

Generations

SPECIAL EXPANDED EDITION



_____ *The Official Publication of the National Ataxia Foundation*

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_____ *Volume 41, Number 4*

_____ *Winter 2013-14*

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

National Ataxia Foundation

57th Annual Membership Meeting

“Betting on Ataxia Research”

Las Vegas, Nevada – March 21-23, 2014

The 2014 Annual Meeting General Sessions will Educate, Inspire, and Inform

As in past annual meetings, the General Sessions for the 2014 National Ataxia Foundation Annual Membership Meeting, “Betting on Ataxia Research,” includes a distinguished group of speakers who will provide the most current research and clinical practices in the field of ataxia. The complete meeting agenda, listed on pages 19-24, includes some topics that are new to the meeting. Aspects of transitioning into

adult healthcare for youth and young adults with disabilities will address the challenges of adolescence related to development of autonomy and identity, and the expectations and demands of the adult healthcare system. The role of whole exome sequencing is a hot new topic for all hereditary diseases. How this will affect genetic testing for the ataxias will be discussed, as well as the various forms of acquired and idiopathic ataxias and MSA. In response to requests for information on what to expect as ataxia progresses, Dr. Susan Perlman, NAF’s Medical Director, will address that important subject. Another often requested topic will be included in this meeting’s agenda: suggestions on how to select a mobility device.


During the 2013 annual meeting in Detroit, meeting attendees were invited to participate in research studies administered by ataxia investigators from Harvard. The results of their research will be presented at this meeting, along with highlights of the 2014 Ataxia Investigators Meet-

Inside This Issue

- Highlights and photos from **International Ataxia Awareness Day** start on page 3
- **Annual Membership Meeting** information and registration forms begins on page 19
- **Humor and personal stories** are on pages 14-17, 38-39 and 41-42
- Part two of **Four Components of Physical Therapy** begins on page 36
- Get step-by-step instructions for enrolling in the **Ataxia Patient Registry** on page 51

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Generations is published by the National Ataxia Foundation, Inc., Minneapolis, MN.

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The deadline for the Spring issue of *Generations* is Friday, March 7, 2014.

Annual Membership Meeting
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ing. Many other sessions will be presented by world-leading ataxia experts at the 2014 Annual Membership Meeting.

Registered attendees at this annual meeting will have a special opportunity to meet leading ataxia investigators at a scientific poster session dedicated for patients and families. On Thursday, March 20 from 5:15-6:15 p.m., posters will

be available for viewing. Scientists will be present at their posters to answer questions about their ataxia research projects. All forms of ataxia will be represented at this poster session. If you are interested in attending this special event, be sure to schedule your travel plans to arrive in Las Vegas by early afternoon on Thursday.

The Annual Membership Meeting Planning Committee is excited about the quality of speakers who will be presenting at the 2014 annual meeting. ❖

Recognitions of International Ataxia Awareness Day

— September 25, 2013 —

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 and India.

Individuals raised awareness about ataxia and the activities raised more than \$200,000 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 International Ataxia Awareness Day, we honor those who are affected by ataxia, those who we have lost, their families, friends and caregivers.

IAAD Recaps

Fourth Annual Virtual Walk n' Roll

Individuals and groups participated in the Fourth Annual Virtual Walk n' Roll for ataxia. The Virtual Walk n' Roll this year raised \$3,064 as of November 12, thanks to the teams and individuals that supported them.

www.ataxia.org/walk/virtual. Top participants this year were Sunny (Sunaro) Prom (www.sunnyprom.com/sca3/), Carrie Henrichsen, and Michael Cammer, John and Chris Rakshys of the Central PA Ataxia Support Group.

Alabama Ataxia Support Group

Submitted by Becky Donnelly

Our group participated in the NAF Virtual Walk n' Roll in support of IAAD. Many thanks to Alan English for spearheading this activity for our group.

Denver Third Annual Run, Walk n' Roll

Submitted by Charlotte DePew

The Third Annual Denver Run, Walk n' Roll for Ataxia was held on Sunday, September 8 at Denver's beautiful City Park, home to the Denver Zoo and the Museum of Natural History and Science. The event was held in honor of a long-time sufferer of ataxia, Jim Lehr (1936-2012), whose family was present and gave

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International Ataxia Awareness Day

Continued from page 3

a loving testimonial.

The warm, sunny morning event was attended by over 230 participants and donations to date are \$40,000. This amount is much more than our goal and we are so thankful for the generosity of those who gave.

The event began with a yoga warm-up and a lovely rendition of the National Anthem sung by a young lady discovered by a committee member at a local high school musical. Along with the walkers and rollers, we had about 15-20 runners, one of which was an eight-year-old boy who completed the 5K!

Music, vendors, a NAF tattoo application booth, and socialization kept everyone entertained until the last of our runners, walkers, and rollers finished. Delicious frozen treats, such as gelato and ice cream cones, were a bigger hit than the bananas, bagels, and water. Since all bases were covered in the snack area, everyone was satisfied. To top off a great event, we drew winners, using their registration bib numbers, for some fabulous donated items such as gift cards, gift certificates, gift baskets, and services. We had a generous donation for \$500 worth of re-upholstering for which we held a silent auction and brought in \$750.

Everyone enjoyed the morning and the occasion seemed to have something for everyone. The 2014 RWnR will be held on Sunday, September 7, 2014. We have already booked the same venue at City Park and with a slight modification to the course. The 2014 course will accommodate a greater variety of distances, to include a metered 5K, all on flat black-top road.

Atlanta Third Annual Walk n' Roll

Submitted by Greg Rooks

In recognition of IAAD, the Greater Atlanta Ataxia Support Group held the Third Annual Atlanta Walk n' Roll for Ataxia on September 21, benefitting NAF. The event was held again



The Atlanta Third Annual Walk n' Roll for Ataxia raised over \$12,000.

this year at Shorty Howell Park in Duluth, GA. Our Walk n' Roll continues to grow a little each year. This year we had approximately 100 participants and seven teams. Our teams are starting to get competitive with each other and design their own team shirts to wear to the event. In total our Walk n' Roll raised over \$12,000. If you'd like to see how much fun we had, watch our video of the Walk n' Roll posted on YouTube at <http://youtu.be/Ijr7ylTNbsA>.

Minnesota Fourth Annual Walk, Stroll n' Roll

Submitted by Bill Sweeney

The Fourth Annual Minnesota Walk, Stroll n' Roll "happening" took place on September 14, raising over \$53,000 for NAF. Teams from throughout Minnesota – Duluth, Rochester, St. Cloud, and the Twin Cities – were greeted by sunshine and warm weather which kept the crowd of 350 comfortable and happy. The ►►



The Minnesota Fourth Annual Walk, Stroll n' Roll raised over \$53,000.

Walk was held in memory of Twin Cities Support Group members Denis Kelly, Bruce Bolinger, and Joe Cain – and we were honored to have many Kelly family members attend.

Drawings were held for a host of donated gifts, and, for the first time, MN Walk registrants were able to purchase raffle tickets for three grand prizes donated by supporters: a 40" television, a Michael Birwarer print and a Minnesota Vikings #28 jersey signed by NFL MVP Adrian Peterson. All registrants received a colorful NAF/MN Walk bandana which added to the festive nature of the MN Walk.

Michelle Nash gave an emotional talk about her family's experience with ataxia. Her mother, Barb Pogulis, and brother, Eric Pogulis, are afflicted with SCA-2 and she provided a very personal account of the challenges faced by an ataxia family. Char Martins, RN of the U of Minnesota Ataxia Clinic, updated the crowd about the diagnosis and treatments of ataxia, and Diane Hutter, RN of the University's Ataxia Research center, discussed current ataxia research efforts.

Loads of thanks to the organizing committee headed by Terry Sweeney, emcee Susie Jones, our speakers, NAF staff, the staff of the University of Minnesota, our many business sponsors who donated food and drawing gifts, and the nearly 500 business and individual donors who made this event a financial success!

We look forward to celebrating our Fifth Annual Walk in September 2014!

2013 MN Walk, Stroll n' Roll Team and Event pictures can be viewed on Dropbox at the following link: www.dropbox.com/sh/l3v7w18qtlftu3o/UcI79xih0p.

Detroit Fifth Annual Walk n' Roll

The Detroit Ataxia Support Group recognized IAAD by holding the Fifth Annual Walk n' Roll in William G. Milliken Park in downtown Detroit on Saturday, September 21.

A picnic was held immediately following the walk which also included a raffle. Almost \$2,500



The Detroit Fifth Annual Walk n' Roll raised nearly \$2,500.

was raised. Our friends and family walked and rolled with us.

Jacksonville Walk and Roll n' Bowl

Submitted by Mac Kelso

The Northeast Florida Ataxia Support Group met on Saturday, September 21 at Bowl America in Mandarin for the first Walk and Roll n' Bowl for IAAD. The event started at noon and the registration fee was \$10 at the door. We had over 60 signup. All participants who gave a \$20 donation to NAF received a free Walk and Roll n' Bowl t-shirt at the event. Mayor Alvin Brown of Jacksonville gave a written proclamation, declaring September 25 as Ataxia Awareness Month for Jacksonville. Our guest speaker, Guangbin Xia, MD, PhD, gave an excellent speech on stem cell research advances and tied it to the need for awareness, fundraising, and research. Bowling commenced at 1 p.m. We all were competing for top high score of three games to win an authentic autographed Mickey Mantle baseball. Throughout the day many raffles were held for winning ticket numbers given at the door when registering. Fun was had by all, great food, socializing and prizes too. The Northeast Florida Ataxia Support Group Walk and Roll n' Bowl fundraiser for IAAD was truly a great success, and raised over \$4,300 through the combination of the web site and the event. We are already planning for next year's event.

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International Ataxia Awareness Day
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Submitted by *Guangbin Xia, M.D., Ph.D.*
Assistant Professor-Department of Neurology,
University of Florida

I went to Jacksonville and attended Walk n' Roll and Bowl for fundraising event, in which I gave a keynote speech.

Central Massachusetts Sixth Annual Walk n' Roll

Submitted by *John Mauro*

The 2013 Walk n' Roll was our most successful yet! The Sixth Annual Walk n' Roll, sponsored by the Ride for John, was held on Saturday, October 5. We had a large number of teams who met or exceeded their fundraising goal. We had more participants than ever, and welcomed new teams from New York, New Hampshire and Boston to our event. As of today, we exceeded our overall goal of \$10,000 raising \$17,600. Way to go everyone!

Massachusetts senator Mike Moore was in attendance and spoke about his efforts with Rep. Paul Frost to pass a bill for Sept. 25 as National Ataxia Awareness Day. Massachusetts will be the first state to pass this proclamation into law.

Anne Wolf from BalanceWear came to show the balance wear vest.

Representatives from the University of Massachusetts Medical School were in attendance. This was their first Walk n' Roll. We hope to establish a growing relationship and count on their continued participation.

University of Massachusetts cognitive lab from Amherst made the sixth appearance at our Walk n' Roll. A great group lead by Rebecca Spencer.

