cure will soon be found."

On August 25, Governor Deval Patrick signed into law a bill establishing Ataxia Awareness Day in the Commonwealth. The bill was a collaborative effort of Senator Michael Moore, Representative Paul Frost and John Mauro. This bill is permanent and will recognize September 25 as Ataxia Awareness Day for the next 100 years.

<http://auburnmassdaily.com/2014/08/25/governor-signs-bill-establishing-ataxia-awareness-day/>

On October 4, a Special Tribute from the State



**Left to right: Elizabeth Sullivan, Tanya Tunstall and Dr. Henry Paulson with the Michigan proclamation**

of Michigan was signed by Virgil Smith, State Senator, honoring the Detroit Area Ataxia Support Group on the occasion of IAAD.

On September 5, a Mayoral Proclamation was signed at City Hall by Mayor Kevin R. Utz for IAAD, Westminster, Carroll County, MD.

On September 20, there was an Official Citation presented to John Mauro by Senator Michael Moore for his dedication and tireless efforts to bring education and awareness about ataxia and also his work in establishing ataxia awareness day in the commonwealth of the state of Massachusetts.

On September 20, the Central New York Ataxia Support Group received two proclamations to recognize IAAD. The proclamations were from the City of Syracuse with the County of Onondaga (joint proclamation), and the New York State Assembly. Assemblyman Al Stripe joined them to personally deliver the proclamation from the New York Assembly. He talked with the group about what was happening in the assembly.

On September 23, a proclamation was signed by Georgia governor Nathan Deal declaring September 25 as International Ataxia Awareness Day (IAAD) in the State of Georgia at the state capital. [http://gov.georgia.gov/sites/gov.georgia.gov/files/related\\_files/document/ATAxia%20Awareness%20Day%20Proclamation%202014.pdf](http://gov.georgia.gov/sites/gov.georgia.gov/files/related_files/document/ATAxia%20Awareness%20Day%20Proclamation%202014.pdf) ►►

On September 24, the renewal of the Pennsylvania House Resolution No. 944 to recognize IAAD was signed.

On September 25, Maryland Governor Martin O'Malley signed the Proclamation in the State of Maryland.

### Media Coverage

The following press releases and articles highlighting IAAD can be found at <http://ataxia.org/news/ataxia-news.aspx>.

**Benton Evening News** on June 11 – Minnesota woman running for her father, a Benton graduate. <http://www.bentoneveningnews.com/article/20140611/News/140619840#ixzz34vW70aPK>

**Aurora Sentinel** (Aurora, CO) on August 7 – Featured Nate Redman, one of the Denver Ataxia Support Group members, about his equestrian therapy. <http://www.aurorasentinel.com/news/rare-condition-help-comes-horseback/>

**KARE11** (Golden Valley, MN) on August 25 – Posted a notice about the Minnesota Walk, Stroll n' Roll on their website: <http://www.kare11.com/story/entertainment/events/coffee-with-kare/2014/08/25/walk-stroll-n-roll-for-ataxia/14582171/>

**Hank Stoltz TV Show** on August 26 – John and Dana Mauro, Senator Michael Moore talked about ataxia, the Ride for John Fundraiser and IAAD. <http://youtu.be/kmJukPdO7uY>

**Balita** on September 12: Families to 'Walk n' Roll' on Sept. 20 for ataxia that afflicts many. <http://www.balita.com/families-to-walk-n-roll-on-sept-20-for-ataxia-that-afflicts-many-2/>

**South Hills Almanac** on September 17-23 – The Ataxia Support Group information was posted in the local newspaper on page 21 (website is [www.thealmanac.net](http://www.thealmanac.net)).

**Auburn News** on September 19 – "Walking and rolling to find a cure." <http://www.southbridgeeveningnews.com/pdf/AUB.2014.09.19.pdf>

**Auburn Daily** (Auburn, MA) on September 20 – "Ataxia Walks and Rolls to Success." <http://auburnmassdaily.com/2014/09/24/ataxia-walks-and-rolls-to-success/>

**Riviera Broadcasting** (station is Power 98.3

KKFR) on September 21 – Played a recorded PSA by the Arizona Ataxia Support Group. It was for IAAD and to promote their First Annual Bowl n' Roll event.

**Standard Examiner** (Ogden, UT) on September 23 – "Hereditary affliction plagues ataxia sufferers." <http://www.standard.net/Health/2014/09/23/Ataxia-story-needs-to-run-before-Sept-27.html>

**World This Morning** on September 25 – [http://www.dailymotion.com/video/x26v5u4\\_world-this-morning-international-ataxia-awareness-day\\_lifestyle](http://www.dailymotion.com/video/x26v5u4_world-this-morning-international-ataxia-awareness-day_lifestyle)

**Auburn News** on September 26 – "Seventh annual Walk n' Roll brings awareness to ataxia." <http://www.southbridgeeveningnews.com/pdf/AUB.2014.09.26.pdf>

**WXLO Community Outreach Radio Show** on October 7 – [http://youtu.be/WN478bl4QbM?list=UUuIQqQoVIYW3q1Jq\\_vI-5g](http://youtu.be/WN478bl4QbM?list=UUuIQqQoVIYW3q1Jq_vI-5g)

**The New Hampshire Ataxia Support Group**  
Submitted by Jill Porter

I found an opportunity at my Yoga class and was able to do at least one thing to promote awareness. Before class started I asked if I could say something and then gave a short overview of IAAD, what ataxia is, the symptoms and the importance of raising awareness for this rare disease. The class was at Catholic Medical Center and after the class I saw that people did take the book-marks and one woman stopped me to thank me for talking about ataxia telling me she worked in research at the hospital and understood how important it was to raise awareness.

**Delaware Park Trophy Race  
in Honor of IAAD**

Submitted by Joe and Cathy DeCrescenzo

This year for IAAD, Cathy and I arranged for Delaware Park to hold a trophy race in honor of International Ataxia Awareness Day. I had forwarded to them a front page copy of the last *Generations*, which explained IAAD.

## International Ataxia Awareness Day Continued from page 9

Cathy and I were able to present the Winning Plate Trophy in the Winner's Circle.



**Cathy and Joe DeCrescenzo present the winner's trophy at Delaware Park**

So everyone who attended the races last on Thursday, September 25, learned about IAAD and its impact on those affected.

### **Central Massachusetts Support Group**

*Submitted by John Mauro*

We took part in the second Abilities Expo at the Boston Convention Center. An interactive NAF ataxia booth gave those that stopped by a chance to try to balance on a balancing board to see how it would feel to have ataxia for a moment. The Abilities Expo was overall a great event in the month of September and we did a lot of education on International Ataxia Awareness Day.

John Mauro spoke to a group of juniors and seniors at Auburn High School. 300 students watched the presentation on ataxia and listened to John explain what a person with ataxia deals with every day. John challenged the students to help with his efforts of bringing much needed awareness on this rare disease. Many of the stu-



**Left to right: Jim Coyne, Dana Mauro, Anabela Azevedo and John Mauro at the Abilities Expo**

dents took part in the walk n' roll or volunteered their time to help staff a "Kid's Zone" at the walk.

For the second consecutive year, many movie theaters in the area played the ataxia PSA prior to each movie during the week of September 25.

One of the big highlights was posting a fact a day on Facebook. Dana Mauro put together a 30-second video on one fact each day on ataxia. It turned out bigger than expected. It reached 16 different countries and had over 10,000 views a day. We received many e-mails of thanks for the videos which enabled people with ataxia an easy way to share information, symptoms and awareness with their family and friends.

I would also like to acknowledge and thank my wife Dana and three great friends – Dave Carson, Zack Carson, and Barry Ouelette – for helping me bring life to some Public Service Announcements on ataxia. Many hours were spent writing, filming and editing these PSAs. These were also shared on many of the ataxia Facebook pages and can also be found on the National Ataxia Foundation website.

### **Seek A Miracle Ataxia Group**

*Submitted by Chandu George, India*

I managed to do a small IAAD event and also got the IAAD Proclamation signed by the Organization of Rare Diseases India.

I attended the conference on Rare Diseases and Orphan Drug Development Initiatives in India, where I gave a presentation on the views of ataxia patient perspectives, which covered different aspects like behavioral, social, and psychological. It was well received by the group. I even got a standing ovation. I was invited to share ideas with world-renown doctors like Dr. Hugh Dawkins (Director of the Office of Population Health Genomics in Australia), who was so touched and moved by my presentation that he praised some points that I portrayed in "True Life Struggles of Ataxians" as a strong message for doctors and researchers in the need for curing rare diseases like ataxia.

This conference was a once-in-a-lifetime ►►

event for me. I would like to thank Dr. Ramaiah Muthyala (President/CEO of the Indian Organization for Rare Diseases) for giving me this opportunity and many thanks to Sue Hagen (NAF) for the help in preparing my PowerPoint presentation.

Here is the link to pictures of the conference: <https://picasaweb.google.com/101437185779701235793/IORD-September1819th2014ConferencePics?authuser=0&authkey=Gv1sRgCOj157vqgtX04AE&feat=directlink>

**Bin Adam Foundation**

*Submitted by Wajeeha Khan, Secretary*

We organized many awareness programs through a walk event, seminar, awareness program, and newspaper. You can find photos on our Facebook page ([www.facebook.com/binadamfoundation](http://www.facebook.com/binadamfoundation)) or website ([www.binadam.net](http://www.binadam.net)).



**The Bin Adam Foundation raising ataxia awareness in Pakistan**

Our NGO’s project, “ATAXIA PK,” is the first Pakistani research group who are solely working for this rare disease in Pakistan.

For more information please contact us at [binadamfoundation@gmail.com](mailto:binadamfoundation@gmail.com)

**Central PA Ataxia Support Group Second Annual Picnic for IAAD**

*Submitted by Mike Cammer*

Sunday, September 28 was a beautiful day for the Second Annual Picnic in recognition of IAAD at the Leader Farm in Hershey, PA. There were a total of 20 people in attendance. After a



**The Central PA Ataxia Support Group at their Second Annual Picnic for IAAD**

nice picnic lunch, there was plenty of time to sit around and chat or enjoy the merry-go-round (yes an actual, working merry-go-round!), miniature golf, bocce ball and golf cart rides around the farm. It was a great time to just socialize and just have fun. I also took my trike along and several people rode it around. Jennifer Leader really enjoyed riding again as was evident by the smile on her face. A great time was had by all!

I want to thank Mike and Karen Leader for allowing us to have the picnic on their farm. They were wonderful hosts!

**CNY Potluck Luncheon**

*Submitted by Mary Jane Damiano*

The Central New York Ataxia Support Group met on Saturday, September 20 to recognize International Ataxia Awareness day. We had a potluck luncheon. Five members were present.

**Social Media/E-mail Ataxia Awareness**

*Submitted by Jill Porter*

I wrote an e-mail to someone who kept promising to make a donation and that person did step up and go to the webpage and donate, also posting on her Facebook page asking others to step up. I sent out an additional email to another potential donor to see what might develop.

J.J. Hall posted two ataxia pictures on Facebook and included the link to [www.ataxia.org](http://www.ataxia.org) and asked everyone to share it. It had been shared by at least 10 of my friends. I also sent a tweet to GMA and Robin Roberts, asking for a retweet

International Ataxia Awareness Day  
Continued from page 15

to raise awareness along with a link, but it was not retweeted.

Submitted by Mike Cammer

I sent an e-mail about IAAD, information about ataxia, a link to a video on YouTube

(<http://www.youtube.com/watch?v=Fs9FuMRiYRU&index=2&list=PLPsd5jWwz2hFZXXEW9kgeV0A0jbi6MeY>) and the link to the National Ataxia Foundation’s website ([www.ataxia.org](http://www.ataxia.org)) if they wanted more information, to our Director’s office and public affairs officer and they put this out to all 1,300 staff members. I have received feedback from several people and found out that one person has three family members with ataxia.

Submitted by Lawrence “The Dreamer” Chen ([idiopathic@lhaven.net](mailto:idiopathic@lhaven.net))

I had planned a big coming out on September 25 for IAAD ... unfortunately, I’m still working an IT job (Sr. Unix Systems Administrator at Kansas State University), and Shellshock happened.

But I did write the first “coming out” post on my personal blog, *Apnarcoplexic.com*: (<http://lkc.me/5Q>). And I wore the T-shirt ...

**Thank you all for a making IAAD 2014 such a great ataxia awareness event!** ❖

## Vehicle Donation

The donation of your vehicle to the National Ataxia Foundation will help support the important work that is being done on behalf of all who are affected by ataxia.

To donate your car, truck or motor home, call 1-800-240-0160 or visit [www.donateacar.com](http://www.donateacar.com). Your vehicle will be picked up at your home, office or other place that you designate. Be sure to have the certificate of title with the vehicle.

## A Closer Look at the NAF Website – [www.ataxia.org](http://www.ataxia.org)

# Research Participants Needed


Many people who have been diagnosed with ataxia would like to participate in research to help find answers that will bring us closer to treatments and a cure. Many ataxia researchers need individuals who are willing to participate in research. For that purpose, the National Ataxia Foundation has a dedicated webpage where recruitment notices for ataxia studies, that have Institutional Review Board (IRB) approval, can be posted: <http://www.ataxia.org/research/research-subjects-needed.aspx>.

Some studies are limited to participants that have a specific diagnosis, such as Friedreich Ataxia or SCA 1. Some studies require that you travel to the

institution where the research is taking place and there may or may not be funds to support your travel costs. Other studies may require a blood sample from the participant, which can be drawn at your local clinic and shipped to the researcher’s lab. All research participants are informed of any risks that there may be by participating in the study and each person must sign an “Informed Consent” prior to being involved in the study.

Check this page often as new research studies may be added for which you would qualify to participate.

Thank you for helping researchers find answers to end ataxia.



# Harry T. Orr, PhD Is Recognized for Outstanding Research Achievements

The National Ataxia Foundation is pleased to announce that Harry Orr, PhD has been elected as a member of the Institute of Medicine (IOM). Established in 1970, the IOM is the health arm of the National Academy of Sciences, which was chartered under President Abraham Lincoln in 1863. The IOM asks and answers the nation's most pressing questions about health and health care. Being elected into membership of the IOM recognizes that Dr. Orr has made a major contribution to the advancement of the medical sciences, health care, and public health and is being recognized as one who has demonstrated outstanding professional achievement and commitment to service. It is one of the highest honors in the fields of health and medicine.

In addition to being elected into the IOM, Dr. Orr was an honoree at the University of Minnesota Dean's Distinguished Research Lectureship which celebrates outstanding research achievements at the University of Minnesota Medical School. This lectureship was created to encourage excellence in the faculty and further build support for scientific discoveries. We are proud, but not surprised that Dr. Orr received this honor of outstanding research achievements. As one of the researchers who discovered the SCA1 gene, Dr. Orr has made seminal contributions to the genetics of ataxia and other neurodegenerative diseases.

Dr. Orr is known world-wide for his important work in ataxia research. Dr. Orr, along with Dr. Huda Zoghbi from Baylor College of Medicine, found the first gene for ataxia in 1993, Spinocerebellar ataxia type1 (SCA 1). Dr. Orr

established the first transgenic mouse model of a polyglutamine neurodegenerative disease and uses it to elucidate SCA1 pathogenesis.

While Dr. Orr is known for his work as a "bench scientist" he is passionate about the patients who are affected by the diseases that he studies. His efforts in past Ataxia Investigators Meetings have brought scientists and patients and family members together to learn and inspire one another. He continues to train and bring new scientists into the field. He has an unwavering commitment to a better understanding of the disease with the specific purpose of bringing therapies to the patients.

As the Foundation's Research Director, Dr. Orr has volunteered countless hours in coordinating, facilitating, and reviewing worldwide ataxia research proposals submitted to the Foundation and in monitoring NAF's current research efforts. "Dr. Orr's wisdom in guiding the Foundation's research efforts has been profound and has strengthened NAF's ability to fund the best

science in the world," stated Michael Parent, Executive Director of NAF.

Dr. Harry T. Orr has dedicated his life to find answers in developing effective treatments and ultimately a cure for ataxia. Many of you have met Dr. Orr at the NAF annual membership meetings and know firsthand his compassion and commitment to those affected by ataxia. We would like to sincerely thank him for his dedication and commitment to the Foundation and the ataxia community and congratulate him on these prestigious awards. ❖



**Dr. Harry Orr**

# Tips for Living with Ataxia

*Submitted by Bailey Vernon, MPH, CHES  
Johns Hopkins University Ataxia Center*

Ataxia can be a devastating diagnosis for an individual and their entire network of family and friends. The diagnosis can create a lot of mixed emotions to include grief, anger, fear, sadness, guilt, shame and many more. Unfortunately without a cure for cerebellar ataxia, treatment focuses on managing the symptoms. Symptoms can vary significantly from person to person.

It is not uncommon for someone to experience hesitation when it comes to meeting others with ataxia, this may be because they either do not want to see what the future holds or they wonder why their ataxia appears worse. It is important to remember that many factors impact the presentation and progression of ataxia to include genetics, gender, age, other health conditions, lifestyle, social support and attitude. Even though the progression of the disease cannot be controlled, it is important to engage in healthy lifestyle practices.

*Exercise* – Evidence suggests that regular exercise is important in managing ataxia and can help improve mood, function and independence. Find exercise that you enjoy and adapt it into your daily routine.

*Eat Healthy* – Make sure to eat a balanced diet

full of fruits, vegetables and whole grains. Moderation is key!

*Manage Your Stress* – Stress can make symptoms worse, so it can be helpful to identify what causes the stress and find techniques to reduce it.

*Get Enough Sleep* – Practice good sleep hygiene and seek treatment for any sleep-related problems to maintain good health.

*Limit Alcohol* – Alcohol may intensify coordination problems and make walking, balance and speech more impaired.

*Find the Positive* – Attitude can have a large impact, so try to find gratitude in the small things, find coping mechanisms that work for you and learn to navigate the new “normal.”

*Build Your Care Team* – Develop a network of individuals that are dedicated to your care. This may include your family and friends, but also health care providers like neurologists, physical therapists,

speech therapists, counselors, nurses, and dietitians.

*Seek Support* – A good support network goes a long way, whether it is support groups, family and friends or health care professionals.

*Know Your Community* – Learn what resources are available in your community that will help you through this journey.

*Educate Yourself* – “Knowledge is power.” Know where to find reliable information.

*Know Your Limits and Make Adaptations* – It is important to keep doing the things that you enjoy. Try to focus on the things that you can do and be creative in making adaptations.

*Support Your Care Partner(s)* – Ataxia impacts entire communities, so find ways to continuously support one another. Try to maintain open communication.



**Bailey Vernon**

## Deadline

The deadline to submit materials for the upcoming spring issue of *Generations* is Friday, March 20, 2015. Please submit content by e-mail to [joan@ataxia.org](mailto:joan@ataxia.org).



# Bullying of Students with Disabilities Addressed in Guidance to America's Schools

The National Ataxia Foundation is pleased that the U.S. Education Department's Office for Civil Rights (OCR) is taking a strong stand against bullying of students with disabilities. On October 24 a guidance, in the form of a letter, was issued to educators detailing public schools' responsibilities under the Americans with Disabilities Act. The purpose of the guidance is to remind school administrators and teachers that bullying is wrong and must not be tolerated – including against students with disabilities. If a student with a disability is being bullied, federal law requires schools to take immediate and appropriate action to investigate the issue and, as necessary, take steps to stop the bullying and prevent it from recurring.

At this link you will find a fact sheet for parents on schools' obligations under federal law to address bullying: <http://www2.ed.gov/about/offices/list/ocr/docs/dcl-factsheet-bullying-201410.pdf>. Another resource is the federal Web site, [www.stopbullying.gov](http://www.stopbullying.gov), which provides useful information on bullying prevention and remedies. NAF applauds all efforts to eliminate any type of bullying in public schools.

Gabrielle Ford's incredible journey of triumph over tragedy is filled with amazing coincidences. As a child, Gabrielle loved dance and dreamed of becoming a prima ballerina. That dream was shattered by a rare genetic neuromuscular disease,

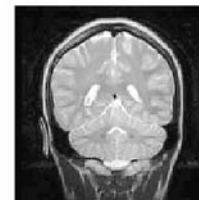
Friedreich Ataxia, that would eventually place her in a wheelchair. Gabe endured constant and cruel bullying from classmates which took her on a path of depression and isolation. That all changed when Izzy, a long-eared coonhound pup, entered Gabe's life. Izzy became Gabe's best friend and constant companion. When this special friend mysteriously developed a condition mirroring Gabe's, Gabe re-entered the world to get Izzy the best treatment available. Gabe found her way back to the stage as an outspoken advocate against school bullying. Speaking out for the voiceless, Izzy gave her the courage to speak out for another voiceless group: the thousands of children bullied in American schools every day. Gabe had the following to say regarding bullying:

"No one person is the same; you have the right to be different, your own person, but no one has the right to make fun of you. Ataxia was not a choice I made, but how people treat each other is. Ataxia wasn't a choice I made, muscle disease was not a choice my dog Izzy made, but bullying is a choice. Who do you want to be?"

Gabrielle's future plans include leading the dogs on a float as America's Voice for the Bullied in the Orlando Christmas Parade 2014. She will also be featured on the cover of the November/December "Dream Teen" magazine and in May 2015 she will be the keynote speaker at the UAW Woman's Conference in MI. ❖



PATIENTS with  
SCA1, SCA2, SCA3, SCA6 and  
MSA-C  
needed for an MRI study  
at the University of Minnesota, Minneapolis



Travel expenses reimbursed.  
Contact: Diane Hutter  
(612) 625-2350  
hutte019@umn.edu

## Caregiver's Corner

# Mental Health/Depression

### Depression Triggers

Because many older adults often deal with heart disease, stroke, diabetes, cancer and Parkinson's disease, and because depression can occur with these illnesses, some health care professionals may mistakenly think that depression is a normal for the elderly. Depression can and should be treated when it occurs with other illnesses, since untreated depression can delay recovery or worsen outcomes. And because symptoms of depression displayed by older people may look different from those in younger people, seniors are often under-treated for depression and other mental health problems.

Many older adults may be ashamed to admit when they feel "blue," thinking that it is a sign of weakness or failure. Clinical depression is not a failing; it is an illness. And mental illnesses are simply disorders that require treatment. We need to reassure the ones we care for that it is OK to feel down. Older adults need opportunities to express feelings such as anxiety, depression, frustration or grief, and receive recognition that these feelings are normal and valid.

### Insomnia: Sleep On It

One of the newest discoveries about treating depression is that treating sleep disorders, like

insomnia, helps people feel less depressed. Nearly half of all people with depression report trouble sleeping, and people with insomnia are nearly twice as likely to be depressed. It makes sense: Lying awake, unable to sleep makes problems seem worse, which makes depression worse. Curing insomnia in people with depression could double their chance of a full recovery.

The best insomnia cures don't involve taking drugs; recent research shows that a form of treatment called "cognitive behavioral therapy for insomnia" works best by teaching the person to establish a regular wake-up time and stick to it; get out of bed during waking periods; avoid eating, reading, watching TV or similar activities in bed; and eliminate daytime napping.

About the worst thing a sleepless person can do is drink alcohol. Although it makes you feel sleepy, alcohol leaves you feeling groggy and unrested when you wake up in the morning. A person with severe insomnia needs a doctor's help; for the occasional sleepless night, try a warm bath before bed, a massage, warm milk or a soothing non-caffeinated beverage (other than alcohol!). Bedrooms should be slightly cooler than the rest of the house, dark, and quiet.

*Source: New York Times*

### Resources For You

*The Center for Mental Health Services*

(800) 789-2647 [www.mentalhealth.gov](http://www.mentalhealth.gov)

Provides information about mental health.

*National Suicide Prevention Lifeline*

1-800-273-TALK (8255)

[www.suicidepreventionlifeline.org](http://www.suicidepreventionlifeline.org)

A free and confidential, 24/7 hotline available to anyone in suicidal crisis or emotional distress.

*Source: The Comfort of Home® Caregiver Assistance News*

## Matching Gifts

Many employers will match your gift to the National Ataxia Foundation through a Matching Gifts Program.

This valuable benefit will allow you to have twice the impact on the lives of families affected by ataxia when you make a donation to NAF. Please give generously and encourage your co-workers to do the same.



# The National Ataxia Foundation's Statement on Stem Cell Research and Therapy

(10/21/14)

The Medical Research Advisory Board and Board of Directors of the National Ataxia Foundation issued a statement about stem cell research and therapy. The bulleted items have been pulled from the statement which is available to read below in its entirety.

- Some clinics in the United States and around the world are promising stem cell-based treatments for ataxia without oversight and other standard patient protections.

- The only thing they do provide is cruel health fraud, at an exorbitant price, preying on the desperation that patients and families feel in the face of this untreatable neurological disease.

- There are currently no stem cells that can fix the brain, improve ataxia, or prevent the worsening of ataxia.

- Some stem cell therapies may even worsen ataxia or cause other unanticipated serious health consequences.

- A patient electing to try unauthorized "stem cell" injections may be disqualified from future trials of authorized disease modifying therapies for ataxia.

- Stem cells have great potential and we are moving forward as fast as we can, but there are no shortcuts. We must use scientific principles that have been proven in the laboratory before we begin putting stem cells into people who are affected with ataxia. We must safeguard patients from unproven treatments that may cause serious harm.

## **Read the complete statement of the National Ataxia Foundation below:**

Since 1978 the National Ataxia Foundation has been funding world-leading scientific and clinical research in the pursuit of finding treatments

and a cure for ataxia. From the discovery of genes to the development of mouse models, NAF has been at the center of advancing ataxia research. We will not give up in the search for a cure for ataxia, a devastating, progressive disease that robs individuals of freely moving, speaking, swallowing, and many other activities that most people take for granted.

The National Ataxia Foundation is deeply concerned that some clinics in the United States and around the world are promising stem cell-based treatments for ataxia without oversight and other standard patient protections. They boast stunning rates of cures without scientific evidence to back those claims. In essence the only thing they do provide is cruel health fraud, at an exorbitant price, preying on the desperation that patients and families feel in the face of this untreatable neurological disease.

Stem cell therapy may one day be a reality for ataxia, as it is now for blood cancers which bone marrow transplants can cure, but the science for neurological disease is not at that point yet. Scientific research, in general, is a long and involved process. Even though we have a greater understanding of the disease mechanism for the ataxias, translating that into a cure with stem cell therapy will take more research. We believe there is promise for stem cell therapies in some neurologic disease, but for now patients need to know that currently there are no stem cells that can fix the brain, improve ataxia, or prevent the worsening of ataxia. Some stem cell therapies may even worsen ataxia or cause other unanticipated serious health consequences. Another consideration for a patient electing to try unauthorized

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*Continued on page 22*

*Stem Cell Statement*  
Continued from page 21

“stem cell” injections is being disqualified from future trials of authorized disease modifying therapies for ataxia.

There are different types of stem cells and each has its own purpose; the blood forming stem cells regenerate blood, they cannot spontaneously make a brain cell. Patients must understand that the technology to make stem cells from various sources and get them to become and do what we want without causing cancer or other harmful

side effects is not fully understood. The simple fact, disappointing as it may be, is that scientists are not at that point in stem cell research. And we must be wary of doctors or clinics who claim that they are.

Stem cells have great potential and we are moving forward as fast as we can, but there are no shortcuts. We must use scientific principles that have been proven in the laboratory before we begin putting stem cells into people who are affected with ataxia. We must safeguard patients from unproven treatments that may cause serious harm. ❖

## Fragile X Conference Highlights

*Submitted by Padmaja Vittal, MD, MS, Rush University Medical Center, Chicago, IL  
Recipient of the NAF/ABF Clinical Research Training Fellowship in Ataxia*

The National Fragile X Foundation's 14th International Fragile X Conference was held at the Hyatt Regency Hotel in Orange County, CA July 16-20.

The meeting was very well attended by patients, caregivers and health care professionals with a broad range of presentations catering to a variety of needs. Several talks were given in the realm of basic science and clinical science and posters were presented by researchers across the world.

Drs. Elizabeth Berry-Kravis and Randi Hagerman presented a plenary session discussing clinical trials of new medications targeting brain mechanisms in Fragile X Syndrome (FXS).

The plenary session by Dr. Deborah Hall discussed Fragile X Associated Tremor/Ataxia Syndrome (FXTAS), which is an inherited degenerative disorder causing tremor, ataxia and memory issues. FXTAS is caused by a 55-200 CGG repeat expansion (premutation) in the

fragile X mental retardation 1 (FMR1) gene located on the X chromosome. She discussed who is at risk to get it and how to treat symptoms of this disease.



**Dr. Padmaja Vittal**

Drs. Berry-Kravis, Hall and I have a new IRB-approved study funded by the National Ataxia Foundation and the American Brain Foundation looking at genetic variations in a second gene. The hope is that this research would allow us to predict if patients will develop symptoms of the disease or remain symptom free. For the duration of the conference, patients with these disorders were the center of the universe, and it was a humbling experience to witness the courage, patience and grit of patients as well as their caregivers.

We encourage patients and caregivers to attend more such conferences as it connects you directly with health care professionals, other patients with the disease and support networks. ❖

## 2015 NAF Annual Membership Meeting Agenda & Overview

*Please Note: Due to circumstances beyond our control, this meeting agenda is subject to change.*

The National Ataxia Foundation (NAF) Board of Directors and the National Ataxia Foundation Western Region Support Groups invite you to attend the 58th Annual Membership Meeting (AMM). Please join us at the Sheraton Denver Downtown in Denver, CO to learn, share, network, have fun, and enjoy the sites.