There were auction items, a 50/50 raffle, music by our resident DJ Tony Kapulka, food and fun. Healthsource of Auburn donated a one-hour body massage and was on site providing free sports massages. www.youtube.com/watch?v=EpB5s626Wcs&list=FLRax0fQ0bjm90R2PSixQY0g



Los Angeles and Orange County 2013 Youth Ambassadors (left to right): Moira Greenway, Paris Gomez and Sophie Yi

LA/OC Fifth Annual Walk n' Roll

Submitted by *Theresa Gonzales and Daniel Navar*

The Orange County Support Group collaborated with the Los Angeles Support Group to host the Fifth Annual Walk n' Roll for Ataxia Awareness on Saturday, September 28. The event was held in beautiful Southern California at Shoreline Park on the ocean view coast of Long Beach. The event included a free event t-shirts to the first 300 participants, prize drawings, a silent auction and entertainment. It was a tremendous success, teams and participants raised over \$46,000 in donations. It was a great day!

For more information about the Orange County Ataxia Support Group, please visit www.ataxia.org/chapters/OrangeCounty/default.aspx.

NCASG Fifth Annual Walk n' Roll and Fitness Faire

Submitted by *Joanne Loveland*

This was our best event. We had a great group of volunteers, our games and Walk n' Roll combo was fun for all participating. There were 72 that attended the event on Saturday, September 28, which was a record for us. The raffle and silent auctions items were the nicest we have ever had. As I left for our event Saturday morning, our website showed over \$9,000 and I also had over \$500 in checks, so I knew we had exceeded our goals! The website set the tone, and things just fell into place after that. We raised \$3,900 at the event and over \$16,000 in all. ▶▶



The North Texas Ataxia Support Group pauses for a photo during their Trail Walk n' Roll.

North Texas Trail Walk n' Roll and Picnic

Submitted by David Henry, Jr.

Our group held a Trail Walk 'n Roll on Saturday, September 28, and a fun picnic get together at the Mike Lewis Park pavilion. We reserved picnic tables and each family brought something to share. The park had some nice trails and some members rode recumbent trikes. We have many fun families and had about 38 attend. It was a good day.

San Diego Seventh Annual Charley McLaughlin Walk n' Roll

Submitted by Jane Jaffe

San Diego Ataxia families recognized IAAD by holding their Seventh Annual Charley McLaughlin Walk n' Roll at Tuna Harbor Park in beautiful downtown San Diego on Saturday, September 28. Free commemorative t-shirts were given out to the first 200 participants.



June Wood and Mary Roth lead the start of the San Diego Walk n' Roll followed by Oceanview Church cheerleaders.

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 more than 280 walkers and rollers who helped raise awareness of ataxia and over \$20,000 for ataxia research.

There were over 75 volunteers working at the event. The planning committee members were Earl McLaughlin, Pat Ward, Jane Jaffe, Joan Hay, June Wood, Harold Ward, Walter Wallenborn, Roger Wood, Mike and Marla Clickenbeard.

We would like to thank our sponsors – A-1 Self Storage, Century 21, The Ability Center, Ben Bridge Jewelers, Cookies by Design, Farmer Insurance-Clickenbeard Agency, Knights of Columbus Council No. 11127 and SDG&E – for their support this year.

The Eighth Annual Charley McLaughlin Walk n' Roll for Ataxia will be held on Saturday, September 27, 2014.

Dining to Fight Ataxia

Submitted by Joe DeCrescenzo

The Delaware Support group invited friends, family and associates throughout the state and southeast Pennsylvania to dine with them at selected restaurants who agreed to donate a portion of the revenue back to NAF. Seven local restaurants participated this year on nine different dates raging from August 12 through September 24. They were Ruby Tuesday (three locations and three dates), IHOP, Home Grown Café, Route 40 Diner, Bob Evans, Trattoria Di Napoli and Soffritto's Italian Grill. Literature and book-marks supplied by NAF were available at each event for the attendees to learn about ataxia. The fundraiser raised over \$800.

Third Annual Bingo for Ataxia

Submitted by JoAnn Simpson

The Third Annual Ataxia Awareness Bingo was held in Berlin, MD on Saturday, September

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28. Once again we had a very successful event in honor of Dana Simpson. Family and friends in addition to local civic groups, churches, businesses and individuals supported our efforts. Together we raised funds to help researchers work towards a cure for this condition. The event raised \$4,200.

Jeans Day for Ataxia

Submitted by Angela Li

My cousin Rosa Greenwood organized an awesome Jeans Day fundraiser at her company, Dominoon, on September 27 on behalf of Jolanta Chyla, who was diagnosed with ataxia. Many companies will allow employees to wear jeans instead of their regular business casual attire to work on a specific day for a donation to a specific non-profit organization. Rosa gave out information about my mom as well as the National Ataxia Foundation. They raised \$180 just by wearing jeans to work!

Zumba – Second Annual Fitness in the Park

Submitted by Jalean Retzlaff

The Second Annual “Zumba in the Park” event raised over \$200 on Saturday, September 21. A third Fitness in the Park is being planned for next year.

Fort4Fitness

Submitted by Cheri Bearman

An estimated 28,000 spectators and participants filled Parkview Field and downtown Fort Wayne, Indiana, on Saturday, September 28 for the Sixth Annual Fort4Fitness Fall Festival. There were 10,217 participants registered for the five events during the two-day weekend event.

On Saturday, September 28, I participated in the Fort4Fitness event, walking the four-mile race with my husband, Gil, in recognition of IAAD. With the help of family and friends, we raised \$400 for the National Ataxia Foundation.



Cheri Bearman at the Fort4Fitness event in Fort Wayne, Indiana

The gifts were given in memory of my mom, Marcella “Sally” Kukelhan, who had SCA3 (aka MJD). Though we did not win any medals, we helped the NAF win the race to find a cure for ataxia!

CNY Potluck Luncheon

Submitted by Mary Jane Damiano

Our meeting to recognize IAAD was publicized in the newspaper, on the radio, and on television. Jeff Paston handles the publicity for our group.

Fancy Dress Sponsored Ride for Ataxia

Submitted by Miss Taryn Cotton

My livery yard/riding school partook in a fancy dress sponsored ride for ataxia on September 2. ►►



Taryn Cotton rides Melody at the Fancy Dress Sponsored Ride for Ataxia.

Western Michigan Support Group

Submitted by Lynn Ball

My support group, for awareness, all enrolled in a new program, at the recently established, college of Human Medicine in Grand Rapids Medical Mile. To be eligible you had to have a rare, chronic disease. A med student will be assigned to you, make home visits to you and study your disease. What a good way for awareness in the medical community.

Proclamations/Resolutions

Proclamations or Resolutions declaring September 25 as International Ataxia Awareness were signed in Florida, Georgia, Massachusetts, New Hampshire, New York, Pennsylvania and Ontario-Canada.

June 28 – New resolution No. 180 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, 2013, 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.”

August 7 – A proclamation was signed by Georgia’s governor Nathan Deal declaring September 25th as International Ataxia Awareness Day (IAAD) in the State of Georgia.

September 3 (*Submitted by Benedict Benninger, Municipal Councillor, Ward 2*) – As a Municipal Councillor and Ataxian, the Mayor and other Councillors agreed to recognize September 25 through a proclamation posted in the Municipal Offices. A proclamation was signed by Rob Deutschmann, Mayor, Township of North Dumfries Township, Ontario, Canada.

September 6 – Alvin Brown, Mayor of Jacksonville, gave a written proclamation, declaring September 25 as Ataxia Awareness Month for Jacksonville at the first Walk and Roll n’ Bowl held at Bowl America.



Mac Kelso, Cory Hannan and Guangbin Xia with the Jacksonville proclamation

September 18 – There was a public signing ceremony in the Governor and Council Chamber at the State House that several of our members attended. The New Hampshire proclamation was signed by Governor Maggie Hassan. The New Hampshire Ataxia Support Group plans to follow through to have a bill signed in 2014. New Hampshire is the sixth state to pass this resolution.



Shown at the signing of the New Hampshire proclamation are (rear, left to right) Aphrodite Giotas, Steve Giotas, Lori Giotas, Kathy Gardner, J.J. Hall, Senator David Boutin, (seated, left to right) Jill Porter, Governor Maggie Hassan, and Ken Porter.

September 28 – The Central New York Ataxia Support group received three proclamations to recognize IAAD. The proclamations were from the City of Syracuse with the County of Onondaga (joint proclamation), New York State Assembly, and the Village of North Sya-

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Continued from page 9

cuse. Three politicians were present to present the proclamations. The politicians presenting the proclamations were County Legislator Kathy Rapp, New York State Assemblyman Al Stirpe, and the Village of North Syracuse Deputy Mayor Chuck Henry.



Shown at the signing of the New York proclamations are (back, left to right) Chuck Henry, Kathy Rapp, Al Stirpee, (front, left to right) Saul Beckman and Mary Jane Damiano.

September 24 – The renewal of the Pennsylvania House Resolution No. 424 to recognize was signed.

September 24 – A proclamation was passed in Massachusetts thanks to the collaborative efforts of Senator Michael Moore, Representative Paul Frost and John Mauro. Massachusetts will be the first state to pass this proclamation into law.



Shown with the Massachusetts proclamation are (left to right) Moira Cristy, Senator Michael Moore and John and Dana Mauro.

Media Coverage

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

KUSA –TV Denver on September 7 – The day before the Run, Walk n’ Roll event, Channel 9 News aired an interview done with two Denver Area Support Group members, that no doubt helped to increase awareness about ataxia, publicized the event. Because of it, we gained a new member. You can access that interview through the following link: www.9news.com/rss/story.aspx?storyid=354061.

Florida Times Union on September 11 – “Health notes: St. Vincent’s open a ‘first care’ walk-in clinic on Roosevelt Boulevard.” Mentioned in the article is the Jacksonville Walk n’ Roll & Bowl for Ataxia, guest speaker and information about ataxia.

New York Amsterdam News on September 12 – An article titled “Fourteenth Annual International Ataxia Awareness Day”

Central Massachusetts Convention and Visitors Bureau on September 16 – “Ride for John: Annual Walk and Roll for Ataxia – Saturday, October 5.”

Auburn, MA Daily on September 16 – “Walk or Roll to Support Ataxia Awareness.”

The University of Adelaide Australia on September 18 – “Shining Light on neurodegenerative pathway.”

Eagle Star Review (Syracuse, NY) on September 18 – “Annual ceremony keeps ataxia in the public eye.”

Florida Times Union on September 19 – Announcement and slideshow for the “Jacksonville Walk n’ Roll.” This included a slideshow of the items for the silent auction.

The Riverdale Press (Bronx, NY) on September 26 – “Spreading awareness of obscure but deadly disease.”

Syracuse, NY channels 3 and 5 up to and on September 28 – Laura Hand made several announcements about ataxia and our Ataxia ►►

Awareness Day Ceremony. Her announcements were aired before and up to September 28.

WAER on September 28 – Syracuse University's radio station aired a story about our Ataxia Awareness Day Ceremony.

TelegramTowns on October 3 – "Ataxia Group founder prepares for Walk n' Roll."

Central Massachusetts on October 1 – John Mauro appeared on half-hour TV show on City Vibes Charter TV3.