The 2015 AMM will bring together 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 5TH

<i>EVENT</i>	<i>LOCATION</i>	<i>TIMES</i>
<b>NAF Registration</b> .....	TBA .....	9:00 a.m. – 8:00 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.		
<b>Silent Auction Item Drop Off</b> .....	TBA .....	9:00 a.m. – 8:00 p.m.
All items being donated for the Silent Auction are due in the Silent Auction room by Friday, March 6 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. <b>Bring an item to donate and then have fun bidding on the items of your choice.</b> Thank you for supporting this event and sharing items from your local area.		
<b>Leadership Meeting</b> .....	Governors Square 14 .....	1:00 – 3:00 p.m.
Designed to provide information and support to 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 <a href="mailto:lori@ataxia.org">lori@ataxia.org</a> prior to the meeting.		
<b>International Ataxia Awareness Day (IAAD) Meeting</b> .....	Governors Square 14 .....	4:00 – 5:00 p.m.
Anyone who is interested in learning more about IAAD, organizing an IAAD event, or getting involved in IAAD is encouraged to attend.		

### FRIDAY, MARCH 6TH

<i>EVENT</i>	<i>LOCATION</i>	<i>TIMES</i>
<b>Silent Auction Item Drop Off</b> .....	Plaza Ballroom (AD) .....	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.		
<b>Silent Auction Item Bidding</b> .....	Plaza Ballroom (AD) .....	8:30 a.m. – 5:00 p.m.
<b>NAF Registration</b> .....	Plaza Foyer .....	8:30 a.m. – 5:00 p.m.
<b>Exhibitors</b> .....	Plaza Foyer .....	8:30 a.m. – 5:00 p.m.
<b>General Sessions</b> .....	Plaza Ballroom (BCEF) .....	9:00 a.m. – 12:15 p.m.
Friday morning will start the General Sessions in the Plaza Ballroom. 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.		
<b>Activity Room</b> .....	Governors Square 15 .....	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. Temporary NAF Tattoos will be available during Activity Room hours each day. Volunteers will be on hand to help apply tattoos as needed.		

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

**Coloring:** Coloring activities will be available Friday and Saturday during Activity Room hours. Coloring is a therapy recommended for handwriting. Information describing the benefits of coloring will be available.

**Speed Friending:** This facilitated session will allow attendees to meet other attendees they may want to connect further with throughout the meeting. Participants are invited to bring a friend and contact cards to exchange Friday at 1 p.m.

**Lunch** ..... On Your Own ..... 12:15 p.m.

**Birds of a Feather (BOF) Group A\*** ..... Various Meeting Rooms ..... 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** ..... Plaza Ballroom (BCEF) ..... 7:00 p.m.

Please join us for the Welcome Reception. All registered meeting 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 have included 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 .....	<b>Camille Daglio, AMM Co-Chair &amp; North Central Region Representative</b>
9:30 a.m. ....	NAF Update .....	<b>Michael Parent, NAF Executive Director</b> NAF – Minneapolis, MN
10:00 a.m. ....	Ataxia 101, Medications..... & Medical Marijuana                      St. Joseph’s Barrow Neurological Institute – Phoenix, AZ	<b>Terry Fife, MD</b>
10:30 a.m. ....	Becoming an Adult with Ataxia .....	<b>Abigail Collins, MD</b> Children’s Hospital Colorado – Aurora, CO
11:00 a.m. ....	Relationships & Sexuality .....	<b>Terry Chase, MA, ND, RN</b> Colorado Mesa University – Grand Junction, CO
11:45 a.m. ....	Q&A .....	<b>Panel</b>
12:15 p.m. ....	Lunch	

**Birds of a Feather\*** ..... Various Meeting Rooms ..... 2:00 – 5:00 p.m.

**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. Questions regarding these sessions may be directed to Sue Hagen, NAF Patient Services Director [susan@ataxia.org](mailto:susan@ataxia.org) or (763) 553-0020.

Birds of a Feather Sessions 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 diagnosed with ataxia:

**SCA1 BOF** ..... 2 – 5 p.m. ....Governors Square 16

Facilitator: Dr. Khalaf Bushara

**SCA2 BOF** ..... 2 – 5 p.m. .... Governors Square 17

Facilitator: Dr. Stefan Pulst

**SCA3 BOF** ..... 2 – 5 p.m. .... Governors Square 11

Facilitator: Dr. John Day

**SCA6 BOF** ..... 2 – 5 p.m. .... Governors Square 9

Facilitator: Dr. Susan Perlman

**All Other SCAs (Including SCA 5, SCA7 and SCA 8) & DRPLA BOF** ..... 2 – 5 p.m. ....Governors Square 12

Facilitators: Dr. Laura Ranum & Dr. Terry Fife

**AOA, Episodic & Other Recessive Ataxias BOF** ..... 2 – 5 p.m. ....Plaza Court 7

Facilitator: Dr. Brent Fogel

**Under Age 30 with Ataxia BOF** ..... 2 – 5 p.m. .... Governors Square 10

Facilitators: Dr. Abigail Collins, Terry Chase, MA, ND, RN & Naomi Hubert

\*\*The following groups are for **family members** who do not have ataxia:

**Spouses and Partners without Ataxia BOF** ..... 2 – 5 p.m. ....Governors Square 14

Facilitators: Bailey Vernon, MPH, CHES & Melissa Gibbons, MS, CGC

**SATURDAY, MARCH 7TH**

<i><b>EVENT</b></i>	<i><b>LOCATION</b></i>	<i><b>TIMES</b></i>
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<b>Continental Breakfast</b> .....	Plaza Foyer .....	8:00 – 9:00 a.m.
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<b>NAF Registration</b> .....	Plaza Foyer .....	8:00 a.m. – 5:00 p.m.
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<b>Exhibitors</b> .....	Plaza Foyer .....	8:00 a.m. – 5:00 p.m.
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<b>Silent Auction Bidding</b> .....	Plaza Ballroom (AD) .....	8:30 a.m. – 1:00 p.m.
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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 3:30 – 7 p.m. on Saturday.**

<b>General Sessions</b> .....	Plaza Ballroom (BCEF) .....	8:30 a.m. – Noon
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Continue all day in the Plaza Ballroom (BCEF). A 30-minute Question and Answer session will follow the morning and afternoon General Sessions with a panel of the speakers who presented during those sessions.

<b>Activity Room</b> .....	Governors Square 15 .....	10:00 a.m. – 5:00 p.m.
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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. Saturday will continue to have the temporary NAF tattoos, Nintendo Wii, and coloring available.

Healing through Writing: For this facilitated session, interested participants are asked to prepare a writing piece to share. Participants are invited to share their writing piece Saturday at 1 p.m. in the Activity Room. Your piece doesn’t have to be freshly written for this event. It can be something you wrote at any time that you would like to share. Anyone is welcome to come share and/or listen.

<b>Lunch</b> .....	On Your Own .....	Noon
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<b>Family Planning Options Session</b> .....	2 – 5 p.m. ....	Governors Square 10
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Facilitators: Dr. Khalaf Bushara, Jessica Oberlin, & Melissa Gibbons, MS, CGC (Description on page 31)

**Birds of a Feather (BOF) Group B\*** ..... Various Meeting Rooms ..... 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** ..... Plaza Ballroom (BCEF) ..... 7:00 p.m.  
 The cost of the banquet is included in your registration fee, however all beverages will be available at a cash bar. The banquet includes a plated dinner entrée that you will select when you register for the meeting. When you arrive at the meeting **please reserve your seating and verify your entrée selection prior to the banquet.** Volunteers will be at the banquet ticket tables near 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**

<i>TIME</i>	<i>TOPIC</i>	<i>SPEAKER</i>
8:30 a.m. ....	Special Needs Planning ..... Workshop with Q&A	<b>Kelly Piacenti, MA</b> Metlife Center for Special Needs Planning – Somerset, NJ
9:30 a.m. ....	Physical Therapy .....	<b>Julie Hartman, PT, DPT</b> Craig Rehabilitation Hospital – Denver, CO
10:00 a.m. ....	Implications of Genetic Testing ..... and Ataxia on Families	<b>Melissa Gibbons, MS, CGC</b> Children’s Hospital Colorado – Aurora, CO
10:30 a.m. ....	Personal Story: My Journey with Ataxia .....	<b>Michael Cammer, CPASG Co-Leader</b> Downingtown, PA
11:00 a.m. ....	NAF Research Update.....	<b>Laura Ranum, PhD</b> University of Florida – Gainesville, FL
11:30 a.m. ....	Q&A .....	<b>Panel</b>
Noon .....	Lunch	

**Birds of a Feather (BOF)\*** .....Various Meeting Rooms ..... 2:00 – 5:00 p.m.  
 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. Questions regarding these sessions may be directed to Sue Hagen, NAF Patient Services Director at [susan@ataxia.org](mailto:susan@ataxia.org) or (763) 553-0020.

Birds of a Feather Sessions 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 BOF** ..... 2 – 5 p.m. .... Governors Square 17  
 Facilitator: Dr. Brent Fogel

**MSA, Sporadic & Gluten BOF** ..... 2 – 5 p.m. .... Governors Square 12  
 Facilitators: Dr. Terry Fife and Dr. John Day

**Over Age 30 Friedreich’s BOF** ..... 2 – 5 p.m. .... Governors Square 11  
 Facilitators: Dr. Susan Perlman (2 – 4 p.m.); Terry Chase, MA, ND, RN & Charlotte DePew (2 – 5 p.m.)

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

**Parents (Non-Friedreich’s) BOF** ..... 2 – 5 p.m. .... Governors Square 16  
 Facilitator: Dr. Abigail Collins

**Parents (Friedreich’s) BOF** ..... 2 – 5 p.m. .... Governors Square 14  
 Facilitators: David Zilles (2 – 5 p.m.); Dr. Susan Perlman (4 – 5 p.m.)

\*The following groups have been designed for **non-affected family members**:

**Family Members (Over 30) Without Ataxia (other than parents, spouses, or partners) BOF** ..... 2 – 5 p.m. .... Plaza Court 7  
 Facilitators: Camille Daglio (2 – 3:30 p.m.); William Sweeney (2 – 5 p.m.)

**Family Members (Under 30) Without Ataxia (other than parents, spouses, or partners) BOF** ..... 2 – 5 p.m. .... Governors Square 9  
 Facilitator: Bailey Vernon, MPH, CHES

**Sunday, March 8th**

<i>EVENT</i>	<i>LOCATION</i>	<i>TIMES</i>
<b>NAF Registration</b> .....	Plaza Foyer .....	9:00 – 11:00 a.m.
<b>Exhibitors</b> .....	Plaza Foyer .....	9:00 – 11:00 a.m.
<b>General Sessions</b> .....	Plaza Ballroom (BCEF) .....	9:00 a.m – 12:30 p.m.

Sunday morning wraps up the 2015 Annual Membership Meeting with the NAF Business Meeting and final round of General Sessions in the Plaza Ballroom (BCEF) 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**

<i>TIME</i>	<i>TOPIC</i>	<i>SPEAKER</i>
9:00 a.m. ....	NAF Business Meeting .....	<b>Char Danielson, NAF President</b> NAF – Minneapolis, MN
9:15 a.m. ....	Adaptive Recreation .....	<b>Matt Feeney, Director of Advancement</b> Adaptive Adventures – Denver, CO
9:45 a.m. ....	Adaptive Technology, Accessible Housing, and Home Modification .....	<b>Naomi Hubert, MEd</b> Barrier Free Living – Denver, CO
10:15 a.m. ....	Strategies for Living with Ataxia.....	<b>Bailey Vernon, MPH, CHES</b> Johns Hopkins University – Lutherville, MD
10:45 a.m. ....	The Ataxias: Research in FRDA, SCA, MSA .....	<b>Susan Perlman, MD</b> University of California – Los Angeles, CA
11:30 a.m. ....	Wrap-up: What We Have Learned .....	<b>John Day, MD, PhD</b> Stanford University – Stanford, CA
Noon .....	Q&A .....	<b>Panel</b>
12:30 p.m. ....	Closing Remarks .....	<b>Char Danielson, NAF President</b> NAF – Minneapolis, MN

For those who will be attending the 2015 meeting, be prepared to participate, learn and be inspired by the excellent program. If you cannot attend the annual meeting but would like to have a copy of any or all of the general sessions, they will be available for purchase after the meeting. Sessions are digitally recorded and synced with the presenter’s PowerPoint slides. In addition, selected presentations will be reprinted in future issues of *Generations*. The valuable information presented at annual meetings continues to be a resource for the ataxia community, long after the meeting is over.

**Meeting Presentations and Recordings**

To better serve the entire ataxia community, the National Ataxia Foundation began having the General Session Presentations audio synched by Digital Conference Providers at the 2010 Annual Membership Meeting. These recordings include the speakers' audio presentations synched with their PowerPoint slides.

The recorded sessions from the 2010-2015 AMMs can be purchased directly online at <http://www.dcpvidersonline.com/naf/> or by using the order form on page 41. A limited number of recorded presentations for each meeting are available for viewing at no cost. You are encouraged to take advantage of these sessions offered for free. ❖

## Travel Grant Program Support

For those with ataxia, traveling to the National Ataxia Foundation's Annual Meeting (AMM) may be financially difficult. Our Travel Grant Program was created to assist individuals with some of the costs associated with attending the AMM.

You can help an individual attend the AMM by making a donation to our Travel Grant Program today. Simply designate your donation to the AMM Travel Grant Fund to make an impact.

Thank you for your support.

## 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 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.

***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* \_\_\_\_\_ 2015

*Email Address* \_\_\_\_\_

*Item Number* \_\_\_\_\_

Office Use only

# “Soaring Mile High for a Cure” Meeting Registration Instructions

**Dates:** March 6 – 8, 2015

**Location:** Sheraton Denver Downtown Hotel  
1550 Court Place  
Denver, CO 80202  
1-888-627-8405 or (303) 893-3333

**Meeting 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 membership meeting registration fee.

## **Individuals eligible for the member rate include current:**

- Individual Members (*Individual members may also register their spouse or caregiver for 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 6, 2015*):

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

**Registration Fee February 7 – 27, 2015 – You are strongly encouraged to register before Feb. 6**  
(*includes registrations postmarked February 6 – 27, 2015*):

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

**Registration Fee after February 27, 2015 – You are strongly encouraged to register before Feb. 6**  
(*includes registrations postmarked after February 27, 2015 and all registrations at the door*):

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

**NOTE: The Meeting 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 meeting.\*
- 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 meeting will be charged the following registration fees: children two years and under are free; children three years and over will be charged the full meeting 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 February 6, 2015. 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](http://www.ataxia.org)

## **Early Registration Deadline is February 6, 2015**

**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](mailto: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 session?**

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

### **Do I have to decide when I register for the annual meeting which session I plan to attend?**

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

### **I am a family member without ataxia. May I attend the Bird 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 meeting attendees. You may attend the session that will be most helpful for you but keep in mind the specific focus of the group.

### **PATIENTS with EARLY SYMPTOMS of FRIEDREICH’S ATAXIA**

**age 10 and above needed for an MRI study to  
evaluate the chemistry and connectivity of the  
brain and spinal cord in Friedreich’s ataxia**

**at the Center for Magnetic Resonance Research  
at University of Minnesota**

You will lie in the scanner for ~1.5 hour while listening to the  
music of your choice. Reimbursement for travel expenses is  
available and you will be compensated for your time.

Please note that we cannot scan you if you have Harrington rods,  
and we cannot scan people with diabetes at this time.

If you are interested or have questions, please call  
Diane Hutter @ (612) 625-2350 or e-mail [hutte019@umn.edu](mailto:hutte019@umn.edu).



**I am a non-family member 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
- 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. For the privacy of the issues talked about in this session we ask that those with ataxia attend the BOF sessions for Ataxians.

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 there is a history of ataxia in their family.
- MSA, Sporadic and Gluten Ataxia for those who are over 12 years old and have been diagnosed with MSA, Sporadic, or Gluten Ataxia and 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 (Non-Friedreich) for parents of a child(ren) who is/are affected by any form of ataxia other than Friedreich ataxia.
- Parents (Friedreich) for parents of a child(ren) who is/are affected by 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 one session on Family Planning Options on Saturday from 2 – 5 p.m. which will be facilitated by a neurologist and genetic counselor. 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](mailto:lori@ataxia.org) or Sue Hagen at [susan@ataxia.org](mailto:susan@ataxia.org) or call (763) 553-0020 and ask to speak with Sue or Lori.

## 2015 NAF Annual Membership Meeting Registration

*Online registration available at [www.ataxia.org](http://www.ataxia.org). Instructions can be found on page 29.*

NAF will send out all meeting materials and handouts through e-mail. For those who do not have access to e-mail, materials will be mailed out and a limited amount of hard copy handouts will be available at the meeting upon request.

**1.** \*Full Name: \_\_\_\_\_ Name on Badge: \_\_\_\_\_  
 \*Address: \_\_\_\_\_ \*City/ State/ Zip: \_\_\_\_\_  
 Country: \_\_\_\_\_ \*Phone: \_\_\_\_\_ E-mail: \_\_\_\_\_  
 Adult (18+)  Teen/Child (3-17)  Infant (2 & under)  PCA Is this your first NAF AMM?  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 AMM?  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 AMM?  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 AMM?  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> <span style="float: right;"><b>Y or N</b></span>				
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> <span style="float: right;"><b>B, V or VE</b></span>				
3. Will you be using a Scooter (S), Manual Wheelchair (M), Electric Wheelchair (E), or a Walker (W)? <span style="float: right;"><b>Blank, S, M, E or W</b></span>				
4. Will you be bringing an assistance dog? <span style="float: right;"><b>Y or N</b></span>				
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> <span style="float: right;"><b>Y or N</b></span>				

\*Indicates required information. PCA = Personal Care Attendant.

**Copy this form if registering more than four attendees**

## 2015 NAF Annual Membership Meeting 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:** SCA1 **B:** SCA2 **C:** SCA3 **D:** SCA6 **E:** All other SCAs (including 5, 7, 8) & DRPLA  
**F:** Under 30 w/ Ataxia **G:** Spouses/Partners w/out Ataxia  
**H:** AOA, Episodic & Other Rare Recessive Ataxias (does not include Friedreich Ataxia)

**– Group B on Saturday –**

- I:** Unknown w/ Family History **J:** Unknown w/out Family History – MSA, Sporadic & Gluten  
**K:** Over 30 (Friedreich Ataxia) **L:** Family Members (under 30) w/out Ataxia  
**M:** Parents (non-Friedreich Ataxia) **N:** Family Members (over 30) w/out Ataxia  
**O:** Parents (Friedreich Ataxia)

<b>Please complete the following for each person (continued from page 32):</b>	<b>#1</b>	<b>#2</b>	<b>#3</b>	<b>#4</b>
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) <b>Select one session only</b>				
7. Do you plan on attending the Family Planning Options session on Saturday from 2–5 p.m.? <b>Y or N</b>				

### 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 Membership Meeting. We need volunteers for the 2015 AMM to be held in Denver, CO on March 6–8. To sign up as a volunteer at the 2015 AMM or to get more information about the volunteer opportunities, please contact Barb and Mike Ofenstein at (303) 903-6903 or [barbarao70@outlook.com](mailto:barbarao70@outlook.com) to sign up.

### IMAGE CONSENT POLICY

By attending the 2015 NAF Annual Membership Meeting 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 Membership Meeting is forbidden, without prior approval in writing by the National Ataxia Foundation. PowerPoint presentations along with information on how to purchase recordings of the presentations will be available on the NAF website after the completion of the meeting. Attendees at the Annual Membership Meeting expect, and deserve, the right to privacy. NAF does photograph and record at the AMM, 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 NAF events. Any materials distributed seeking funds for other organizations or for individual benefit will be removed.

## 2015 NAF Annual Membership Meeting 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><b>Yes, I would like to be a member of NAF!</b> Please add an <b>ADDITIONAL</b></p> <p><input type="checkbox"/> \$35 (Annual Individual)   <input type="checkbox"/> \$55 (Annual Household)</p> <p><input type="checkbox"/> \$100+ (Annual Patron)   <input type="checkbox"/> \$500 (Lifetime)   <input type="checkbox"/> \$55 (Annual Professional)</p> <p><input type="checkbox"/> \$50 (Individual Outside U.S.)   <input type="checkbox"/> \$70 (Household and Professional Outside U.S.)</p> <p><input type="checkbox"/> Recurring membership \$_____ /month (for more information, please call NAF)</p> <p><b>You may register for the meeting as a member if you sign up today!</b></p> <p><i>*Household, Patron and Lifetime memberships include all individuals who share the same residence.</i></p>		
<p><b>Yes, I'd like to support the Annual Meeting Fund (provides travel grants, offsets registration fees, helps cover costs associated with the meeting)</b></p> <p>Here is my sponsorship contribution!</p> <p><input type="checkbox"/> \$125 (Offset of Registration)   <input type="checkbox"/> \$400 (Travel Grant)</p> <p><input type="checkbox"/> Other: \$_____ (Any amount is helpful!)</p>		

REGISTRATION FEES (includes all General Sessions, reception, and banquet)	On or Before 2-6-2015	From 2-7 to 2-27-2015	After 2-27-2015 or at door	Quantity	Total
<input type="checkbox"/> <b>NAF Member</b> (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"/> <b>Non-Member</b>	\$180	\$205	\$255		

**TOTAL CHARGES:**

**PAYMENT INFORMATION:**    Visa    MasterCard    Discover    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 6, 2015

**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](mailto:joan@ataxia.org)

# Registration Information and Denver Resources

## Meeting Registration

The meeting registration form is also available on NAF's website, [www.ataxia.org](http://www.ataxia.org). Please fill out the registration form completely, including your travel information, as we need all the information to finalize plans.

Registration is open and you are encouraged to register before February 6, 2015 to receive the discounted early registration rate. General registration rates are applied after February 6, 2015. Registrations after February 27 will only be accepted on-site at the conference. 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 meeting 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.

## 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 Membership Meeting. 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 NAF office at (763) 553-0020 or [joan@ataxia.org](mailto:joan@ataxia.org). Visit [www.ataxia.org](http://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 2015 Annual Membership Meeting. Thank you for taking the time to renew or become a member of the National Ataxia Foundation.

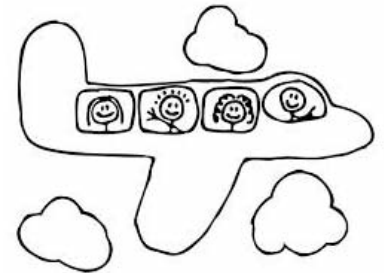
## Conference Deductions by Attendees

<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

Because of the generosity of several donors, the National Ataxia Foundation is able to offer Travel Grants to help with a portion of the travel costs associated with attending the meeting. Adults or children with ataxia are eligible to apply for a travel grant. Individuals interested in the program are required to submit a Travel Grant application. Applications will be accepted until January 9, 2015. Travel Grant applicants will be notified of the status of their application after the application deadline and after all applications have been reviewed.



Visit the NAF website, [www.ataxia.org](http://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 [lori@ataxia.org](mailto:lori@ataxia.org) to request one.

*Registration Information and Denver Resources*  
Continued from page 35

### **About Denver “The Mile High City”**

Welcome to Denver, where 300 days of sunshine, a thriving cultural scene, diverse neighborhoods, and natural beauty combine for the world’s most spectacular playground. A young, active city at the base of the Colorado Rocky Mountains. Denver’s stunning architecture, award-winning dining and unparalleled views are all within the walking distance from the 16th Street pedestrian mall, a mile-long pedestrian promenade of outdoor bistros, microbreweries, shopping and entertainment. The 16th Street Mall offers a free and accessible bus that travels 16th Street on a regular basis daily. Free and close attractions to the conference hotel are the Federal Reserve Money Museum and Denver U.S. Mint. Tours of the Denver U.S. Mint fill up quickly, so make your reservation early if you are interested in a tour.

Denver really is exactly one mile high. The air is thinner and dryer. Here are some tips to help you avoid altitude sickness:

**Drink Water** – Before your trip to Denver, and while you are here, drinking plenty of water is the number one way to help your body adjust easily to our higher altitude. The low humidity in Colorado keeps the air dry, like the desert, so you need about twice as much water here as you would drink at home.

**Monitor Your Alcohol Intake** – In Denver’s rarified air, golf balls go 10 percent farther ... and

so do cocktails. Alcoholic drinks pack more of a wallop than at sea level. It is recommended that you go easy on the alcohol in the mountains and in Denver, as its effects will feel stronger here.

**Eat Foods High in Potassium** – Foods such as broccoli, bananas, avocado, cantaloupe, celery, greens, bran, chocolate, granola, dates, dried fruit, potatoes and tomatoes will help you replenish electrolytes by balancing salt intake.

**Watch Your Physical Activity** – The effects of exercise are more intense here. If you normally run 10 miles a day at home, you might try six miles in Denver.

**Pack for Sun** – With less water vapor in the air at this altitude, the sky really is bluer in Colorado. But there’s 25 percent less protection from the sun, so sunscreen is a must. Denver receives over 300 days of sunshine each year (more than San Diego or Miami). Bring sunglasses, sunscreen, lip balm ... even in winter.

**Dress in Layers** – Two days before your trip to Denver, check the weather and use this information to pack appropriately. Because Denver is closer to the sun, it can feel warmer than the actual temperature during the daytime, but then become chilly after sundown, particularly in the spring and fall. It is best to layer your clothing.

Please visit [www.denver.org](http://www.denver.org), <http://www.denver.org/about-denver/transportation/accessibility-services/>, <http://www.denver.org/deals/>, and [http://drmac-co.org/images/PDFs/GTG2014\\_ENGLISH.pdf](http://drmac-co.org/images/PDFs/GTG2014_ENGLISH.pdf) for a complete list of attractions, planning, and transportation information.

### **Weather in Denver**

In Denver the average high temperature in March is 52 degrees and the average low temperature is 26 degrees.

### **Amendment 64, State of Colorado, Use and Regulation of Marijuana**

The following link provides information on the laws and regulations in Denver, Colorado regarding medical and retail marijuana: <https://www.colorado.gov/pacific/marijuanainfodenver/residents-visitors>. (Source: State of Colorado) ►►

## **E-mail Blasts**

E-mail blasts from the National Ataxia Foundation are sent out periodically on ataxia research, events and other timely issues of interest. Please email your e-mail address to [julie@ataxia.org](mailto:julie@ataxia.org) so you don’t miss out on important information.

## Sheraton Denver Downtown

Sheraton Denver Downtown is the official conference hotel of the 2015 NAF Annual Membership Meeting. Sheraton Denver Downtown is located on the 16th Street Mall and 25 minutes from the Denver International Airport at 1550 Court Place, Denver CO 80202.

Perfectly located on the 16th Street Mall, a mile-long pedestrian promenade of outdoor bistros, microbreweries, shopping and entertainment, and situated in the heart of Denver's financial and business districts, the Sheraton Denver Downtown Hotel welcomes you. The 16th Street Mall offers a free and accessible bus that travels 16th Street on a regular basis daily: <http://www.rtd-denver.com/FREEMallRide.shtml>.

The majority of guest rooms and meeting space being held for NAF is in the Plaza Tower of the hotel. Access with a room key is required in the elevators to reach floors with guest rooms. If you require assistance with the elevator to reach your guest room floor please see a Front Desk Agent. Visit the Sheraton Denver Downtown website – <http://www.sheratondenverdowntown.com/> – for more information.

## Sheraton Denver Downtown Hotel Smoking Policy

All guest rooms and public spaces are 100% non-smoking. A \$300 USD cleaning fee will be charged to any guest who violates the smoking policy. A link to the Sheraton Denver Downtown Hotel, Hotel Policies: [http://www.starwoodhotels.com/sheraton/property/overview/announcements.html?propertyID=3205&language=en\\_US](http://www.starwoodhotels.com/sheraton/property/overview/announcements.html?propertyID=3205&language=en_US).

## Internet at the Sheraton Denver Downtown

NAF AMM attendees staying at the Sheraton Denver Downtown will enjoy complimentary Internet in their guest room for up to three devices depending on the bandwidth. Attendees will see the complimentary in-room internet option when they login while in their guest room. Additional charges may apply for more than three devices or for internet services selected outside the guestroom.

At the Link@Sheraton all guests at the Sheraton Downtown Denver have access to complimentary high-speed Internet access, printing capabilities, docking stations for laptops and more. The Link@Sheraton is a unique virtual and physical lounge space which enables guests to work, relax, socialize, and, most importantly, stay connected.

### Link@Sheraton Highlights:

- 8 complimentary computers
- 3 complimentary printers
- Docking stations for laptops



**The Sheraton Denver Downtown will be the site of the 2015 Annual Membership Meeting**

Conveniently located in the Hotel Lobby next to 15|Fifty.

## Parking at the Sheraton Denver Downtown

Valet parking and self-parking are available. NAF has discounted parking rates available for AMM attendees. NAF's discounted rate for valet is \$22 and for self-parking is \$18 daily. All day Saturday and Sunday the daily self-parking rate is \$10. The Sheraton Denver Downtown parking garage is located underground with direct access via elevator to the hotel lobby and has a clearance of 6' 4".

## Registration Information and Denver Resources

Continued from page 37

**Oversized Parking** – The Sheraton Denver Downtown can accommodate a limited number of oversized vehicles at a lot that is nearby, but not directly located at the hotel. The pricing is \$35 per night (pricing subject to change without notice). The Oversized Lot can be accessed through the hotel valet. For more information about the oversized parking, contact Towne Park at (303) 352-2454.

### Service Dog Information

The service dog relief area at the Sheraton Denver Downtown is located in the Tower Building Port Cocher.