Central Massachusetts on October 5-6 – John Mauro City Vibes Charter TV3 interview was on, and a radio show on October 6 in the morning. <http://youtu.be/8TsxrTUR5OI>

The (Dartmouth/Westport) Chronicle on September 25 – An article appeared as a Letter to the Editor titled "Resident recognizes Annual Ataxia Awareness Day."

Ataxia Awareness

Shared by Chip Carroll

I sent this to my local neurologists and newspapers:

"As you may know, I have been diagnosed by the NIH in Bethesda, MD with a rare neurological progressive disease called spinocerebellar ataxia. In order to promote awareness, the National Ataxia Foundation has asked me to pass on this attached information kit to you. As a public service, I ask that you get involved or at least publish some of this information. On page four is a press release for your convenience. September 25 has been set for International Ataxia Awareness Day. I am a long-time resident of Raritan Township and you may use my name in any publication. Thank you for your consideration."

Central Massachusetts Support Group

Submitted by John Mauro

Over the last week for IAAD we had all of the movie theaters play the IAAD logo before a show started. We had 32 theaters showing it. Between Auburn and Worcester bookmarks were given

out at the libraries. A mailing went out to all 2,300 Hanover employees on IAAD. There were 10 places over the state that projected the IAAD logo on buildings in the commons. Oh, and I had a glass of wine.

Central PA Ataxia Support Group

By Chris Rakshys

We got an updated resolution prepared and signed by the PA House of Representatives. In 2006, my predecessor Mr. Bill Lee, initiated the original passing of this resolution. Each year I am able to email Representative Helm, and she has agreed to re-new the resolution. I send a reminder e-mail to her assistant, and "Poof" it's done!



Members of the Central PA Support Group at their picnic

Our group celebrated with a casual picnic and had about 21 ataxians and family members attend.

The New Hampshire Ataxia Support Group

Submitted by Jill Porter

The NHASG began spreading the word about ataxia by participating in Macy's Shop for a Cause Event and spreading the word to raise funds for ataxia.

We distributed ataxia bookmarks to libraries in Bedford, Concord, Manchester, Merrimack and Weare. Churches in New Hampshire and New York, distributed bookmarks in their Sunday

International Ataxia Awareness Day
Continued from page 11

bulletins along with individuals speaking about ataxia. Our group, along with friends and family, continued to spread the word about ataxia and why it is so important to find a cure.

Members of our support group participated in the Central Massachusetts Walk n' Roll October 5 in Auburn, MA. We will walk, roll, ride or stroll. Great job, Kathy! She led our team and had raised \$1,200 before we even participated in the Walk n' Roll.

Seek A Miracle Ataxia Group

Submitted by Chandu George

I did not organize an event but I was able to attend one for IAAD on September 25. Professor, Dr. Ramaiah Muthyala, who is from the University of Minnesota, was here in my city. He was invited to give his presentation on "Rare Orphan Drugs" at a conference that was organized by the Indian government and some pharmaceutical companies. Dr. Ramaiah already knew me and he invited us to ask queries in the conference. We participated and also spread the word on IAAD, though to be frank, it wasn't helpful because we couldn't understand the answers to our queries due to the fact that they were in medical terminology.

Social Media/E-mail Ataxia Awareness

Submitted by Matt Malott

I put this on Facebook, with a link to NAF's IAAD Article.

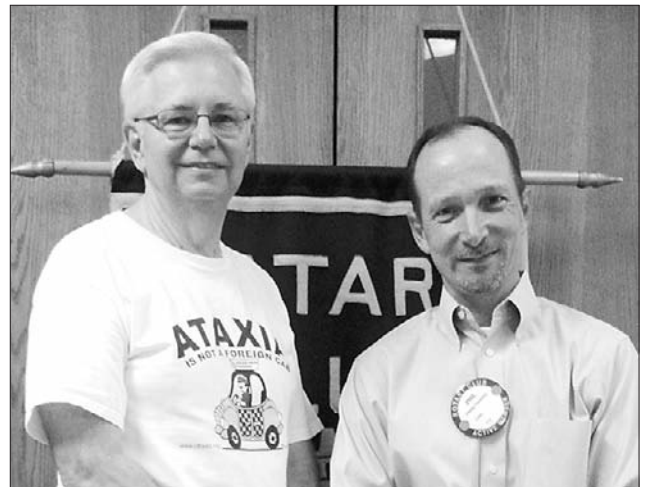
"September 25th is Ataxia Awareness day. If you want some interesting reading, do a google search for 'spinocerebellar ataxia.' I have met many great people over the last year in various stages of the disease, and it's quite amazing what they (and their support people) are going through. I was diagnosed with the disease a little over a year ago. I don't have anywhere near the challenges that most people have and hopefully won't for a long time. If you see me squinting,

stumbling, or mumbling only laugh for a minute or two, and be aware that over 150,000 people in the U.S. are dealing with this disease for which there is currently no cure.

Presentation to the Garner (NC) Rotary Club

Submitted by Ron Smith

I made a presentation to the Garner (NC) Rotary Club on ataxia as a part of IAAD. It went well and answered a lot of questions, as well as showing a video. I am also a club member.



Ron Smith and Phil Cummings of the Garner (NC) Rotary Club

Submitted by Judy Hamilton

I posted the NAF IAAD link and thumbnail on my Facebook page for my friends to see to help raise awareness about this disease. Some know about my daughter who was diagnosed at 18 with Friedreich Ataxia, and some don't. I also forwarded the e-mail to a friend of 25 years whose niece also has FA and hoped he would also post and forward the e-mail to his friends. We like to help with whatever things we can do.

Thank you NAF for your e-mail to distribute and the organization behind the needs.

Submitted by George Chandu, India

The following greeting was sent out via e-mail on September 25:

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“Greetings from SAMAG,

September 25th a new day with new hopes and a day dedicated to raising awareness on ataxia, Here’s wishing all a happy (International Ataxia Awareness Day) 2013, please join hands and raise awareness on ataxia by observing IAAD in any way you can.

Best wishes, SAMAG”

Wearing Ataxia Gear to Raise Ataxia Awareness

Submitted by Donna Gorzela

Well, it ended up being a good day for spreading awareness. This morning I sent out a lot of e-mails and Facebook posts. I received lots of responses from people that knew nothing about ataxia previously. Then I did my grocery shopping wearing my ataxia sweatshirt which always seems to attract attention.

It worked, an older man asked me about it! Then, tonight, I went to a meeting of the Andover Commission on Disabilities and got to

make an announcement there. I think a lot more people have heard of ataxia after today!

Submitted by Virginia Miller

I participated in IAAD in September by simply putting in two articles I wrote, one each in a New Hampshire and Vermont paper. I explained my condition, including my 27 years since I was diagnosed, and 14 years in a wheelchair. I am managing at home with the help of my sons who live with me. Very few that I know are aware of ataxia because of its rarity. Since my article, I have received a few calls asking about it, some saying they were glad to know what’s wrong with me. Therefore I clarified it for a few. ❖

E-mail Blasts

E-mail blasts from the National Ataxia Foundation are sent out periodically covering ataxia research, events and other timely issues of interest to those with ataxia, their families and caregivers, as well as doctors and those doing ataxia research.

Please send your e-mail address to joan@ataxia.org so you don’t miss out on important information.

Want to Go Green?

Generations, the National Ataxia Foundation’s quarterly newsletter, is a valuable part of your membership. You can receive the newsletter by U.S. mail or you can “go green” by having it sent directly to your e-mail address.

Please note that even if you opt out of the e-mail blasts you will receive the *Generations* newsletter when you subscribe by e-mail. All current members receive four issues of *Generations* a year.

If you are not receiving yours, or would like to change how you receive the newsletter, please contact joan@ataxia.org or call (763) 553-0020.

Brain Tissue Donation

Many individuals have made plans to have their brain donated after their death for ataxia research purposes. The National Ataxia Foundation honors the courage of making this deeply personal decision.

If you have any form of ataxia other than Friedreich Ataxia and are interested in learning about brain donation, please contact the National Ataxia Foundation at naf@ataxia.org or call (763) 553-0020. If you have Friedreich Ataxia please contact Dr. Arnulf Koeppen at arnulf.koeppen@va.gov or call (518) 626-6377. Thank you.

Steel Wheels

By Asad Rafi

This is an edited excerpt from Asad Rafi's memoir titled "Steel Wheels." If you would like more information please contact Asad at asad.rafi@gmail.com.

Living in a wheelchair, with a disease such as Friedrich Ataxia, is only possible with the help of many people. Friends, family and helpers, they know who they are, and many things would not have been possible without them.

I was born in a quiet and progressive Pakistan in December. There was no internet available, television was in its formative years and the radio used to be the main source of information and entertainment.

My youth was a period full of fun, excitement and love. However, my school years were unsettled because of so much traveling for my father's work. It was a very educating experience for me, going to different schools and living in different cities. My love for sports began at an early age. I grew agitated and restless as to why I was not selected to play on the school team but decided not to think too much about it and not get frustrated. It took sometime but eventually six or seven of my neighborhood friends got together and we formed our own teams and played matches. These matches are some of my best

childhood memories. Apart from playing with my friends I loved keeping dogs as pets. Timmy was my first dog, but my favorite was Jerry, I thought of him as my brother and best friend. In my teenage years, I was very fortunate to have visited America a number of times. Those times are very nostalgic when I think of them today, being wheelchair-bound.

When I was 17, running became more difficult for me, I was often short of breath. I was beginning to lose my balance and kept falling down. I was diagnosed with scoliosis. The surgery was risky to straighten out the curvature and was never performed. I wore a back brace for three years, it covered my back and stomach with buckles at the rear that were fastened, to prevent the curve of my back from further deterioration.

I worked for IBM for 15 years in Karachi. It was during this time that I went from wearing a brace to using a walker which supported me and helped prevent me from falling down. During the oppressive and stifling heat, the electricity for our office would be cut. It took me ages to climb the stairs with my walker and I'd reach the office totally out of breath. My walking ability continued to deteriorate and I was losing my balance often. It was becoming impossible for me to walk.

I lost coordination of my arms and legs, became unbalanced, fell frequently, and would get hurt on numerous occasions. My symptoms gradually pointed the doctors toward a diagnosis of Friedrich Ataxia. I was officially diagnosed when I was 20. I was introduced to a wheelchair and had its benefits explained to me. The wheelchair came as a shock to me. It felt like a prison, restricting me from where I wanted to go and what I wanted to do. I felt like all my dreams and ambitions were shattered.

My doctor, in America, helped me change my attitude in life to a positive one. He explained ►►

There's Still Time to Donate

There is still time to donate to the 2013 NAF Annual Ataxia Research Drive. Checks postmarked by December 31 or on-line donations made on or before midnight December 31 will be eligible for a tax deduction in 2013.

Your 2013 research gift will help support promising ataxia research studies for fiscal year 2014.

to me the advantages of being in a wheelchair; that I should think of it as transporting me from one place to another in quick time, and also a way to prevent me from falling! From that day forward, I was more positive and felt a much brighter outlook towards life. Now, the wheelchair, was just a challenge in life to overcome.

The three attitudes that have helped me in my struggle are the following: 1) Never Give Up; 2) Have Belief in your Abilities; and 3) Have Faith in God.