### Hotel Reservations

Standard room reservations at the Sheraton Denver Downtown can be made online at <https://www.starwoodmeeting.com/Book/naf2014>.

For guests who prefer to phone in their reservations call Hotel Reservations at 1-888-627-8405 and ask for the National Ataxia Foundation's group rate under the name "Nat'l Ataxia Foundation 2015." A credit card is required at the time of booking. Notice of cancellation must be received 72 hours prior to your arrival date. Request rooms in the Plaza Tower to be closest to convention spaces.

Reservations at group rate will be available until February 13, 2015. The NAF group rate is \$159 + taxes, currently 14.75%. Please note there is limited availability on discounted rate rooms.

### ADA Hotel Rooms and Equipment

ADA rooms were available on a first-come, first-serve basis. To inquire about the availability of an ADA room at the Sheraton Denver Downtown please contact the National Ataxia Foundation at (763) 553-0020 or [lori@ataxia.org](mailto:lori@ataxia.org). ADA rooms cannot be reserved through the hotel. The width of the bathroom door in the ADA guest rooms is 34".

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 Denver Services and Resources section of this article. NAF is unable to provide ADA equipment however the Sheraton Denver Downtown may have some extra shower chairs, grab bars, or detachable shower heads available. Be sure and request these items when making your reservation if needed. The width of the bathroom door in the standard Plaza Tower guestrooms is 33". The hotel is able to take the bathroom room door off if necessary in Plaza Tower guest rooms. The width of the bathroom door in the standard Tower guest rooms is 21½". The height of the beds in every guest room is 28".

The following information can be used as a guide as you plan your **transportation needs** in Denver. 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.

### Denver International Airport Ground Transportation

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](http://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 links to websites such as the Transportation Security Administration and the U.S. Department of Transportation. Also visit the website of the Denver International Airport, <http://www.flydenver.com/>.

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. Please note: At the Denver International Airport there are three concourses, A, B, and C and the ►►

Main Terminal. In the center of each of these buildings is an information booth where travelers can seek assistance if needed. We look forward to having you attend the 2015 Annual Membership Meeting and wish you Happy Flying!

The Ground Transportation Information Counter at the Denver International Airport is located in the central area on Level 5 of Jeppesen Terminal. Counter hours are 6:00 a.m. to 11:30 p.m. daily. Visit [http://www.flydenver.com/parking\\_transit/transportation\\_den](http://www.flydenver.com/parking_transit/transportation_den) or call (303) 342-4059 for a complete listing of ground transportation options to and from the Denver International Airport.

**Wheelchair Transportation** – travelers traveling to and from the Denver International Airport can choose from among several companies that provide wheelchair transportation services. Individuals needing this service should make arrangements with a service provider in advance. The door-to-door companies listed below pick up passengers at curbside on the west side of Jeppesen Terminal, level 5.

- *Dashabout* – (800) 720-3274 (this company requires two-to-three day advance notice)
- *Metro Cab* – (303) 333-3333
- *Mobility Plus (Yellow Cab)* – (303) 777-7777 (24-hour, on-demand wheelchair accessible service)
- *Mobility Transport Service* – (303) 295-3900 (this company requires 24-hour advance notice)
- *RTD Access-a-Ride* – (303) 292-6560.

**RTD Paratransit Services, Access-a-Ride** – provides curb-to-curb public transportation to riders who have a disability that prevents them from making some or all of their trips on fixed route buses. This service is sometimes called “ADA Paratransit Service.” Access-a-Ride service must be reserved 1-3 days in advance. The service is provided with lift-equipped vans which are scheduled through the Access-a-Ride Call Center office. Access-a-Ride service operates in

the same areas and during the same days and hours as the fixed route non-commuter bus service. The service can be used for any trip purpose. The User’s Guide on the Access-A-Ride website – [http://www.rtd-denver.com/accessARide\\_UsersGuide.shtml](http://www.rtd-denver.com/accessARide_UsersGuide.shtml) – provides information about RTD’s Access-a-Ride service, including who is eligible to use the service, how to request a ride, fares, and other important information. If you still have questions after reading this user’s guide, you can call the Access-a-Ride office at (303) 299-2960 or (303) 299-2980 if you use a TTY. Upon request, copies of this user’s guide can also be provided in large print, audiotape, or on computer disk.

The following information can be used as a guide as you plan your **stay** in Denver. 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.

## Denver Area Services and Resources

### **Wheelchair Van Rental**

#### **AAVans**

1-888-880-8267

<http://www.aavans.com/colorado-co/denver-handicap-vans-for-sale>

#### **Performance Mobility**

333 E. 76th Ave., Denver, CO 80229

(303) 288-0140 1-877-864-8267

<http://www.performancemobility.com/locations/denver-north-co/>

#### **Wheelers Accessible Van Rentals**

250 E. Dry Creek Rd., Ste. 114

Littleton, CO 80122

(720) 322-0101

[co@wheelersvanrentals.com](mailto:co@wheelersvanrentals.com)

[www.wheelersvanrentals.com](http://www.wheelersvanrentals.com)

*Registration Information and Denver Resources*  
Continued from page 39

### **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 Denver. 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.

### **Personal Assistance Services of Colorado (PASCO)**

(303) 233-3122  
<http://www.pascohh.com/>

### **Childcare**

If you need childcare, please make arrangements prior to attending the meeting. Please note that 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.

### **Tots on the Spot**

(970) 214-8373  
<http://www.totsonthespot.com>

### **Accessible Equipment, Wheelchair, and Scooter Rentals**

**Major Medical Supply Brighton**  
7000 N. Broadway, Denver, CO 80221

(303) 654-0720  
<http://www.majormedicalsupply.com/>

### **nu motion**

13450 E. Smith Rd., Aurora, CO 80011  
(303) 781-1474 1-800-525-8586  
<http://www.numotion.com/>

### **Penfield's Office Business Center**

Sheraton Denver Downtown Hotel  
(303) 626-2547  
[www.penfieldsoffice.com](http://www.penfieldsoffice.com)

### **Scootaround Inc.**

(888)441-7575  
<http://scootaround.com/>

### **Pharmacy**

#### **Rite-Aid**

750 16th St.  
(303) 534-7802

#### **Walgreens**

801 16th St.  
(303) 571-5316  
<http://www.walgreens.com/pharmacy/?tab=Pharmacy>

### **ADA Assistance Office**

Denver Office of Disability Rights (DODR)  
201 W. Colfax Ave., Dept. 1102 (2nd Floor)  
Denver, CO 80202

Voice: (720) 913-8480 Fax: (720) 913-8470  
TTY: (720) 913-8475

<http://www.denvergov.org/Default.aspx?alias=www.denvergov.org/disabilities> ❖

## **There's Still Time to Donate**

Thank you to those who have donated to the 2014 Research Drive. Checks post-marked by December 31 or on-line donations made before midnight will be eligible for a tax deduction in 2014. Your research gift offers hope to ataxia families in furthering vital world-wide ataxia research.

## **CFC Number**

The mission of the Combined Federal Campaign (CFC) is to promote and support philanthropy by providing federal employees with an effective workplace giving program.

The National Ataxia Foundation's CFC number is 10752. This program provides a convenient way to donate to the Foundation, and provides great benefit to those with ataxia. Please give generously.

**NAF SESSION RECORDINGS ORDER FORM**

**58<sup>th</sup> Annual Membership Meeting**  
**Soaring Mile High for a Cure**

Sheraton Downtown Denver Hotel, March 6-8, 2015



**Visit Us Online at: [www.dcprovidersonline.com/naf/](http://www.dcprovidersonline.com/naf/)**

Select your sessions individually or buy a package! Purchase the Full Course Package option before the conference start to receive the discounted rate of only \$89.00!

The sessions are recorded live and are made available shortly after the meeting concludes.

**PACKAGE OPTIONS :**

**FULL COURSE PACKAGE DOWNLOAD - AUDIO SYNCHRONIZED WITH PRESENTATION MATERIAL!**

**\$89.00 Pre-Meeting... \$129.00 Post-Meeting**

Purchase the download subscription and receive the Full Course Package. This option includes all available session audio (MP3 format) and session video (MP4 Format). With each download subscription you will enjoy unlimited access to your purchased files. You may download as many times as desired for one set price. Your account will not expire, so be sure to keep your login information for future access and purchases. Steps to download can be found listed below. Sessions are delivered online at: [www.dcprovidersonline.com/naf/](http://www.dcprovidersonline.com/naf/)

**FULL COURSE PACKAGE ON DVD-ROM - AUDIO SYNCHRONIZED WITH PRESENTATION MATERIAL!**

**\$89.00 Pre-Meeting... \$129.00 Post-Meeting**

Purchase the DVD-ROM and receive the Full Course Package. The DVD-ROM plays on your computer and includes of all available session audio (MP3 format) and audio synchronized with the presentation material (MP4 format). The DVD-ROM includes the same content as our download subscription mailed to you on a disc. The DVD-ROM ships post meeting.

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## From the Desk of the **Executive Director**

By Michael Parent, NAF Executive Director

Happy holidays!

As 2014 is ending and 2015 will soon begin, I am reminded of all the wonderful people who have helped make 2014 a stellar year. It is with deep appreciation that I give a heartfelt thank you to all of the lead organizers, volunteers, sponsors, participants, and donors who supported Walk n' Rolls for Ataxia and other International Ataxia Awareness Day events throughout the country this year. Your efforts raised ataxia awareness across the nation touching tens of thousands of people and raised more than \$300,000.

Thank you to our incredible Chapters Presidents, Support Groups Leaders, and Ambassadors, who each day make a powerful impact on local ataxia families. Thanks are given to all

of our amazing members and recurring gift members who help sustain the Foundation in providing important programs and services.

We acknowledge the tireless efforts of the Western Region members and volunteers who worked so hard to make the 2014 NAF Annual Membership Meeting a great success. We also gratefully recognize our Co-Lead Organizers, Drs. Orr and Lynch, for their outstanding contributions in making the 2014 Ataxia Investigators Meeting (AIM) a world-class scientific ataxia conference.

We are truly grateful to all those who supported the 2014 NAF Annual Ataxia Research Drive in supporting vital and promising ataxia research to help end ataxia. Without your support, many crucial ataxia research studies would have gone unfunded. We are indebted to all of our partners and corporate and foundation friends.

I am truly thankful to each NAF Board Member and the members of the Medical and Research Advisory Board for their dedication and commitment in helping those affected by ataxia and to a dedicated staff who works hard each day in serving ataxia families. A special thank you to all the scientific peer reviewers in guiding us to fund the most promising ataxia research.

As I am writing this article in November, I wanted to point out that November is National Caregivers Month. The National Ataxia Foundation is aware of the vital roles that caregivers serve for those with ataxia each and every day. We applaud your faithful and steadfast commitment in helping those who are so deserving of our help. Thank you for all that you do.

We look ahead to 2015 with great promise as important ataxia research continues to bring us more answers and for the continued support of our donors, volunteers, and friends. Wishing you a safe and happy New Year. ❖

**Happy Holidays from your  
friends at the NAF Office!**



# Lisa's Story

*Written by Lisa*

I can remember being a very happy, playful, active child who thought of nothing but toys, candy and my puppy. I was an average four year old and the apple of my father's eye.

I believe my parents realized there was something wrong before I realized it. Dad noticed I would often trip when I was about five, but Mom didn't agree. Maybe she knew in her heart but didn't want to face it. It was a form of denial. Between ages five and seven is when I started to realize there might be something wrong. Each time I would fall, my friends would help me and I begged them not to bring me home. I didn't want my parents to see that I'd fallen again.

My Mom finally acknowledged something was wrong and decided to bring me to my pediatrician. After telling him the symptoms, I had to go to the local hospital for tests. I was there for a week and had many tests. They couldn't find anything wrong so I thought it must all be a mistake.

A few weeks later I was sent to a neurological specialist. This is the first time I'd experienced anger. I was angry at my parents, my doctor and at myself. I think I felt like I was going through these experiences completely alone. The specialist examined me in his office and I was then sent to his waiting room while he talked to my parents. I realize I was only seven, but I felt completely dehumanized. I felt I had a right to know what was going on in my life.

On the way home my parents told me I had to go back into the hospital for testing. The tests were very painful, but I think the most painful thing was not being talked to about what was happening. I think we all weren't ready for it to be discussed.

It was very difficult for the doctors to diagnose me. It seemed as if everything was going to be fine because they couldn't find anything wrong. One incident that occurred, and I remember it as if it happened yesterday, was being put on a stage in an auditorium with about 100 doctors comprising the audience. I was examined, tested, and demonstrated to this attentive audience. I felt like the elephant man. Although I was a bit frightened, I enjoyed being the center of attention.

After intensive testing and probing my doctors finally came up with a diagnosis. The doctor said I would have trouble walking for the rest of my life. That's all I was told, and when I heard that I felt such a feeling of relief and joy. When I look back at it now, I think it was a wise choice not to tell me the extent of the disease. I think my family and I could have been a little more honest about this from the beginning instead of using denial. I've learned that denial is a stage we all must go through when facing serious ailments.



**Lisa**

The years that followed my diagnosis were very difficult. All through these years I was going through a process of acceptance. I knew in my heart that I would eventually have to use a wheelchair, but I wanted to give it a fighting chance. I finally lost the battle when I entered high school at 14. When it happened I felt great relief. My life would be so much easier on wheels.

My high school years were one of the best experiences of my life. I was coming from an able-bodied world into the world of the disabled. I can remember my first day at high school. I

*Continued on page 44*

*Lisa's Story**Continued from page 43*

rolled in and saw disabled people all around. I was very frightened at first until I realized I was one of them. It took me a while before I got used to being around other disabled people, but once I did, I felt good. From that point on I was able to establish many close friendships.

My college years seemed to be proceeding well academically and socially. The only downfall that was apparent was my physical condition. Things started changing. I was getting weaker, my coordination was worsening and my speech was slurring. I could feel these changes in my body, yet I still held on to my physical independence. Yes, things were more difficult, but I adapted, modified my lifestyle and functions. I wanted my independence.

In my senior year at college I had to make one of the biggest and heaviest decisions of my life. What made it difficult was that my parents stepped out of the decision making process. It was my ultimate decision. My Mom gave me support and her knowledge as a nurse, but she didn't feel right choosing for me. My final decision was to have an operation. I had to take that chance. I had the operation with great success. Technically things were good, yet my disease progressed much faster. This was very hard to

deal with. I'd been facing a progressive disease all my life, progressing at a slow rate and now things were different overnight.

At this time I experienced an overwhelming amount of emotions. I would switch from denial to anger, to depression, to hope and finally to acceptance. After many hours of supportive and loving talks with my Mom, I was able to return to my basic values in life.

Living with a progressive disease is perhaps one of the most difficult ways of facing life, but can also be a very challenging experience. I will not deny, at times, I have gone through depression and suffered many frustrations, but I believe these feelings have made me a much stronger person. I also feel I fear death less because of constant changes in my life and believe the final change to death will be challenging.

*Generations* was very dear to Lisa. With each edition, she knew somewhere within its pages she would find a grain of hope. Finding this paper put me once again in close touch with her.

*Lisa lived with Friedreich Ataxia for 48 years and passed away in 2010. It was simply a good feeling to be in touch once again with the Generations magazine. At 78, with a recent diagnosis of Friedreich Ataxia, I hope to face this challenge with her courage.*

*Submitted by her Mom. (Her paper was edited for Generations.)* ❖



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# My Story: From Riding a Harley to a Catrike

*Submitted by Mary Fuchs*

Ataxia is not who I am, it is what I have. I was diagnosed with hereditary Friedreich Ataxia (FRDA) in August 1998. But that is not where my story begins.

My life before ataxia: I was born in a small Michigan German farming community in 1949, was the third of four children, and had a normal (but clumsy) childhood. After high school, I had a career as a Licensed Practical Nurse (LPN) and ultimately owned a home health care business “Home Sweet Home Services.” Married three times, three wonderful kids, three grandkids, and three step-grandkids. I am now married to Frank, my soul mate and caregiver – when I let him. We married in May 1998 before I knew I had ataxia. We got married on a Harley Davidson and rode it out of the church side saddle, dress and all. BEST DAY EVER. We continued living in Michigan, but after the FRDA diagnosis, we moved to the Phoenix, AZ area in April of 2002 to get away from cold and snow.

If you can’t tell yet, I have lot of adventure or WILD in me. We try to do at least one thing each year we call “Fat Moments.” Examples: zip-lining in Costa Rica in 2004, 21-day white water rafting called “Colorado River Rampage Adventure” in 2008 (this was with a handicap adventure group), a 14-day Australian cruise that included horseback riding in 2007, and Hawaii in 2013. (I was able to get into the ocean, easy for most but not if you are in a wheelchair.) My next desire or item on my “bucket list” is to sky dive

or parasail.

Back to my FDRA. I had strange neurological issues for a few years before being tested (e.g. gait or the airplane walk, slurred speech, balance, weak muscles). In 1997, a year before my FDRA diagnosis, I had a mild head injury from an auto accident. When my balance and gait got worse, I thought it was from that auto accident, but no



**Mary Fuchs**

such luck. I had a very sharp neurologist at Michigan University Hospital in Ann Arbor, MI., who tested me for ataxia/FDRA, when genetic diagnosis was still in its infancy. The results indicated I had FDRA. My older sister, Charlotte also has late adult-onset FDRA. We have no clue where it came from but could blame it on one of our grandparents, who married as first cousins, which was common in the 1800’s among ethnic groups. At least we have the adult late onset version and

our repeat numbers are low, yeah!

Diagnosis was FDRA, now what? No big deal at first, just a wiggle and wobble to my walk for the first four to five years. Then I began to fall and started using a walker, Then I started to fall with the walker. I fractured my wrist three years ago and had to progress to a motorized wheel chair which was and still is safer for me. Safety is always first.

But my story does not stop there! For me, it is now about the “Fight for a Cure” and “Ataxia Awareness.” I found the Arizona Ataxia Support

*Continued on page 44*

*My Story: From Riding a Harley to a Catrike*  
*Continued from page 45*

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group when we first moved here. I needed them and they needed me. They were experiencing “burn out” and I had lots of energy, time, and new ideas to give. I have been the co-coordinator since August 2010.

After these 16 years of living with ataxia. My priorities are diet, exercise, support, education, encouragement, safety, and FAITH, which is huge for me. We can’t “stick our head in the sand and hope it goes away.” We all have gifts and talents. My message is: “USE THEM.” It’s not about what you’ve lost or can’t do, it’s about doing things differently.

SO YOU HAVE ATAXIA! You also have the National Ataxia Foundation, you have Facebook, chat rooms, support groups, and you have yearly conferences (Denver 2015). YOU ARE NOT ALONE. In today’s world of electronics and communication, it’s soooooo easy to connect. You can’t and shouldn’t be alone, you need people.

I saved the best for last, I am not sure if you

know about “Ride Ataxia” and Kyle Bryant. Through the Ataxian Athletic Incentive (AAI) grant program, Ride Ataxia has facilitated the funding and purchase of adaptive cycling equipment for aspiring Ataxian Athletes so they may start their personal Ride Ataxia adventure. I applied for an AAI grant last year. What a job, didn’t get picked. I was so disappointed. Saw Kyle in Las Vegas, he said “try again.” So I did, sending in all my five letters from last year, plus five more (only needed two), with the application. I WAS PICKED! I am so excited! Think when Kyle called, I may have hurt his ear drum with my screams for joy. Riding my Catrike is so cool, it gives me new energy (like I needed that), I feel (almost) normal, and I feel free and more empowered.

I may or may not ride in a race, but I’ll ride it A LOT in my community, ATAXIA AWARENESS here I come. So from a tricycle as a youth ... to getting married and riding a Harley Davidson out of the church ... back to riding an adaptive trike by Catrike.

It’s not about you or me, it’s about HELPING FIND A CURE. RIDE-ON! ❖

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## Can’t Find the Reset Button!

*Submitted by Jason Wolfer*

I found myself at a place the other day where I was thinking about all the gizmos, gadgets, and high tech things that have become a part of my life. To be more specific, I was pondering on all the times that a said piece of tech, one in which I had come to rely on, would not turn on or function correctly. This is a phenomenon that seems to be tied directly to Murphy’s Law as it is always seeming to happen at the most inopportune time. I was imaging how nice it would be to be able to schedule these break-downs in advance, since we all know that these things are inevitable. If a piece of equipment, say, like your smart phone, would just be up front with you

when you set it up for the first time. It would be a very helpful feature if it would tell you beforehand that after the first week, after you have gotten it all set-up the way you like it, with all the applications installed that you like to use and arranged in a pleasing way, that it was going to experience some kind of glitch, resulting in the need to do a re-set and the loss of your customized set-up. Being forewarned would be very helpful. Just think about how handy it would be if you knew beforehand that your tech would fail on a certain day, at a specific time. You would be better prepared, probably even have a plan to deal with or fix the issue. ❖

# Give It Up – Driving

*Submitted by Pete Meyerhoff*

One of the earliest signs of my ataxia involved driving. I had just returned from winning a set of tennis against an old (we were the same age) adversary. I felt pretty frisky. I was in my driveway. The garage door opener did its thing. I timed it perfectly. I was in the garage and all I had to do is stop. Disaster! I stepped on the gas pedal instead of the brake. Total confusion, as I blasted through the rear wall of the garage. I was lucky that the roof didn't come down on me.

Moving the right foot from the gas pedal to the brake pedal is a routine maneuver that car drivers perform flawlessly thousands of times. But watch out if you have ataxia. I don't know whether I can blame this entirely on early ataxia symptoms. I like to, because I had established a reputation as a volunteer driving instructor of 25 or so students.

It cost a couple of thousand dollars to fix the garage.

Fast forward, a couple of years later. I had already been diagnosed with Sporadic Ataxia. It was early in the morning when I tried to park at

the Post Office. I was alone in the car. Same problem, I drove too fast pulling into the parking spot. I stomped on the gas pedal instead of the brake. I narrowly missed a Post Office wall and a car parked next to me. No one saw the crazy maneuver, but I decided right there and then to give up driving.

It is not an easy decision. So much depends on having a car. Luckily, my wife drives. I help only with street directions and traffic situations. As long as manual coordination is not required, I am still useful.

Moral of my story: "When it's time, GIVE IT UP!"

*pmeyerhoff@comcast.net* ❖

## Correction

In the transcribed version of my presentation given at the 2014 Annual Membership Meeting that was printed in the original *Generations* Fall 2014 issue, I apologize if I inadvertently implied that Dr. Fogel was anything other than fully supportive of the translational research that he and so many other clinician researchers are actively engaged in to find disease-modifying therapies for ataxia. He is truly a leader of the next generation of doctors who will solve these challenges.

*Dr. Susan Perlman*

## Study Participants Needed in Pittsburgh

A research team affiliated with Carnegie Mellon University and the University of Pittsburgh is looking for participants for a study investigating the role of the cerebellum in auditory and speech learning.

The study will take 1-2 hours, and primarily involve computer-based tasks involving auditory and visual stimulus materials. Participants must be located within 180 miles of Pittsburgh, 18 years or older, and able to hear words spoken at a typical conversational level.

Interested participants should call Corrine Durisko, Study Coordinator, at (412) 624-7475 or [cgaglia@pitt.edu](mailto:cgaglia@pitt.edu). The testing location is flexible and will be determined based on the preference of each study participant.

# Chapter and Support Group News From Around the Country

## Mississippi Chapter

Submitted by Camille Daglio

The Mississippi Chapter held our annual picnic on Sunday, September 7 at the home of Susan and Peter Hanks. Chef Peter Hanks provided hamburgers cooked over a flaming grill with all the fixings, including desserts.



Members of the Mississippi Chapter at their annual picnic

A short meeting was held after lunch to discuss our fundraising project for 2014. It was decided to raffle off an iPad Air with the drawing to be held in November. After the meeting, we continued the afternoon visiting with old and new members in our group while enjoying the view of the golf course. We had 19 people in attendance.

## Chesapeake Chapter Meeting

Submitted by Carolyn Davis

A meeting of the Chesapeake Chapter was held in Virginia the morning of October 18. It was the first ataxia event half the participants had ever attended. Discussion centered on NAF

priorities, such as the Annual Ataxia Research Drive, CoRDS Patient Registry, and the Annual Membership Meeting. We looked at tools and information available on NAF's website, and skills and resources were shared among those in the group. Topics were suggested for future meetings, including ones to be scheduled in January and April. There was also enthusiasm to organize a Walk n' Roll for Ataxia in 2015.

**Charity Fairs** – With the 2014 Combined Federal Campaign in full swing, NAF has been invited to attend kick-off events at various federal workplaces. Glenn and Carolyn Davis manned exhibits at the Fort A.P. Hill and Rivanna Station charity fairs this fall. There is a variable range of employee participation in these fairs, but it is a great opportunity to raise awareness about ataxia and encourage support of charitable causes, including our own. There are now at least

60 additional people in Virginia who have heard about ataxia.

**Movement Disorder Symposium** – Johns Hopkins held a Movement Disorder Symposium on November 8. They have held this event in the past for the Parkinson's patient community but this year opened it to all movement disorders. The morning sessions featured presentations on brain pathology, genetics, and neuroplasticity, as well as panel presentations on patient advocacy in research and how to manage a movement disorder. Participants were able to attend two of the nine breakout sessions in the afternoon.

Networking lunches organized around the various disease groups allowed for the ataxia ►►

community to interact during that hour and to ask questions of Dr. Liana Rosenthal, who is with the Ataxia Center at Johns Hopkins, and Dr. Joe Savitt, who is with the Parkinson’s and Movement Disorders Center of Maryland. About 40 of the symposium participants attended the ataxia lunch.

**NINDS Nonprofit Forum** – “Progress Through Partnership” was the theme of the 2014 Nonprofit Forum of the National Institute of Neurological Disorders and Stroke, one of 27 Institutes and Centers at the National Institutes of Health in Bethesda, MD. This annual forum provides an opportunity for advocates in the nonprofit community to have a dialog with each other and with the researchers and program directors at NIH. The program was held on the NIH campus September 23-24.

As the theme suggests, there was a great deal of emphasis on patients as partners in research, not just subjects. Patients and patient groups should be involved in all phases of research, including up front, to make sure the right questions are asked and the research matches what the patients need and want.

The National Center for Advancing Translational Sciences at NIH, established in December 2011, is tasked with bringing more treatments to more patients more efficiently. Of the several thousand genetic diseases, only about 500 currently have treatments. In general it takes 14 to 17 years and two billion dollars or more to

develop a treatment – with a 95% failure rate along the way. NCATS facilitates and supports collaboration among research organizations, government agencies, educational institutions, industry, and patient groups with the goal of bringing new treatments and cures to patients more quickly.

Ataxia was represented in the planning and presentation of the Forum by Ron Bartek, President of the Friedreich’s Ataxia Research Alliance, and Cynthia Rothblum-Oviatt, Science Coordinator for the A-T Children’s Project. Attending from the Chesapeake Chapter were Carolyn Davis and Jenean McKay.

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**Central PA Ataxia Support Group**

*Submitted by Chris Rakshys*

We had a few new faces at our fall meeting on Saturday, October 25. Our guest speaker, Dr. J. Gabriel Hou (aka Dr. Gabe) a local neurologist from Lehigh Valley Neurology, gave a presentation that focused on different gait disorders. He incorporated very interesting YouTube videos of the different types – neurologically related: Parkinsonian, ataxic (cerebellar), diplegic, scissoring, to name a few – so that we got a sense of what each one looks like. It was very fascinating!

After the presentation, we had time to discuss the Boscov’s Friends Helping Friends fundraiser

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**Members of the Central PA Ataxia Support Group**

Chapter and Support Group News  
Continued from page 49

event that was spearheaded by Mike Cammer. Many thanks to the Schmidts, the Leaders and Joan Govan for their help in raising over \$500 which will be given to NAF. There will be no winter meeting but we look forward to seeing everyone in the spring.

**Arizona Ataxia Support Group**

Submitted by Angela Li

What a busy summer! The Arizona Ataxia Support Group had many good times. We had a pool party and gym outing at SpoFit, a completely accessible fitness and recreation center geared towards people with all types of abilities. Our summer meeting was held in August with a great turnout and knowledgeable speakers. On September 6, we organized a car wash fundraiser held at East Valley Auto in Mesa.

The AASG enjoyed delicious food after an outing in October to see a performance by the Chandler Symphony Orchestra. We enjoyed pieces with the title “From Russia ... with Melody.”

If you would like to join us for events or be added to our email list please contact Angela at [angelali1010@gmail.com](mailto:angelali1010@gmail.com) or (847) 505-4325 or Mary at [mary11115@msn.com](mailto:mary11115@msn.com) or (480) 212-6425. Join our Facebook group: Arizona Ataxia Support Group.

**Northern California Ataxia Support Group**

Submitted by Alan Acacia

Twenty-five people attended our quarterly meeting in October, including some new members. The meeting was successful on several different levels.

Our “Living with Ataxia” discussion group talked about how we can lead rewarding lives even though we have ataxia. There was one group for women with ataxia, one for men, and a third for family, friends and other caretakers. It was a special time to talk with one another about the emotional and practical realities of ataxia, the highs and lows, and how we manage to survive. Each of the smaller groups reaffirmed how meaningful personal discussion is.

The formation of local area groups is moving forward since 40 percent of our members live over a 100 miles (round-trip) from our meetings. By our October meeting, a number of members from various locations had contacted our local group coordinator. Several more people signed up at the meeting. If you are interested in helping create local groups, contact Shirley Hanks at [shirley@hanks.com](mailto:shirley@hanks.com).