Through all of this, I have been fortunate enough to have three or four true friends. What makes them special is that their attitude towards me has not changed at all, even after being transferred into a wheelchair and being unable to walk. They treated me just like one of them, joking with me often and having a whale of a time.

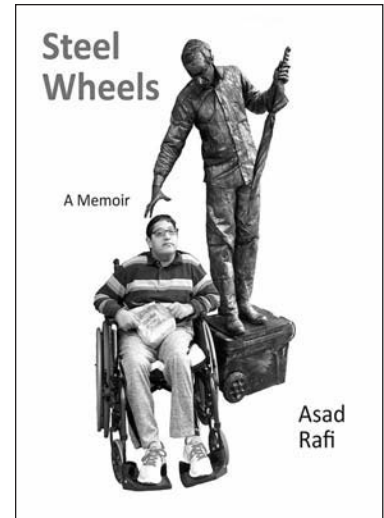
Being in a wheelchair has not stopped me from having an active social life, which includes dance parties, hanging out with friends at restaurants and their houses. I have also been fortunate enough to be invited to various interviews on different television channels. The television anchors asked me about my disease and how I managed to live my life in a positive way, despite being in a wheelchair.

I understand how you might feel and can certainly appreciate the difficulties and challenges you go through. Remember this: you are not alone.

Do not feel sorry for yourself; there is a tremendous life waiting for those of us with FA.

But you must develop a positive attitude. Remember you only live once and you must make the most of it. Being frustrated in life only makes you feel more miserable. Open your eyes to the possibilities that may be waiting for you. Reach out to those who are able to help you. Don't accept this disease by lying down or being stuck in a wheelchair. Grab life with as much strength and energy as you can muster and make of it whatever you can. Befriend others with similar ailments. Take up a hobby or interest that energizes you. Even if you cannot exercise your body, exercise your mind, for it is a powerful force for us. The most important thing is you should never let your disability come in the way of what you want to achieve.

For my own future, I still have dreams and ambitions. Completing a memoir had been one of them. Given the time and support other things that I would like to achieve are becoming an international speaker, doing something of substance for people who have disabilities and continue to write more memoirs. ❖



Friedreich Ataxia Study

Patients with early symptoms of Friedreich Ataxia ages 10 and above are 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 at (612) 625-2350 or e-mail hutte019@umn.edu.

Hasan Banks – Moving Forward

By Gail Auerbach

The amazing story of NPC Men's Physique Competitor Hasan Banks began in 2009 when he was diagnosed with a neurological disorder known as Spinocerebellar Ataxia Type 7 (SCA 7), a disorder known to affect regions of the brain that control motor skills.

Hasan was told by his doctors that it wouldn't be long before he would become wheelchair bound. What doctors didn't know was that for Hasan, accepting a limited future was never an option.



Hasan Banks takes a nap with his son

After becoming frustrated and angry from not getting any answers from his doctors, Hasan looked into ways he could take a proactive approach to his condition. He began to learn that he needed to focus on the things that he could control, a decision that led him to investigate how adapting a healthier lifestyle could assist him in his journey.

Deciding to take an active approach to his health and make fitness a priority, Hasan developed an unrelenting desire to continue to push himself even further and began spreading the message that anything is possible with hard work and dedication. He then turned to bodybuilding as a means to keep pushing himself forward. As he continued his quest for knowledge, he quickly

became aware just how much is required to step onto a competitive bodybuilding stage. In 2012 he began competing in an attempt to fulfill his dream and to continue pushing himself even further.

Although he could have easily sat back and complained about the hand he'd been dealt, he instead realized that his higher power would never give him more than he could handle, and sitting around feeling sorry for himself would be a waste of precious time and valuable energy.

Following the birth of his son in 2012, his life was changed yet again. This event only further fueled his determination to train harder, become stronger, and continue to define his life on his own terms – not allowing to be defined by a diagnosis.

More important than stepping on stage, life now revolved around staying healthy and mobile so that he not only would be able to watch his son grow, he would be also be able to take part in all of the normal activities that a father does with his son.

Over the past several months Hasan has added muscle and improved his balance and coordination. He's become happier and a healthier father. Now he is able to be active and play with his son, no longer allowing frustration to get the best of him.

Refusing to sit back and be complacent, not making excuses about why he couldn't do something, he decided to take action. Hasan took his future into his own hands. He realizes that he can't change his diagnosis, but he's determined to put his best foot forward and never give up.

His plans include continuing his fitness journey with the support of his family, and his new team (Team GIAFIT) under the guidance of his coach Jason Giardino with the goal of one day earning his IFBB Pro Card.

Whether Hasan earns his Pro Card or not ►►

is uncertain, but if there's one thing we can be certain of, it's that Hasan will continue to make improvements to his physique and continue to spread ataxia awareness with the hope of motivating his fellow athletes and others with disabilities along the way.

A special thanks to Dave Palumbo, founder of RX Muscle, for allowing us to reprint the article.

A special note from Hasan's trainer:

My name is Jason, "Coach Gia" Giardino (coaching@teamgiafit.com), and I'm Hasan's

trainer and coach. This kid is nothing short of amazing. He continues to push the limits every-day and defy what the doctors have told him. Over the past six months he's changed my prospective on life and has me always saying, "It could always be worse" when things don't go right, a phrase he uses quite often.

For another story on Hasan banks please follow this link – <http://eyeonfitness.com/fitness/nothing-is-impossible/>

If you are interested in contacting Hasan please e-mail him at hasan.banks@gmail.com. ❖

Still Active in Retirement

By D.S. "Chip" Carroll, Jr.

My name is Chip Carroll and I have Spinocerebellar Ataxia. I also have a form of arthritis called ankylosing spondylitis. It is a form of arthritis that primarily affects the spine, although other joints can become involved. I have had it most of my life.

About 10 years ago I started to experience weakening of the legs and slurred speech. I continued my career in medical sales although my legs weakened and speech continued to slur. Searching for an answer, I visited many different medical professionals and had multiple MRIs over the course of five years. I often felt like I was on a medical merry-go-round. The medical field that I so believed in, was spinning me around in circles. I was accepted to participate in an ongoing study of hereditary diseases for genetic testing at the National Institute for Health (NIH) in Bethesda, MD. The genetic blood testing was inconclusive but a clinical evaluation suggested SCA. I started to experience sharp electric like bolts that went through my eye to my brain. Thank goodness they lasted for only 10 seconds. This is called a trigeminal neuralgia (TN).

In order for some of us to avoid mistakes or falls we go inch by inch, step by step, word by word, letter by letter. We are slow and measured, but we win more personal challenges in one day than most people do in a lifetime. We are winners. It is important to us all and for future generations to join the CORDS Registry or an NIH study.

I retired four years ago after 40 years in sales. To keep active I wrote a book, "Memoirs of an IMPURFECT SALESMAN: Truths Taught through Forty Years of Experience." With my cryptic cursive chicken scratch, short terms of writer's block and some of the effects of my health, it took me three-plus years to complete, and it will most likely be the last, entirely hand written, thing I do. But complete it I did, and although the book is loaded with tips for salespeople, it has many humorous stories, pictures and cartoons. I hope you find it to be inspirational as well as informative. For more information please go to my website www.dscarrolljr.com. ❖



Chip Carroll

From the Desk of the Executive Director

By Michael Parent, NAF Executive Director

As the year 2013 comes to a close and we look towards the future, I am reminded by all who helped make 2013 a stellar year in terms of ataxia awareness and in supporting promising ataxia research and important programs for ataxia families.

As of this writing, the research drive is underway and we continue to see the generosity of so many in supporting vital ataxia research. I am so thankful to all of you who contributed to this year's important research drive. A special thank you also to the families, individuals, support groups, chapters, and ambassadors who conducted events and Walk n' Rolls to help raise ataxia awareness and funds to support NAF's important mission and to the donors, sponsors, and volunteers of these events.

Our heartfelt gratitude goes to our anonymous donor who so generously supported this year's research studies through a three-year, \$1.5 million dollar research commitment, to The Michael and Patricia Clementz Family Fund for SCA3 Research for their unwavering commitment to support research, and to The Gordon and Marilyn Macklin Foundation for their continued support and generous \$150,000

research match challenge.

It is with humility and gratitude when I say thank you to all of you. You make it possible for us to dare to dream of better days to come, your gifts give hope and support the best science in the world. No one individual or group can do this alone, but together we are finding answers to help end ataxia. Thank you so very much.

As we enter 2014, the NAF 57th Annual Membership Meeting (AMM) will be held March 21-23, 2014 at Bally's Las Vegas. Please make plans now to attend the world's largest gathering of ataxia families. Just prior to the AMM will be the 5th Ataxia Investigators Meeting (AIM). On Thursday, March 20 from 5:15-6:15 p.m. there will be an opportunity to meet many of the investigators through a Poster Session. You don't want to miss this rare opportunity to meet world leading ataxia investigators face-to-face who will discuss with you their current ataxia research findings. If you are going to attend the annual membership meeting, please plan on arriving early to Las Vegas to attend the Poster Session dedicated to persons with ataxia and their families.

We look forward in seeing you in Las Vegas. Thank you.



Neuro Film Festival

Your Story Could Win Up to \$1,000!

Do you have a compelling – and inspiring – story to tell that makes the case for why more research is needed to cure brain diseases such as Alzheimer's disease, stroke, brain injury, Parkinson's disease, and others?

Submit a short video, no more than five minutes in length, to the American Brain Foundation's 2014 Neuro Film Festival® and you could win up to \$1,000 and a trip to Philadelphia to see your video premiered during the world's

largest gathering of neurologists and neurology professionals at the American Academy of Neurology's Annual Meeting.

The video submission deadline is February 26, 2014. Complete contest rules and submission guidelines are available online at www.americanbrainfoundation.org/go/neurofilmfestival.

The American Brain Foundation funds research to find better treatments and cures for brain disease. Find out more online by visiting AmericanBrainFoundation.org.

2014 NAF Annual Membership Meeting Agenda and 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 NAF Western Region Support Groups invite you to attend the 57th "Betting on Ataxia Research" Annual Membership Meeting (AMM). Please join us at Bally's in Las Vegas to learn, share, network, have fun, and enjoy the sites.

The 2014 AMM will bring together NAF members and their families to meet and learn from world-leading ataxia researchers and clinicians, while building new friendships and reuniting with old friends. Come and be part of the largest ataxia gathering in the world!

THURSDAY, March 20

<i>Event</i>	<i>Location</i>	<i>Times</i>
NAF Registration	Grand Salon	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.		
Silent Auction Item Drop Off & Viewing ...	Grand Salon	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 21 at 4 p.m. Auction items range from something that represents your state or country, art work, sports memorabilia, theme baskets, hand-crafted items, hotel stays and weekend getaways. Bring an item to donate and then have fun bidding on the items of your choice. Thank you for supporting this event and sharing items from your local area.		
Exhibitors	Grand Salon	Noon – 5:00 p.m.
Exhibitors will be present as their schedules permit. If you would like to recommend a company or service provider to be an exhibitor at the meeting please contact NAF at joan@ataxia.org . If you are interested in information about exhibiting you will find more detailed exhibitor information and an application form on NAF's website.		
Leadership Meeting	Bronze 3 & 4	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 lori@ataxia.org prior to the meeting.		
Walk n' Roll Meeting	Bronze 3 & 4	4:00 – 5:00 p.m.
Anyone who is interested in learning more about organizing a Walk n' Roll for Ataxia event or getting involved in an existing event to support the important work of the NAF is invited to attend.		
AIM Poster Session	Skyview 5	5:15 – 6:15 p.m.
A great opportunity for you to view the research posters that are being presented at the Fifth NAF Ataxia Investigators Meeting. Ataxia investigators will be present to answer questions about their posters and ataxia research projects. Don't miss this opportunity to meet face-to-face with ataxia researchers from around the world.		

FRIDAY, March 21

<i>Event</i>	<i>Location</i>	<i>Times</i>
Silent Auction Item Drop Off & Viewing ...	Grand Salon	8:00 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.		

NAF RegistrationGrand Salon.....8:00 a.m. – 5:00 p.m.

Exhibitors.....Grand Salon.....8:00 a.m. – 5:00 p.m.

General SessionsGrand Ballroom (Gold/Silver).....8:30 a.m. – 12:30 p.m.

Friday morning will start the General Sessions in the Grand 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.

Activity RoomPalace 110:00 a.m. – 1:00 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.

Yoga: Yoga for all abilities will be held from noon to 12:30 p.m. on Friday.

LunchOn Your Own12:30 p.m.

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

Attendees will have the opportunity to attend small group sessions. See pages 21-22 for more information about these small group sessions.

Meet & Greet Reception.....Grand Ballroom (Gold/Silver).....7:00 p.m.

Please join us for the Meet & Greet 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. 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>
8:30 a.m.....	Welcome & Announcements	Camille Daglio, NAF AMM Co-Chair, and Cherilyn McLaughlin, Western Region Representative
9:00 a.m.....	NAF Update	Michael Parent, NAF Executive Dir. NAF – Minneapolis, MN
9:30 a.m.....	Ataxia Patient Registry.....	Liz Donohue, Director of CoRDS Sanford Research – Sioux Falls, SD
10:00 a.m.....	How Doctors Find the Cause of Sporadic Ataxia: From Basic Blood Tests to Exploring the Genome	Brent Fogel, MD, PhD University of California – Los Angeles, CA

10:30 a.m.....FRDA Update	David Lynch, MD, PhD <i>University of Pennsylvania- Philadelphia, PA</i>
11:00 a.m.....Cerebellar Ataxia Research	Alexandra Durr, MD, PhD <i>ICM – Paris, France</i>
11:30 a.m.....Why should I be seen at an	Christopher Gomez, MD, PhD <i>University of Chicago – Chicago, IL</i>
Noon	Q&A Panel
12:30 p.m.....Lunch	

BIRDS OF A FEATHER 2 – 5 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. Children under 12 years old should not attend a Birds of a Feather session. Questions regarding these sessions may be directed to Sue Hagen, NAF Patient Services Director, at susan@ataxia.org or (763) 553-0020.

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

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

SCA1 & SCA 2 BIRDS OF A FEATHER 2 – 5 p.m. in the Palace 6 & 7 Room

For those who have been diagnosed with SCA1 or SCA2. Facilitators: Dr. Orr and Dr. Schut (2-5 p.m.)

SCA3 BIRDS OF A FEATHER 2 – 5 p.m. in the Bronze 3 Room

For those who have been diagnosed with SCA3. Facilitators: Dr. Paulson and Dr. Durr (2-5 p.m.)

SCA6 BIRDS OF A FEATHER 2 – 5 p.m. in the Palace 2 Room

For those who have been diagnosed with SCA6. Facilitator: Dr. Gomez (2-5 p.m.)

ALL Other SCAs (including SCA 5, SCA 7, and SCA 8) BIRDS OF A FEATHER 2 – 5 p.m. in the Bronze 4 Room

You will need to have a diagnosed with SCA other than SCA 1, 2, 3, or 6. If you do not have a diagnosis of **hereditary** ataxia please attend the Unknown without Family History BOF session. Facilitators: Dr. Ranum, Dr. LaSpada and Dr. Brian Brooks (2-5 p.m.)

UNKNOWN WITH FAMILY HISTORY – EPISODIC & AOA BIRDS OF A FEATHER..... 2 – 5 p.m. in the Skyview 4 Room

For those who have been diagnosed with an Unknown Type of Ataxia with Family History, including Episodic Ataxia and AOA. Facilitators: Dr. Todd and Dr. Fogel (2-5 p.m.)

UNKNOWN WITHOUT FAMILY HISTORY – SPORADIC, MSA, & GLUTEN BIRDS OF A FEATHER..... 2 – 5 p.m. in the Skyview 2 Room

For those who have been diagnosed with an Unknown Type of Ataxia without Family History, including Sporadic, MSA, and Gluten Ataxia. Facilitators: Dr. Wilmot, Dr. Walsh, and Kiera Berggren, MA/CCC-SLP, MS (2-5 p.m.)

OVER AGE 30 FRIEDREICH BIRDS OF A FEATHER 2 – 5 p.m. in the Silver & Gold Ballroom

Facilitators: Dr. Puccio and Dr. Lynch (2-4 p.m.); Ralph Miller, Yoga Instructor (3:30-5 p.m.)

UNDER AGE 30 WITH ATAXIA BIRDS OF A FEATHER..... 2 – 5 p.m. in the Skyview 6 Room

For those with any type of ataxia who are under the age of 30. Facilitators: Dr. Shakkottai and Polly Swingle, PT (2-5 p.m.); Dr. Coffield (2-3:30 p.m.)

The following groups are for **parents of children** who are diagnosed with ataxia:

PARENTS (NON-FRIEDREICH) BIRDS OF A FEATHER..... 2–5 p.m. in the Skyview 1 Room

For parents whose child(ren) are diagnosed with any form of ataxia other than Friedreich ataxia. For this Birds of a Feather group time will be used to listen and share experiences. This will be a powerful time for everyone. Facilitators: Dr. Collins (2-5 p.m.); Dr. Coffield (3:30-5p.m.)

PARENTS (FRIEDREICH) BIRDS OF A FEATHER..... 2–5 p.m. in the Skyview 3 Room

Group time will be used to listen and share experiences. This will be a powerful time for everyone. The session will begin with identifying some expectations of the group members and addressing their issues/concerns. Facilitators: David Zilles (2-5 p.m.); Dr. Puccio, Dr. Perlman and Dr. Lynch (4-5 p.m.)

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

SPOUSES & PARTNERS WITHOUT ATAXIA

BIRDS OF A FEATHER 2–5 p.m. in the Skyview 5 Room

Attended by spouses and partners to share experiences and concerns. For the privacy of the issues talked about in this session we ask that those with ataxia attend the BOF sessions for Ataxians. Facilitators: Bailey Vernon (2-5 p.m.); Dr. Dobkin and Dr. Hoche (2-3:30 p.m.)

FAMILY MEMBERS (Over 30) WITHOUT ATAXIA (other than parents, spouses, or partners) BIRDS OF A FEATHER 2–5 p.m. in the Palace 1 Room

Attended by family members (siblings, children, etc.) of those with ataxia to share experiences and concerns. For the privacy of the issues talked about in this session we ask that those with ataxia attend the BOF sessions for Ataxians. Facilitators: Camille Daglio, and William Sweeney (2-5 p.m.); Dr. Dobkin (3:30-5 p.m.)

FAMILY MEMBERS (Under 30) WITHOUT ATAXIA (other than parents, spouses, or partners) BIRDS OF A FEATHER..... 2–5 p.m. in the Conference Room

Facilitators: Dr. Perlman (2- 4p.m.), Dr. Hoche (3:30-5 p.m.), Ralph Miller, Yoga Instructor (2-3:30 p.m.)

SATURDAY, March 22

<i>Event</i>	<i>Location</i>	<i>Times</i>
NAF Registration	Grand Salon.....	8:00 a.m. – 5:00 p.m.
Exhibitors	Grand Salon.....	8:00 a.m. – 5:00 p.m.
Silent Auction Bidding	Grand Salon.....	8:30 a.m. – 12:30 p.m.
This long-standing NAF tradition begins at a NEW TIME – 8:30 a.m. – with the final bidding ending at a NEW TIME – 12:30 p.m. It’s a fun way to help raise funds for NAF and for you to bid on wonderful items. Good luck! The winning bids will be posted by 4 p.m. Winners must pick up and pay for their items from 4 -7 p.m.		
General Sessions	Grand Ballroom (Gold/Silver)	8:30 – 11:30 a.m.
Continue all day in the Grand Ballroom. 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.		
Activity Room	Palace 1	10:00 a.m. – 5:00 p.m.
Nintendo Wii: An opportunity to observe and play the Nintendo Wii game system, Coloring activities. Healing through Writing: For this facilitated session, from 1-2 p.m., interested participants are asked to prepare a writing piece to share. 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 share and/or listen.		
Lunch	On Your Own	11:30 a.m.
General Sessions	Grand Ballroom (Gold/Silver).....	1:45 – 4:45 p.m.
Banquet	Grand Ballroom (Gold/Silver).....	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. 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.	AIM Overview and Highlights	Harry Orr, PhD <i>University of Minnesota – Minneapolis, MN</i>
9:00 a.m.	Clinical Trials and SCA 7	Brian Brooks, MD, PhD <i>NIH – Bethesda, MD</i>
9:30 a.m.	Research Review & Tissue Donation Program	Laura Ranum, PhD <i>University of Florida – Gainesville, FL</i>
10:00 a.m.	Physical Therapy for Ataxia	Polly Swingle, PT <i>The Project Recovery, LLC – Livonia, MI</i>
10:30 a.m.	Adaptive Cognitive Therapy/Caregiving	Roseanne DeFronzo Dobkin, PhD <i>Rutgers – Piscataway, NJ</i>
11:00 a.m.	Q&A Panel	
11:30 a.m.	Lunch	
1:45 p.m.	Living with Ataxia	Kyle Bryant, Ride Ataxia Founder <i>FARA – Downingtown, PA</i>
2:15 p.m.	Transitioning into Adult Healthcare	Caroline Coffield, MSW, PhD <i>Rutgers – New Brunswick, NJ</i>
2:45 p.m.	Yoga for all Abilities	Ralph Miller, Yoga Instructor <i>Gilbert, AZ</i>
3:15 p.m.	Balanced-Based Torso-Weighting	Cynthia Gibson-Horn, PT <i>Motion Therapeutics Inc., Oakland, CA</i>
3:45 p.m.	Results of Cognition Research	Franziska Hoche, MD <i>Massachusetts General Hospital- Boston, MA</i>
4:15 p.m.	Q&A Panel	

SUNDAY, March 23

<i>Event</i>	<i>Location</i>	<i>Times</i>
NAF Registration	Grand Salon	9:00 – 11:00 a.m.
Exhibitors	Grand Salon	9:00 – 11:00 a.m.
General Sessions	Grand Ballroom (Gold/Silver)	9:15 a.m. – 1:00 p.m.

Sunday morning wraps up the 2014 Annual Membership Meeting with the NAF Business Meeting and final round of General Sessions in the Grand Ballroom followed by a Question and Answer Session with a panel of the speakers who presented during this time. Don't miss this general session which includes a wrap-up of all the presentations, so if you missed any during the weekend, you will hear the highlights of each speaker's presentation.