We have formed a group to explore using Facebook and other social media as a way for people to discover and contact the support group. If you have an interest in assisting this effort, contact Alan Acacia at [ace@cds1.net](mailto:ace@cds1.net).

Our newsletter now has a column called ►►



Members of the Northern California Ataxia Support Group

“Recent Questions.” The September issue answered a question about getting a walker from Medicare. Future issues will answer similar inquiries on topics from neurology to nutrition, physical therapy to financial planning. Members can contact Alan concerning any issues they would like to see addressed in the newsletter.



**The Greater Houston Ataxia Support Group**

There is no reason to suffer ataxia in isolation. We invite NAF members to join our community, either by receiving our newsletter, or by attending our meetings. We hope this report will lead you to check us out.

area. Many of those professionals expressed interest in attending and speaking at a support group meeting in the near future.

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**Central Massachusetts Ataxia Support Group**

*Submitted by John Mauro*

We had a packed summer with many events offered to the New England Ataxia groups. We organized a fun night of painting that raised \$200 towards our Walk n’ Roll. We offered a free day of adaptive golf and laser tag with pizza and ice cream for all to finish the day.

We took part in the second Abilities Expo at the Boston Convention Center. We met 25 people with ataxia that did not know about our support groups and gave them knowledge about NAF as a place to go for info and resources. We also had the opportunity to network with other professionals who offer useful services in the

.....

**Atlanta Ataxia Support Group**

*Submitted by Dave, Greg and Lealan*

We had a great turnout for our November meeting. One member, Paul Aust, had attended a Department of Behavior Health regional meeting and learned about the Georgia Crisis line. Donna Fisher, a new member, talked about Rare Disease Day. Dr. “Chip” Wilmot discussed several trials that are in the works.

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**Denver Ataxia Support Group**

*Submitted Patricia Smith-Hysong and Charlotte DePew*

Our regular quarterly group meeting on October 18 had a delicious potluck lunch at the Swedish Medical Center, great socialization and

*Continued on page 52*



**Members of the Atlanta Ataxia Support Group at their November meeting**

Chapter and Support Group News  
Continued from page 51

a speaker who held everyone’s attention.

The speaker was Mr. Richard Vincent, a lawyer who specializes in legal elder and disability issues. He covered many vital topics for all ages and disability states to include wills, powers of attorney and protecting assets. Medicaid qualification was very interesting in learning that not all advisors are fully aware of who may qualify to include government advisors. The information was almost overwhelming but his examples made it realistic and understandable. Excellent informational handouts and brochures reinforced his message. Everyone attending felt it was a most valuable and informative speaker.

Several volunteered to help with the 2015 AMM event at the downtown Sheraton.

The Fifth Annual Denver RWnR will be September 13, 2015 at Denver City Park at 9 a.m. At our October support group meeting, a call went out to members to join the planning committee for the 2015 event. Like the wonderful folks they are, several responded who are willing to work together and put on another great event.

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**Tri-State Ataxia Support Group**

*Submitted by Kathy Gingerelli*

We were a very small group at our September meeting but we still had a couple of new members and filled the night with interesting conversation.

Dr. Kuo spoke about studies being done to track the disease progression using iPads and other tools. ❖

Study ID: HUM00041414 IRB: IRBMED Date Approved: 7/10/2014 Expiration Date: 7/9/2015  
HUM00041414 Approved On: 07/20/2010 Project Approval Expires On: 05/19/2011  
IRB: «IRB»

**Genes in Inherited Neurologic Disorders**

Dr. Burmeister at the University of Michigan is recruiting individuals with ataxia for the research study Genes in Inherited Neurological Disorders. This study is designed to find what and how changes in the genetic material (DNA) cause inherited neurologic disorders, such as ataxia (incoordination). We are recruiting individuals with inherited ataxia, their affected relatives (such as a brother or sister, a cousin, or a parent), and their unaffected family members, where possible. We are currently recruiting persons with an unknown form of ataxia, so at least one affected in your family should first be tested for known causes of ataxia and found to be negative on such a test.

In this study, you will be asked to provide information about your symptoms and diagnosis, if other relatives are similarly affected, and about your ethnic background. You will also be asked to donate a blood sample (up to 8 teaspoons of blood) for DNA testing and related experiments. The blood sample can be drawn by your local physician; you will not need to travel to the University of Michigan.

More detailed information about this study is available in the consent forms: Affected Subjects Consent, Unaffected Relatives Consent.

If you would like further information or are interested in participating, please contact:  
Dr. Margit Burmeister, PhD

Molecular & Behavioral Neuroscience Institute  
University of Michigan,  
5063 BSRB, 109 Zina Pitcher Place;  
Ann Arbor MI 48109-2200  
Telephone: (734) 6472186; email: [margit@umich.edu](mailto:margit@umich.edu)

# NAF Directory of Chapters, Support Groups 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](mailto:lori@ataxia.org) or (763) 553-0020.

*The use of these names and contact information for any purpose other than requesting information regarding NAF or joining a chapter or support group is strictly prohibited. Thank you.*

## Social Networks

### NAF BULLETIN BOARD

**Moderator – Atilla and Bear**

[www.ataxia.org/forum/toast.asp](http://www.ataxia.org/forum/toast.asp)

### NAF CHAT ROOM

**Moderator – Della** ([ddpokernut@yahoo.com](mailto:ddpokernut@yahoo.com))

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### NAF FACEBOOK GROUP

[www.facebook.com/group.php?gid=93226257641](http://www.facebook.com/group.php?gid=93226257641)

### NAF FACEBOOK FANS

[www.facebook.com/lshogren?ref=profile#!/pages/National-Ataxia-Foundation/227766109304](http://www.facebook.com/lshogren?ref=profile#!/pages/National-Ataxia-Foundation/227766109304)

### NAF YOUTUBE CHANNEL

[www.youtube.com/user/NatlAtaxiaFound?feature=mhum](http://www.youtube.com/user/NatlAtaxiaFound?feature=mhum)

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(509) 482-8501  
E-mail: [linda4727@hotmail.com](mailto:linda4727@hotmail.com)  
[www.ataxia.org/chapters/Spokane/default.aspx](http://www.ataxia.org/chapters/Spokane/default.aspx)

– WISCONSIN –

**WISCONSIN SUPPORT GROUP LEADER**

**Jenny Mathison** – Madison, WI

(608) 285-5285  
E-mail: [mjmathison@att.net](mailto:mjmathison@att.net)  
[www.ataxia.org/chapters/Wisconsin/default.aspx](http://www.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](mailto:prentis.clairmont@gmail.com) **Facebook Group:**  
<https://www.facebook.com/groups/1468963499991380/>  
[www.ataxia.org/chapters/Ottawa/default.aspx](http://www.ataxia.org/chapters/Ottawa/default.aspx)

**AMBASSADOR**

**Terry Greenwood** – Winnipeg, Manitoba  
(204) 488-4155  
E-mail: [wpgmagic@gmail.com](mailto:wpgmagic@gmail.com)  
[www.ataxia.org/chapters/TerryGreenwood/default.aspx](http://www.ataxia.org/chapters/TerryGreenwood/default.aspx)

– INDIA –

**INDIA SUPPORT GROUP LEADER (SAMAG)**

**Chandu Prasad George, CH,**  
Hyderabad, Secunderabad, India  
Mobile: 0091-9949019410 +9885199918  
E-mail: [sam\\_ataxiaindia@yahoo.com](mailto:sam_ataxiaindia@yahoo.com) or  
[samag.india@gmail.com](mailto:samag.india@gmail.com)

[www.ataxia.org/chapters/Chandu/default.aspx](http://www.ataxia.org/chapters/Chandu/default.aspx)

Please visit our website: [www.ataxia.in](http://www.ataxia.in)

<http://seekamiracleataxiagroupindia-samagindia.webs.com> ❖

## Studies of Brain and Behavior in Individuals with Premutations of the Fragile X gene (FMR1)

We currently are seeking individuals who carry a premutation allele of the Fragile X gene, FMR1. Some individuals with this premutation allele may show signs of Fragile X-associated Tremor/Ataxia Syndrome (FXTAS) which is characterized by motor and cognitive issues. This study aims to better understand these issues and their bases in the brain in individuals with FXTAS.

Eligible participants will be asked to complete the following:

- questions about family medical history and behavior
- tests of thinking abilities
- testing of sensory processing and movement control
- brain activity recording and imaging
- genetics testing

Testing will be conducted at the Center for Autism and Developmental Disabilities at UT Southwestern. Participants will be compensated for their time.

For more information, please contact us by phone at **214-648-5155** or by e-mail at **[fragilex@utsouthwestern.edu](mailto:fragilex@utsouthwestern.edu)**

# Calendar of Events

The most current event information is available on the NAF website, [www.ataxia.org](http://www.ataxia.org).

## SUPPORT GROUP MEETINGS

– **Saturday, December 20, 2014** –

### Twin Cities Ataxia Support 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](mailto:schultz.lenore@yahoo.com).

– **Saturday, January 3, 2015** –

### New Hampshire

#### Ataxia Support Group Lunch Meeting

**Time:** 11:30 a.m.

**Location:** Fratello's Italian Grille, 155 Dow St., Manchester, NH 03101

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

– **Thursday, January 8, 2015** –

### Tri-State Ataxia Support Group Potluck 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 10003

**Details:** For more information contact Denise Mitchell at [markmeghan2@gmail.com](mailto:markmeghan2@gmail.com) or Kathy Gingerelli at [kgingerelli@msn.com](mailto:kgingerelli@msn.com).

– **Saturday, January 10, 2015** –

### North Texas Ataxia Support Group Meeting

**Time:** 10 a.m. – noon

**Location:** Las Colinas Cancer Center, 7415 Las Colinas Blvd., Irving TX

**Details:** For more information contact David Henry at [cheve11e@sbcglobal.net](mailto:cheve11e@sbcglobal.net).

### Northern California

#### Ataxia Support Group Meeting

**Time:** 11:30 a.m. – 2 p.m.

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

**Details:** For more information or to RSVP contact Joanne Loveland at (952) 323-6895 or [joanne\\_loveland@gmail.com](mailto:joanne_loveland@gmail.com).

### Positive People in PA

#### Ataxia Support Group Meeting

**Time:** 10 – 11:30 a.m.

**Location:** Mercy Suburban Hospital, 2nd Floor Walk-up Room

**Details:** Lunch follows at Applebee's across the street. RSVP is required by Thursday prior to the meeting. To RSVP or for more information contact Liz Nussear at (610) 272-1502 or at [lizout@aol.com](mailto:lizout@aol.com).

### Tampa Bay Ataxia Support Group Meeting

**Time:** 12:30 – 3 p.m.

**Location:** Morsani Center, 13330 USF Laurel Dr. #1013, Tampa, FL

**Details:** For more information contact Nygel Lenz at (727) 451-9165 or [nygellenz@gmail.com](mailto:nygellenz@gmail.com).

– **Wednesday, January 14, 2015** –

### Willamette Valley Ataxia Support Group Meeting

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

**Location:** Albany General Hospital, 1046 Sixth Ave. SW, Albany, OR 97321

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

– **Saturday, January 17, 2015** –

### Denver Area Ataxia Support Group Meeting

**Time:** 1 – 4 p.m.

**Location:** Swedish Medical Center, Spruce C Meeting Room, Second Floor, 501 E. Hampden Ave., Englewood, CO 80113

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

### Twin Cities Ataxia Support 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](mailto:schultz.lenore@yahoo.com).

– **Saturday, January 24, 2015** –

### New Hampshire Ataxia Support Group Meeting

**Time:** 10 – noon

**Location:** Hannaford Market, 5 Colby Ct., ►►

Bedford, NH 03110

**Details:** For more information or to RSVP contact Jill Porter at (603) 626-0129 or [jilleporter@com-cast.net](mailto:jilleporter@com-cast.net).

– **Saturday, January 31, 2015** –

**Los Angeles Ataxia Support Group Meeting**

**Time:** 1 – 3 p.m.

**Location:** Uptown Whittier Senior Center, 13225 Walnut St., Whittier, CA 90605.

**Details:** For more information contact Lora Morn at (310) 664-8808 or [loramorn@gmail.com](mailto:loramorn@gmail.com).

– **Tuesday, February 10, 2015** –

**Utah Ataxia Support Group Meeting**

**Time:** 6 p.m.

**Location:** John A. Moran Eye Center, Salt Lake City, UT

**Details:** For additional information contact Lisa Ord at (801) 585-6635 or [lisa.ord@hsc.utah.edu](mailto:lisa.ord@hsc.utah.edu).

– **Wednesday, February 11, 2015** –

**Willamette Valley Ataxia Support Group Meeting**

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

**Location:** Albany General Hospital, 1046 Sixth Ave. SW, Albany, OR 97321

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

– **Saturday, February 14, 2015** –

**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:** Las Colinas Cancer Center, 7415 Las Colinas Blvd., Irving TX

**Details:** For more information contact David Henry at [cheve11e@sbcglobal.net](mailto:cheve11e@sbcglobal.net).

– **Sunday, February 15, 2015** –

**Mississippi Chapter Meeting**

**Time:** 2 p.m.

**Location:** South Mississippi Electric Power Assn., 7037 Highway 49, Hattiesburg, MS 39402

**Details:** Date is tentative. For more information contact Camille Daglio at [daglio1@bellsouth.net](mailto:daglio1@bellsouth.net).

– **Saturday, February 21, 2015** –

**Greater Atlanta Ataxia Support Group Meeting**

**Time:** 1 p.m.

**Location:** Emory Center for Rehabilitation Medicine, 1441 Clifton Road NE, Atlanta, GA 30322

**Details:** For more information call (404) 822-7451 or [atlantaataxia@gmail.com](mailto:atlantaataxia@gmail.com).

**Orange County Ataxia Support Group Meeting**

**Time:** 2 – 4 p.m. on the third Saturday of every other month.

**Location:** Orange Coast Memorial Medical Center, 9900 Talbert Ave., Foundation Valley, CA 92708

**Details:** For more information contact Daniel Navar at (323) 788-7751 or [danieln27@gmail.com](mailto:danieln27@gmail.com) or Cindy DeMint at (714) 970-1191 or [cindyocataxia@gmail.com](mailto:cindyocataxia@gmail.com).

**Twin Cities Ataxia Support 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](mailto:schultz.lenore@yahoo.com).

– **Wednesday, March 11, 2015** –

**Willamette Valley Ataxia Support Group Meeting**

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

**Location:** Albany General Hospital, 1046 Sixth Ave. SW, Albany, OR 97321

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

– **Thursday, March 12, 2015** –

**Tri-State Ataxia Support Group Potluck 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 10003

**Details:** For more information contact Denise Mitchell at [markmeghan2@gmail.com](mailto:markmeghan2@gmail.com) or Kathy Gingerelli at [kgingerelli@msn.com](mailto:kgingerelli@msn.com).