SUNDAY GENERAL SESSIONS

Time	Topic	Speaker
9:15 a.m.	NAF Business Meeting	Charlene Danielson, NAF President <i>NAF- Minneapolis, MN</i>
9:30 a.m.	Progression of Ataxia	Susan Perlman, MD <i>University of California – Los Angeles, CA</i>
10:00 a.m.	Overview of Lou Ruvo Center for Brain Health	Ryan R. Walsh, MD, PhD <i>Cleveland Clinic – Las Vegas, NV</i>
10:30 a.m.	Selection of Mobility Devices & Caregivers as Part of the Care Team	Meleah Murphy, PT, DPT <i>Cleveland Clinic – Las Vegas, NV</i>
11:00 a.m.	Speech and Swallowing Strategies	Kiera Berggren, MA/CCC-SLP, MS <i>University of Utah – Salt Lake City, UT</i>
11:30 a.m.	Wrap-up: What We Have Learned	George (Chip) Wilmot, MD, PhD <i>Emory University – Atlanta, GA</i>
Noon	Q&A Panel	Charlene Danielson, NAF President <i>NAF - Minneapolis, MN</i>
12:30 p.m.	Closing Remarks	

For those who will be attending the 2014 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

The PowerPoint slides from the general session presentations given will be posted on NAF's website after the meeting. Audio synched General Session Presentations from the 2010-2013 AMMs can be purchased through Digital Conference Providers at <http://www.dcprovidersonline.com/naf/>. ❖

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.

SCA Study

Patients with SCA1, SCA2, SCA3, SCA6, and MSAC are needed for an MRI study to evaluate the chemistry of the brain in ataxias 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.

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

“*Betting on Ataxia Research*”

Meeting Registration Instructions

Dates: March 21-23, 2014

Location: Bally's Las Vegas
3645 Las Vegas Blvd. S.
Las Vegas, NV 89109
1-877-603-4390 or (313) 568-8300

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

Early Registration Fee (includes registrations received or postmarked by February 15, 2014):

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

Registration fee after February 15, 2014 – You are strongly encouraged to register before 2/15/14 (includes registrations postmarked after February 15, 2014 and all registrations at the door):

- Members: \$150/person
- Non-Members: \$205/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 both pages of the registration form by February 15, 2014. Please fill out the name portion of the registration form as you would like it to appear on your name badge.

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

Early Registration Deadline is February 15, 2014

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

National Ataxia Foundation, 2600 Fernbrook Lane, Suite 119, Minneapolis, MN 55447-4752
(763) 553-0020 Fax: (763) 553-0167 E-mail: joan@ataxia.org

“Birds of a Feather” FAQ and Registration Instructions

What is Birds of a Feather?

These are small groups that are facilitated by medical professionals and/or trained and experienced 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 a parent, sibling, etc.

What happens at these session?

Medical professionals will answer questions about research, clinical care, management of symptoms and other questions from the group, as well as providing a time for attendees to discuss issues that are relevant to those in the group.

Can anyone attend a Birds of a Feather session?

Yes, anyone who is over age 12 and has registered and paid the meeting registration fee can attend these sessions.

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 these sessions were the most valuable part of the annual meeting.

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

No, however, it is helpful for planning purposes to know how many people will be attending each session, so you are encouraged to indicate which session you plan to attend at the time you register.

How are the groups determined?

Groups are determined primarily by two categories:

- a. Those who have been diagnosed with ataxia and those who are not diagnosed with ataxia.
- b. Those who are ages 12-30 years old and those who are over 30 years old.

Which “Birds of a Feather” Session should I (or my family member) register for?

*Have you (or your family member) **been diagnosed with ataxia**?*

If yes, are you (or your family member) over 30 years old?

If yes, select one of the following groups that best describes your diagnosis:

- | Birds of a Feather Session | Check this box on the Registration Form |
|--|---|
| SCA1 & SCA 2 | <input type="checkbox"/> SCA 1&2 |
| SCA3 | <input type="checkbox"/> SCA3 |
| SCA6 | <input type="checkbox"/> SCA6 |
| ALL Other SCAs (including SCA 5, 7, and 8) | <input type="checkbox"/> All other SCAs (Includes 5, 7, 8) |
| Unknown With Family History & Episodic Ataxia & AOA | <input type="checkbox"/> Unknown/Episodic/AOA |
| Unknown Without Family History-Sporadic, MSA, & Gluten Ataxia..... | <input type="checkbox"/> Unknown/Sporadic/MSA/Gluten |
| Friedreich (Over Age 30) | <input type="checkbox"/> Over age 30 with Friedreich Ataxia |

If you (or your family member) are diagnosed with ataxia and are between 12-30 years old, select:

- Ages 12-30 With Any Form of Ataxia** Under age 30 with Ataxia

*If you are **not diagnosed with ataxia**, what role do you (or your family member) have in the affected person’s life?*



If you are a parent, does your child have Friedreich’s Ataxia? If yes, please select:

Parents (Friedreich) Parents (Friedreich Ataxia)

If no, please select:

Parents (Non-Friedreich) Parents (non-Friedreich Ataxia)

If you (or your family member) are a spouse or partner, please select:

Spouses & Partners Without Ataxia Spouses/Partners without Ataxia

Are you a family member other than a parent or spouse?

If yes, and you are over age 30, please select:

Family Members (Over age 30) Without Ataxia (other than parents, spouses, etc.) Family Members (over 30) without Ataxia

If yes, and you are between 12-30 years old, please select:

Family Members (ages 12-30) Without Ataxia (other than parents, spouses, etc.) Family Members (12-30) without Ataxia

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

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

I am a non-family member paid PCA. May I attend a Birds of a Feather session?

Paid PCAs are welcome to attend the session with their client however this is not required unless your client needs assistance.

I still have questions about the Birds of a Feather session. Is there someone I can e-mail or speak with?

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

The Cost of the AMM

As we see the rising costs of food at our local grocery stores, conferences costs have continued to climb as well. Many are surprised to learn the true costs in offering the world’s largest conference for ataxia families, the NAF Annual Membership Meeting (AMM). Did you know that it costs NAF more than \$100 for a gallon of coffee and more than \$8 for a small bag of potato chips at an annual membership meeting? A plated meal for the Saturday night banquet costs more than \$100.

That audio visual equipment, just to rent for a couple of days, can cost in excess of \$25,000.

You are aware of the costs to travel. To provide you with the best experts in the field of ataxia, NAF provides support for flights and lodging to the AMM speakers.

Registration fees only pay for a portion of the costs to hold an AMM. To help keep registration costs down and cover the cost of the AMM, NAF is grateful to all of our sponsors, donors, volunteers and host support groups in raising funds to help support the annual membership meeting. Without all of you, the registration costs for the AMM would be significantly higher. Thank you!

2014 NAF Annual Membership Meeting Registration

Online registration available at www.ataxia.org

1. *Full Name: _____
 Name on Badge: _____
 *Address: _____
 *City/State/Zip: _____
 Country: _____ *Phone: _____
 E-mail: _____
 Adult (18+) Teen/Child (3-17) Infant (2 & under) PCA

Please indicate the Birds of a Feather session you plan to attend:
 SCA1 & 2 All other SCAs (includes 5, 7, 8)
 SCA3 Unknown/Sporadic/MSA/Gluten
 SCA6 Unknown/Episodic/AOA
 Under age 30 with Ataxia
 Over age 30 with Friedreich Ataxia
 Spouses/Partners without Ataxia
 Family Members (12-30) without Ataxia
 Family Members (over 30) without Ataxia
 Parents (non-Friedreich Ataxia)
 Parents (Friedreich Ataxia)

2. *Full Name: _____
 Name on Badge: _____
 *Address: _____
 *City/State/Zip: _____
 Country: _____ *Phone: _____
 E-mail: _____
 Adult (18+) Teen/Child (3-17) Infant (2 & under) PCA

Please indicate the Birds of a Feather session you plan to attend:
 SCA1 & 2 All other SCAs (includes 5, 7, 8)
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 Spouses/Partners without Ataxia
 Family Members (12-30) without Ataxia
 Family Members (over 30) without Ataxia
 Parents (non-Friedreich Ataxia)
 Parents (Friedreich Ataxia)

3. *Full Name: _____
 Name on Badge: _____
 *Address: _____
 *City/State/Zip: _____
 Country: _____ *Phone: _____
 E-mail: _____
 Adult (18+) Teen/Child (3-17) Infant (2 & under) PCA

Please indicate the Birds of a Feather session you plan to attend:
 SCA1 & 2 All other SCAs (includes 5, 7, 8)
 SCA3 Unknown/Sporadic/MSA/Gluten
 SCA6 Unknown/Episodic/AOA
 Under age 30 with Ataxia
 Over age 30 with Friedreich Ataxia
 Spouses/Partners without Ataxia
 Family Members (12-30) without Ataxia
 Family Members (over 30) without Ataxia
 Parents (non-Friedreich Ataxia)
 Parents (Friedreich Ataxia)

4. *Full Name: _____
 Name on Badge: _____
 *Address: _____
 *City/State/Zip: _____
 Country: _____ *Phone: _____
 E-mail: _____
 Adult (18+) Teen/Child (3-17) Infant (2 & under) PCA

Please indicate the Birds of a Feather session you plan to attend:
 SCA1 & 2 All other SCAs (includes 5, 7, 8)
 SCA3 Unknown/Sporadic/MSA/Gluten
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 Under age 30 with Ataxia
 Over age 30 with Friedreich Ataxia
 Spouses/Partners without Ataxia
 Family Members (12-30) without Ataxia
 Family Members (over 30) without Ataxia
 Parents (non-Friedreich Ataxia)
 Parents (Friedreich Ataxia)

2014 NAF Annual Membership Meeting Registration

NAF will send out all pre-registration materials and meeting handouts through e-mail. For those who do not use e-mail, materials will be mailed and hard copy handouts will be provided at the meeting.

Please complete the following for each person:	#1	#2	#3	#4
1. Is this your first NAF Annual Meeting? Y or N				
2. Are you attending the Saturday evening banquet? <i>(included with your registration fee)</i> Y or N				
3. If you are attending the Banquet, you have the following meal options: Beef Bourguignonne entree (B), Vegetarian (V) or Vegan (VE) – all are gluten-free. Please indicate your preference. B, V or VE				
4. Will you be using a Scooter (S), Manual Wheelchair (M), Electric Wheelchair (E), or a Walker (W)? Blank, S, M, E or W				
5. Will you be bringing an assistance dog? Y or N				
6. Are you a current paid member of NAF? (If you are unsure of your membership status, contact NAF before submitting your registration form.) Y or N				

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 2014 AMM to be held in Las Vegas, NV on March 21-23.

To sign up as a volunteer at the 2014 AMM or to get more information about the volunteer opportunities, please contact Mike and Michelle Wolfson at (602) 684-5284 or mbwolfson1992@gmail.com.

IMAGE CONSENT POLICY

By attending the 2014 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 Annual Membership Meeting. Attendants 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.

Early Registration Deadline is February 15, 2014

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

2014 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, or call (763) 553-0020 to inquire about your membership status.

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

REGISTRATION FEES (includes all General Sessions, reception, and banquet)	On or Before Feb. 15, 2014	After Feb. 15, 2014	Quantity	Total
<input type="checkbox"/> NAF Member (applies to NAF members who have an Individual, Household, Patron, or Lifetime membership; <i>member rate is applied to one caregiver per individual member with ataxia</i>)	\$125	\$150		
<input type="checkbox"/> Non-Member	\$180	\$205		

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 15, 2014

Please complete all three 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

Registration Information and Las Vegas Resources

Meeting Registration

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

Registration is open and you are encouraged to register before February 15, 2014 to receive the early registration rate. There will be an additional charge for registrations received after February 15, 2014. Registrations after March 3 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.

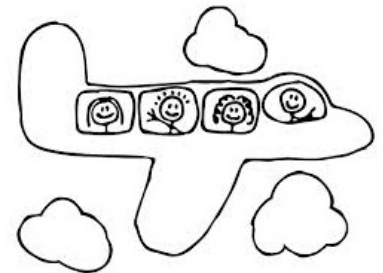
The meeting registration fee includes attendance at all the sessions, light appetizers at the Welcome Reception and a delicious plated meal at the Banquet.

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, your membership renewal is coming soon or if you are uncertain of your membership status, please consider this a great opportunity to contact the office at (763) 553-0020 or joan@ataxia.org. Visit www.ataxia.org to become a member or renew your membership online. This will prevent unnecessary extra fees or errors in your membership status when you register for the 2014 Annual Membership Meeting. Thank you for taking the time to renew or become a member of the National Ataxia Foundation.

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. Adults or children with ataxia are eligible to apply for a travel grant. Applications will be accepted until Jan. 24, 2014. 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, 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 to request one.

About Las Vegas

Las Vegas, an ever-changing fantasy land of a city, has seen unbelievable expansion since it emerged from the desert 100 years ago. The sights and sounds of Las Vegas are enjoyed by over 38.9 million visitors every year.

Vegas Strip – The length of the Strip can be deceptive ... it takes more time than you would think to get from one end to the other. But where else in the world can you marvel at dancing fountains (the Bellagio), see an erupting volcano (the Mirage), or watch pirates and sirens

Registration Information and Las Vegas Resources Continued from page 31

entertain on ships nightly? (Treasure Island, or T.I.) Not to mention downtown's Fremont Street Experience, which is a haven for pedestrians. Be sure to wear comfortable shoes and carry a bottle of water.

Please visit www.visitlasvegas.com and www.lasvegas.com/travel-professionals/agent-tools/special-needs-visitors/ for a complete list of attractions and planning information.

Weather in Las Vegas

In Las Vegas the average high temperature in March is 69 degrees and the average low temperature is 44 degrees.



Bally's Las Vegas

Bally's Las Vegas is the official conference hotel of the 2014 NAF Annual Membership Meeting. Bally's Las Vegas is located directly on the Vegas Strip and minutes from the McCarran International Airport at 3645 Las Vegas Boulevard S., Las Vegas, NV 89109.

Offering more than 2,800 rooms and suites, Bally's Las Vegas is one of the world's largest resorts. Please allow yourself extra time to familiarize yourself with the layout of the hotel. The property also has a 70,000 sq. ft. casino, events center, five fine restaurants, spa, shopping mall, and two world-class showrooms. From upscale dining like Bally's Steakhouse's Sterling Brunch to casual eats including Mexican, American and Asian cuisine, Bally's offers an impressive selection of Las Vegas restaurants. The Bally's Las Vegas Avenue Shops are a shopping experience with more than 20 unique stores and boutiques

with a countless array of souvenirs, jewelry and exclusive fashions. Visit the Bally's Las Vegas website www.ballyslasvegas.com for more information.

Internet at Bally's Las Vegas

NAF AMM attendees staying at Bally's Las Vegas will enjoy complimentary internet in their guest room. When connecting to the internet the full price will be listed on the website. Your discounted price will be reflected on your guestroom billing statement. This discount applies to in-room internet for one device. Additional charges will apply for more than one device or for internet services selected outside the guestroom.

Parking at Bally's

Valet parking and Self-parking are available. Both are complimentary. Bally's complimentary parking garage is located off the Las Vegas Strip with a clearance of seven feet. To get to the parking garage and valet, take Flamingo Rd. East exit, cross Las Vegas Blvd., then take first right into Bally's.

Oversized parking is available in Bally's east lot located off Flamingo Rd. RV's are welcome, however, no hook-ups are available. Please note Bally's Security Department must be contacted upon arrival for oversized parking authorization at (702) 967-4481.

Service Dog Information

The service dog relief area at Bally's is located outside the Food Court Entrance on the lower level.

Hotel Reservations

Standard room reservations at Bally's Las Vegas can be made online at www.totalrewards.com/hotel-reservations?propCode=BLV&groupCode=SBNAF4.

For guests who prefer to phone in their reservations call the Reservation Center at 1-800-358-8777 and ask for the National Ataxia Foundation's group rate. Callers may also use your group code to identify the group, **SBNAF4**. A credit card is required at the time of ►►

booking and a deposit equal to one night's room and tax will be charged. Notice of cancellation must be received 72 hours prior to your arrival date, in order to receive a full refund of your deposit. Parking and valet is provided at no additional fee. Request rooms in the North Tower to be closest to convention spaces.

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 Bally's please contact the National Ataxia Foundation at (763) 553-0020 or lori@ataxia.org. ADA rooms cannot be reserved through the hotel.

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 Las Vegas Services and Resources section of this article. NAF is unable to provide ADA equipment however Bally's 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 guestrooms is 26 inches.

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

Transportation and Getting There

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

Security Administration and the U.S. Department of Transportation. Also visit the website of the McCarran International Airport <https://www.mccarran.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. We look forward to having you attend the 2014 Annual Membership Meeting and wish you Happy Flying!

Please note: If you are flying on United, Hawaiian, Virgin, JetBlue, Alaskan, Sun Country, or arriving from an international location you will arrive at Terminal 3 which is a long building. It is a long walk to baggage claim from Terminal 3.

McCarran Ground Transportation

Lift Equipped Group Shuttles – are available at the McCarran International Airport to Bally's. The cost is approximately \$7 per person one way and \$13 per person round trip. Group shuttles are an economical way to get from the airport to most major hotels. Shuttles run every 15 to 20 minutes. Some shuttles accommodate one wheelchair; some accommodate two. While en route, group shuttles make multiple stops at locations along the way. At Terminal 1, group shuttles are available on the west side of baggage claim, outside door exits 7-13. At Terminal 3, shuttles are located outside on Level Zero on the west end of the building to serve domestic travelers and on the east side of the building to accommodate international travelers. Airport personnel are available to help queue the lines and provide assistance as needed. Shuttles are not owned or operated by Bally's Hotel or Caesar's Properties.

Taxis – All taxi companies in Las Vegas have lift-equipped vans accommodating one wheelchair. Ask in advance for an accessible taxi van (702) 888-4888. At Terminal 1, taxicabs are

Registration Information and Las Vegas Resources
Continued from page 33

available on the east side of baggage claim, outside door exits 1-4. At Terminal 3, taxicabs are located outside on Level Zero on the west end of the building to serve domestic travelers and on the east side of the building to accommodate international travelers. Airport personnel are available to help queue the lines and provide assistance as needed.

Paratransit – If you are certified to ride paratransit, bring your certification and you will be allowed to ride for up to 21 days without a Nevada certification. Visit the RTC website <http://www.rtcnv.com/transit/paratransit/> or Call (702) 228-4800 one to three days in advance to schedule rides. The RTC Paratransit Shuttle Service is available by reservation at Terminal 1 and Terminal 3. The Terminal 1 shuttle stop is just outside the doors on Level Zero and the Terminal 3 stop is located on Level Zero, outside door exit 55.

Other Transportation Resources

Strip Trolley – The trolley operates on the Strip and pulls up to the entrance of each hotel on its route. Most are lift-equipped. For details visit <http://www.lasvegas-how-to.com/trolley.php>.

Monorail – Hop on the Las Vegas Monorail and experience a convenient, state-of-the-art alternative to traveling the world-famous Las Vegas Strip – in 15 minutes or less! Bally's/Paris Las Vegas Station is located at Bally's with access to Paris Las Vegas located next door. You can reach the station by heading toward the pool area through the Bally's Avenue Shops. Visit <http://www.lvmonorail.com/> for schedules and ticket prices.

CAT (Citizens Area Transit) – Bus service is fully accessible, including buses that are lift-equipped. Reduced fares are available for persons with disabilities. Call (702) 228-7433 or visit <http://catride.com/>.

Parking – If you have a parking permit from your home city for your car's dashboard and you will be renting a vehicle in Las Vegas, bring it with you. You may also make advance arrangements for a free 90-day temporary disabled parking permit through the City of Las Vegas. Write to: City Hall, Parking Permit Office, 400 E. Stewart, Las Vegas, NV 89101, (702) 229-6431. Send a doctor's letter explaining the condition and the duration of the condition, and allow two to three weeks for a response. Valet parking is also an option at nearly every hotel.

The following information can be used as a guide as you plan your **stay** in Las Vegas. The National Ataxia Foundation does not endorse products, services, or manufacturer. 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.

Las Vegas Area Services and Resources

Wheelchair Van Rental

Ability Center

(702) 434-3030 Fax: (702) 434-3014

<http://www.abilitycenter.com/lasvegas.php>

Accessible Vans

(702) 815-8015 1-855-720-7146

<http://www.accessiblevans.com/wheelchair-vans-rental-las-vegas-nv.php>

Better Life Mobility Center

1-888-540-8267

<http://www.betterlifemobility.com/Disability-Services/Handicap-Van-Rentals>

Wheelers

Las Vegas McCarran International Airport

1-800-456-1371

<http://wheelersvanrentals.com/US/nevada-wheelchair-van-rentals/>

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 Las Vegas. 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.

Comfort Keepers

(702) 385-1000 Fax: (702) 452-1001
<http://www.comfortkeepers.com/office-142>

Nurse Core

(702) 458-1137 Fax: (702) 458-1423
<http://www.nursecore.com/>

Professional Healthcare Services

(702) 362-0711
<http://professionalhealthcareserviceslv.com>

Right At Home

(702) 367-3400
<http://www.rightathome.net/lasvegas/>

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.

Nannies & Housekeepers U.S.A.

(702) 451-0021
<http://nahusa.com/>

Accessible Equipment, Wheelchair, and Scooter Rentals

The following may be used as a helpful guide for your convenience.

Ability Center

(702) 434-3030 1-800-546-7622
<http://www.abilitycenter.com/lasvegas.php>

Better Life Mobility Center

(888) 540-8267
<http://www.betterlifemobility.com>

Desert Medical Equipment

3555 W. Reno Ave., Suite F
 Las Vegas, NV 89118

(702) 876-9171

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

Freedom Medical Supply & Equipment

8868 S. Eastern Ave.
 Las Vegas NV 89123
 (702) 386-9997 Fax: (702) 228-9996
<http://www.freedommedicalsupply.com/pages/>

Las Vegas Scooters

4350 S. Arville St., Bldg. E, Suite 40
 Las Vegas, NV 89103
 (702) 610-4905 1-866-775-4381
<http://www.702scooters.com/>

Scootaround Inc.