– **Saturday, March 14, 2015** –

**North Texas Ataxia Support Group Meeting**

**Time:** 10 a.m. – noon

**Location:** Las Colinas Cancer Center, 7415 Las Colinas Blvd., Irving TX

*Calendar of Events**Continued from page 59*

**Details:** For more information contact David Henry at [cheve11e@sbcglobal.net](mailto:cheve11e@sbcglobal.net).

**Positive People in PA****Ataxia Support Group Meeting**

**Time:** 10 – 11:30 a.m.

**Location:** Mercy Suburban Hospital, 2nd Floor Walk-up Room

**Details:** Lunch follows at Applebee's across the street. RSVP is required by Thursday prior to the meeting. To RSVP or for more information contact Liz Nussear at (610) 272-1502 or at [lizout@aol.com](mailto:lizout@aol.com).

– **Sunday, March 15, 2015** –

**Chi-town Ataxia Friendship Group Meeting**

**Time:** 1 p.m. on the third Sunday of odd-numbered months.

**Location:** Good Samaritan Hospital, 3815 Highland Ave., Downers Grove, IL 60515

**Details:** For additional information contact Jonas Cepkauskas at (708) 381-5555 or [jonas@chitownataxia.org](mailto:jonas@chitownataxia.org).

– **Saturday, March 21, 2015** –

**Twin Cities Ataxia Support 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](mailto:schultz.lenore@yahoo.com).

– **Saturday, March 28, 2015** –

**Happy Hoosiers Ataxia Support Group Meeting**

**Time:** 10:30 a.m.

**Location:** Cracker Barrel, Gas City, IN

**Details:** For additional information contact Cheri Bearman at (260) 452-6231 or [cheribearman@gmail.com](mailto:cheribearman@gmail.com).

**Mid-Atlantic Ataxia Support Group Meeting**

**Time:** Noon – 2 p.m.

**Location:** Brace Fellowship Church, 9505 Deereco Rd., Timonium, MD 21093

**Details:** For more information contact Bailey Vernon at (410) 616-2811 or [bvernon1@jhmi.edu](mailto:bvernon1@jhmi.edu).

**New Hampshire Ataxia Support Group Meeting**

**Time:** 10 – noon

**Location:** Hannaford Market, 5 Colby Ct., Bedford, NH 03110

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

– **Wednesday, April 8, 2015** –

**Willamette Valley Ataxia Support Group Meeting**

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

**Location:** Albany General Hospital, 1046 Sixth Ave. SW, Albany, OR 97321

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

– **Saturday, April 11, 2015** –

**Kansas City Ataxia Support Group Meeting**

## Remembering NAF in Your Will

There have been a number of true 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 research and provide meaningful programs and services to ataxia families. It is because of these quiet heroes that many research studies and programs have been funded.

We are truly thankful for their humanitarian and compassionate acts and we will be eternally grateful for the impact they have made in helping ataxia families. Their legacy lives on in the hope they have given ataxia families.

Perhaps this is the time to consider adding the National Ataxia Foundation in your will.

**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. – noon

**Location:** Las Colinas Cancer Center, 7415 Las Colinas Blvd., Irving TX

**Details:** For more information contact David Henry at [cheve11e@sbcglobal.net](mailto:cheve11e@sbcglobal.net).

#### **Northern California**

##### **Ataxia Support Group Meeting**

**Time:** 11:30 a.m. – 2 p.m.

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

**Details:** For more information or to RSVP contact Joanne Loveland at (952) 323-6895 or [joanne\\_loveland@gmail.com](mailto:joanne_loveland@gmail.com).

– **Tuesday, April 14, 2015** –

#### **Utah Ataxia Support Group Meeting**

**Time:** 6 p.m.

**Location:** John A. Moran Eye Center, Salt Lake City, UT

**Details:** For additional information contact Lisa Ord at (801) 585-6635 or [lisa.ord@hsc.utah.edu](mailto:lisa.ord@hsc.utah.edu).

– **Saturday, April 18, 2015** –

#### **Denver Area Ataxia Support Group Meeting**

**Time:** 1 – 4 p.m.

**Location:** Swedish Medical Center, Spruce C Meeting Room, Second Floor, 501 E. Hampden Ave., Englewood, CO 80113

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

#### **Orange County Ataxia Support Group Meeting**

**Time:** 2 – 4 p.m. on the third Saturday of every other month.

**Location:** Orange Coast Memorial Medical Center, 9900 Talbert Ave., Foundation Valley, CA 92708

**Details:** For more information contact Daniel Navar at (323) 788-7751 or [danieln27@gmail.com](mailto:danieln27@gmail.com) or Cindy DeMint at (714) 970-1191 or [cindyoc\\_ataxia@gmail.com](mailto:cindyoc_ataxia@gmail.com).

#### **Tampa Bay Ataxia Support Group Meeting**

**Time:** 12:30 – 3 p.m.

**Location:** Morsani Center, 13330 USF Laurel Dr. #1013, Tampa, FL

**Details:** For more information contact Nygel Lenz at (727) 451-9165 or [nygellenz@gmail.com](mailto:nygellenz@gmail.com).

#### **Twin Cities Ataxia Support 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](mailto:schultz.lenore@yahoo.com).

– **Saturday, May 2, 2015** –

#### **Greater Atlanta Ataxia Support Group Meeting**

**Time:** 1 p.m.

**Location:** Emory Center for Rehabilitation Medicine, 1441 Clifton Road NE, Atlanta, GA 30322

**Details:** For more information call (404) 822-7451 or [atlantaataxia@gmail.com](mailto:atlantaataxia@gmail.com).

#### **Boston Ataxia Support Group Meeting**

**Time:** Noon – 2 p.m.

**Location:** Lahey Clinic, 41 Mall Rd., Burlington, MA

**Details:** For more information contact Lanie Cantor at [laniecantor@gmail.com](mailto:laniecantor@gmail.com) or Donna Gorzela at (978) 490-9552.

– **Saturday, May 9, 2015** –

#### **North Texas Ataxia Support Group Meeting**

**Time:** 10 a.m. – noon

**Location:** Las Colinas Cancer Center, 7415 Las Colinas Blvd., Irving TX

**Details:** For more information contact David Henry at [cheve11e@sbcglobal.net](mailto:cheve11e@sbcglobal.net).

#### **Positive People in PA**

##### **Ataxia Support Group Meeting**

**Time:** 10 – 11:30 a.m.

**Location:** Mercy Suburban Hospital, 2nd Floor Walk-up Room

**Details:** Lunch follows at Applebee's across the street. RSVP is required by Thursday prior to the meeting. To RSVP or for more information contact Liz Nussear at (610) 272-1502 or at [lizout@aol.com](mailto:lizout@aol.com).

– **Wednesday, May 13, 2015** –

#### **Willamette Valley Ataxia Support Group Meeting**

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

**Location:** Albany General Hospital, 1046 Sixth Ave. SW, Albany, OR 97321

**Details:** For more information contact Jason Wolfer

*Calendar of Events*  
Continued from page 61

at (503) 502-2633 or [wolfer.jason@gmail.com](mailto:wolfer.jason@gmail.com).

– **Thursday, May 14, 2015** –

**Tri-State Ataxia Support Group Potluck 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 10003

**Details:** For more information contact Denise Mitchell at [markmeghan2@gmail.com](mailto:markmeghan2@gmail.com) or Kathy Gingerelli at [kgingerelli@msn.com](mailto:kgingerelli@msn.com).

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

– **Saturday, February 28, 2015** –

**Rare Disease Day**

**Details:** Each year, Rare Disease Day is observed on the last day of February. 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](http://www.rarediseaseday.org).

– **Friday, March 6-8, 2015** –

**58th Annual Membership Meeting (AMM)**

**Time:** Friday 9 a.m. – 5 p.m., Saturday 8:30 a.m. – 5 p.m., Sunday 9 a.m. – 12:30 p.m.

**Location:** Sheraton Downtown Denver Hotel – Denver, CO

**Details:** Registration fee required to attend. See page 34 for more information or visit <http://ataxia.org/events/annual-meeting2015.aspx>.

– **Friday, March 6-8, 2015** –

**LA Abilities Expo**

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

**Location:** Los Angeles Convention Center, West Hall A

**Details:** Admission is free. [www.abilitiesexpo.com/losangeles/](http://www.abilitiesexpo.com/losangeles/)

– **Friday, May 1-3, 2015** –

**NY Metro Abilities Expo**

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

**Location:** New Jersey Convention & Expo Center, Edison, NJ

**Details:** Admission is free. [www.abilitiesexpo.com/newyork/](http://www.abilitiesexpo.com/newyork/) ❖

## Measuring Ataxia in Children

### *Children with disorders of/damage to the cerebellum wanted for a study of motor control at Massachusetts General Hospital*

Researchers are seeking children and adolescents below 18 years of age with disorders of/damage to the cerebellum (the “small brain”) to participate in a study to develop a brief clinical test battery to rate the severity of cerebellar motor ataxia in children.

Participation would involve one visit to the Massachusetts General Hospital (MGH) lasting up to 40 minutes. Participants will be asked to perform a battery of tests of motor control. There is no medication and no imaging involved.

Participants will receive an ice cream gift certificate as an acknowledgement for participation. We will provide free parking.

Your participation in our study is of great importance and will lead to the development of

a clinical rating scale for cerebellar motor ataxia in children with cerebellar disease.

Children may be eligible to participate in this study if they meet the following criteria:

- Below 18.0 years of age
- Have a disorder of/damage to the cerebellum (i.e. from damage to the cerebellum due to tumors, hemorrhage, stroke, ischemia, infection, pure and complex hereditary ataxia, autoimmune disease, and other disorders that affect the cerebellum)
- Are able to come to one study visit lasting approximately 20-40 minutes

If you are interested in enrolling in this trial, please contact Dr. Franziska Hoche, MD, at [fhoche@partners.org](mailto:fhoche@partners.org) or (617) 726-3669.

# 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 August through October 2014. 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.

Paul Aiello	Fred Donnelly	Yvonne Johnson	Leslie Miles	Robert Schriefer Jr.
David Alessi	Olivia Douglass	Judy Kaiser	Keith Mizutani	Cheryl Serge
Mrs. Robert Allen	Katherine	Marvin Kamen	Ellen Moetsch	Derek Semler
Crystal Allsopp	Dzieszkowski	Lisa Kelso	Minnie Molini	Marion Shields
Leslie August	Richard Edwards	Carole Keniley	Jack Moore	Alaska Shiers
James Ball	Lorraine Emanuel	Noah Keniley	Kai Moreland	Veronica Silva
Jeffery Barberi	Candace Enos	Aya Kitō	Kathryn Morgan	Jim Skok
Michelle Baumgart	Louise Estabrook	Minnie Knutson	Jennifer Mueller	Kathryn Smith
Cheri Bearman	Trinity Falk	Jordan Kohl	Leroy Mueller MD	Jeannie Smith-Ball
Kay Bell	Dixon Faucette	Kotosky Family	Darneal Myers	Kathryn Smithers
Cheryl Belsley	Millie Faucette	Kozan Family	Keri Naccarato	Lorenz Snell
Myrtle Bengard	Christopher Flores	Marcella Kukelhan	Betsy Newman	Terry Snider
Theresa Bent	Michelle Carr-Flores	Lacey Lajeunesse	Larry Nichols	Terry Snyder
Frances Berens	Olivia Fortino	Nathan Lanz	Mary Norman-Coppi	Stafford Family
Sandee Berst	Madelyn Frederick	Lealan LaRoche	John Norton	Linda Steffan
Leota Bittner-Jensen	Albert Frei Sr	Michael Lawlor	Patrick Nugent	St. George Family
Joseph Black	Gregson Gann	Beth Lawson	Kelly Oistad	Susan Stinson
Betsy Brandt	James Garrett	Cheryl Lee	Olivia Omictin	Grandpa Strojny
Jackie Browning	Danae Gordon	Carter Levy	Donald Owens	Teresa Sundquist
Jim Browning	Dan Graham	Emily Levy	Paula Partilla	John Surabian
Peggy	Jean Green	Jim Levy	Willard Peabody	Kyle Swier
Brunnert-Taylor	Teresita Guerrero	Robin Levy	Maura Pederson	William Tait
Michael Cammer	Aaron Gulick	Jen Li	Terri Penk	Ernest Talarico Jr
Susan Chaffin	Bernice Habal	Violeta Lilley	Molly Perkis	Harold Taylor
Michael Chiu	Patricia Hamilton	Harlan Lindberg	Eric Peterson	Phillip Taylor
JoAnn Ciecierski	Sue Hammer	Rita Lobascio	Scott Pettengill	Sandy Taylor
Eugene Clark	Gary Hartsock	Michael Lundquist	Ikue Pollak	Kristina Travisano
Karen Cocquyt	Randolph	Susan Lyons	Sunny Prom	Patty Valiantis
Joseph Coffey	Hasegawa	James Mace	Bill Ramsey	Jacob Van Buren
Louis Coletti	Paul Heimann	Carly Magnuson	Charity Ranger	Rudy Van't Hoff
Roger Cooley	Joseph Henry	Lee Magnuson	Jim Richards	Ed Vodicka
Melinda Cromwell	Jeannie Hernandez	Patrick Marion	Sherri Richwine	Shirley Vodicka
Phyllis Crupper	Phyllis Hoekstra-	Pat Marlow	Elizabeth Riley	Alissa Walden
Russell Crystal	Meima	Lisa Marsh	Janet Riley	JoAnn Walsh
Ronesa Daniels	Johnny Hogan	Steve Marsh	Suzanne Rogers	Barry Washburn
Kennon Davis	Patricia Hogan	Dave Mason	Mary Romero	Leroy Wernsing
Page Davis	Krista Humes	Susan Mason	Eric Roselle	Susan West
Joe DeCrescenzo	Howard Hunnius	Massanova Family	Danya Roselle	David Westrick
Bernadette DeLuca	Jane Jaffe	Brent Masserant	Laura Rosenstein	Susan Wier
Homer Dennison	Larry Jaffe	Angelo Matrisciano	Donald Santa Croce	George Yasui
Charlotte DePew	Lisa Jaffe	Michael McCarthy	Santa Croce Family	Mark Yeater
Sandra DesRosiers	Rebecca Jarrell	Shelby McDonald	Edward	Jeffrey Yeater
Dawn Dizon	Steve Jennings	Meghan McKinney	Schlesinger	Emily Young
Stewart Donald	Pat Jensen	Carol Miles	Heather Schmidt	Jon Zilles





## National Ataxia Foundation

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(763) 553-0020

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### GIFT – HONOR – MEMORIAL

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

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

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

My contribution is:

In Memory    In Honor    Gift Membership

Name \_\_\_\_\_

Occasion \_\_\_\_\_

Send Acknowledgment Card to:

Name \_\_\_\_\_

Address \_\_\_\_\_

City/State/Zip \_\_\_\_\_

From:

Name \_\_\_\_\_

Address \_\_\_\_\_

City/State/Zip \_\_\_\_\_

**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](mailto: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](http://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 \_\_\_\_\_