1-888-441-7575
<http://scootaround.com/>

Pharmacy

CVS Pharmacy

3758 S. Las Vegas Blvd.
 Las Vegas, NV
 (702) 262-9028
www.cvs.com

Ryan's Pharmacy

150 E. Harmon Ave.
 Las Vegas, NV
 (702) 997-8062
www.ryanspharmacylv.com

Walgreens

3765 Las Vegas Blvd. S.
 Las Vegas, NV
 (702) 739-9645
www.walgreens.com

ADA Assistance Office

Las Vegas Convention & Visitors Authority

ADA Coordinator
 (702) 892-0711

Nevada Relay Service

Voice: 1-800-326-6888 or Dial 711
 TTY: 1-800-326-6868 or Dial 711
<http://www.lasvegas.com/travel-professionals/agent-tools/special-needs-visitors/>



Four Components to an Effective Physical Therapy Program for Ataxia

By Polly Swingle, PT
The Recovery Project, LLC

This is the second part of a two-part edited excerpt of the presentation given by Polly Swingle at the 2013 Annual Membership Meeting in Detroit, MI on the essential components of an effective physical therapy program for ataxia patients. Polly Swingle is a physical therapist at Project Recovery in Detroit, MI. In the first part Polly addressed physical issues related to ataxia, research, the physical therapist's evaluation, characteristics of an effective program and measures used to determine improvement. This second part of Polly's presentation includes a description of exercises with complete instructions for a 60-minute physical therapy session.

Characteristics of a Successful Exercise Program

- Static and dynamic balance both in sitting and standing.
- Trunk-limb coordination
- Gait
- Contracture prevention (Range of Motion)

The four main components are: 1) Cardiovascular-working the heart, warming up the body; 2) Balance; 3) Strengthening; and 4) Flexibility.

Physical Therapy Program (60 minute session)

Warm up: 5 minutes

• 5-Minute Walk – If you are ambulatory, this walk can mentally prepare you for exercise. This is where you would walk continuously.

OR

• 5 minutes of a continuous activity such as bike, Nu-step (this is a piece of equipment that looks like a recumbent bike, but it works your arms and legs at the same time; your community or exercise location may have this equipment), arm bike, treadmill, rowing machine, etc.

This 5-minute activity will:

- Increase muscle and body temperature
- Dilate blood vessels
- Increase range of motion
- Provide mental preparation

Balance training: 20 minutes

• Modified Lee Silverman LVST – This is a

protocol that came out about five years ago. It is a program that was developed for individuals with Parkinson's disease. Some of these forms of exercise are used for people with ataxia because they involve moving your arms and legs in very coordinated movements. They are done while sitting and standing, and they challenge your balance in a safe way.

• Romberg – Patient stands with feet together, semi-tandem, and tandem, with eyes open for 10 seconds then closed for 10 seconds in each position.

• Unilateral stance – The standard for adults is to stand on one leg for 30 seconds. That can be your goal. If you do it over, and over and over again, you should see improvement.

There are so many ways for you to work on and challenge your balance, so when you are doing this be sure to target neuromuscular systems that control balance through various levels of challenges such as:

- Control center of gravity (COG) over the base of support (BOS).
- Increase challenge by engaging visual, vestibular, somatosensory and cognitive systems.
- Elicit postural reactions and balance strategies by altering stimuli, surfaces, etc., standing with your feet together, standing with your feet apart, standing on one leg, etc.
- Weighted vests



Strengthening: 20 minutes

- Evidence-based research suggests:
 - Muscle strength decreases with age
 - Weakness is a risk factor for falls
 - High intensity strength training programs can significantly increase lower extremity strength and significantly increase functional balance ability
- Addition of resistance training* to an existing program of balance and flexibility lead to improvements in balance and functional ability.

*Do not add resistance training if you are not able to lift up against gravity because this could cause you harm.

The recommended amount of repetitions is 12-25 at 30-60% of a maximal contraction. Perform each exercise with full ROM and at a slow pace. Research has shown that maintaining a muscle contraction throughout the full ROM will release dystrophin, which will aid in building muscle strength.

Essential components of strengthening program

- Individualized by your therapist, based on the evaluation process to find out which muscles need to be strengthened.
 - Increases in difficulty
 - Is sustainable at home
 - Includes walking program to complement strengthening and balance activities

Strengthening Exercises

- Target pelvic muscles
- Straight leg raise, knee to chest, hip abduction, hip adduction, bridging, long arc quad, hamstrings curls, squats
- If you have access to a facility that has strength building machines, here are the most beneficial strengthening activities. Try for three sets of eight repetitions each, as you are able.
 - Leg Press
 - Hip Abduction/Adduction
 - Calf Press
 - Seated Row
 - Plank

- Bridging
- Abdominal Bracing

- Upper extremity weakness or core – there are hundreds of different exercises that can be done. Ask your therapist to teach you how to activate your core. It is called *abdominal bracing*, where you are squeezing your abdominal and back muscles and activating the core while you are exercising. It is a learning process.

- Proximal weakness in the upper extremities, in particular the shoulders, which seem to be a little bit weaker than the hands or the elbows for those with ataxia. Focus on the working those muscles. It is also suggested that you do not exercise in the same position. Often when you go to therapy, the therapist will tell you to, “Lay on the mat, we are going to do the leg exercises.” That is great, but it is important to exercise in additional postures such as sitting and standing. If you can’t stand independently, maybe standing in the “standing-frame” and doing exercises with your arms so you are activating different muscles. Even laying on your stomach and doing different exercises is a great way to activate some of those back core muscles. If you sit in a wheelchair or scooter, even asking to just sit in a different chair. If you change the surface that you are sitting on, that also can activate different muscles as you are working on the upper extremities.

Stretching/Flexibility: 15 minutes

When you have ataxia, you tend to walk with a stiffer gait pattern and we often see that the hips become very tight and the heel cords can also get very tight because you are not getting an adequate heel strike because you are mostly walking on a flat foot. Working on flexibility will help with normal range of motion. Try for five repetitions that you hold for 30 seconds each.

- Flexibility
 - Hamstrings
 - Heel cords (the calf muscle)
 - Hip flexors (muscles in the front of the

Four Components...
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hip, especially if you are sitting more than standing)

– Quads

If you have some tightness in your arms, where you can't get full range of motion, do stretching of your arms as well. Be sure that you can stretch them all the way up into extensions.

What we have seen to be a success in our practice is a 60-minute long physical therapy session. I have worked in many different settings, and sessions tend to range from 30 minutes to 60 minutes with 60 being the optimal amount of time. I hope no one is just getting just 15 minutes. If you think about it when you go into physical therapy, it can take 5-10 minutes just to set up and discuss the activity. I encourage you

to talk with your therapist about a program as I have structured it in this presentation.

Frequency and Duration of Physical Therapy Sessions

The frequency is based on your insurance benefit. Discuss with your therapist how many visits you are able to get per year and work out a schedule with them. Two times a week for eight weeks is recommended. A duration of eight weeks, which is a minimal time period, will at least give us the opportunity to see a change.

Outcomes

The ultimate goals are to decrease falls, increase safety and functional mobility.

I want to thank you for your attention. ❖

To receive a copy of the first part of Polly Swingle's presentation, contact the National Ataxia Foundation office at (763) 553-0020 or naf@ataxia.org.

Nightly Trips to the Bathroom

Submitted by Jason Wolfer

There are several challenges in life, but the existence of Ataxia in mine has only served to magnify those challenges. What is routine for others who don't know this struggle is paramount to running a decathlon while juggling chainsaws for me. Let me give you an example of just one such obstacle. I wake up at night and desperately need to go to the bathroom. Here is my list of challenges:

The days of instantly springing out of bed are long gone; in fact I'm not sure they ever existed.

I begin to prepare myself for the journey ahead by swinging my legs to the edge of the bed, sit up, and really try to focus. I launch myself off the bed, stand up in victory, only to discover my legs think I'm a newborn calf, and it's then that I realize that I am in for quite a bumpy ride.

As my legs fight for supremacy, my bladder is yelling at my brain, "I'm telling ya, you better hurry."

The leg muscles respond, "Do you want to come down here and try and move this guy?" The eyes are seeing all the potential injury scenarios and thinking, "We just hope someone's in charge" and the toes are thinking, "We need hard hats!" Soon, everyone is involved in the miniature scaled conflict

By some miracle I make it, only to face a very similar return trip.

If you are interested in reading more please follow this link:
<http://jasonwolfer.blogspot.com/2013/10/ataxia-part-1.html> ❖



Jason Wolfer

Where There's a Will, There's a Way

By Heather Yowell

It was a crisp fall day and I had decided to take the dog out before it rained. It was late morning; the sky was overcast with a forecast for showers in the late afternoon. I donned my purple floppy hat, sunglasses, opened the screen door and bounded out onto the porch. The door slammed shut behind me. I never gave it a second thought, that is, until I discovered I was locked outside of the house.

Oh, no! I pulled on the door handle, but it wouldn't budge. My mind raced for a simple solution, but I didn't have one. The dog made her usual rounds through the yard, and then she stopped and looked over at me. Even she knew that something was wrong.

How am I going to get back in the house? I wondered. I needed to call for or help, but whom? There were some neighbors who might be home, but their house was on the other side of the fence. I have a severe balance problem and I wasn't about to attempt to climb the chain link fence. I've heard of people getting hung up on wire fences.

I had to get back inside! The cats were in there, and one was very, very sick. My mind raced as I glanced at the padlock on the gate. Could I get through it without letting the dog out? The animals were my responsibility and my biggest concern. It never occurred to me that I could get hurt, but there was another neighbor who might be able to help me.

Carefully, I leaned on the gate and undid the padlock. Checking to make sure the dog was preoccupied on the other side of the yard; I eased the gate door open and slowly lowered myself until I was sitting on the top step. My joints are always locking up on me, but once I had scooted down those steps I stood erect without even giving my "tricky" equilibrium a second thought.

I made my way straight across the driveway, down the bank, across the next driveway, up over an embankment, down an uneven hill to the neighbor's porch, up the steps and rang the doorbell. All this without the usual staggering often confused as drunkenness! What a relief that someone was home.

Lesson learned: Always check the door latch before going outside! ❖



Heather and her dog Fiona

Vegas Guidebook

Request a "Las Vegas" guide book provided by the Las Vegas Convention and Visitors Authority to help you plan your journey! The complimentary guide book is filled with information about the city. This free guide can be requested by calling 1-877-847-4858 or you may request or download a copy at www.lasvegas.com/planning-tools/free-visitors-guide/.

To find out more about the 2014 NAF Annual Membership Meeting, visit NAF's website www.ataxia.org.

NAF Merchandise

BOOKS

- Healing Wounded Doctor-Patient Relationships**
by Linda Hanner with contributions by John J. Witek, MD \$10
- Living with Ataxia: An Information and Resource Guide** by Martha Nance, MD (2nd ed. 2003) \$14
- Managing Speech and Swallowing Problems: A Guidebook for People with Ataxia**
by G.N. Rangamani, PhD with contributions from Douglas E. Fox, MS (2nd ed. updated 2006) \$7.50
- Ten Years to Live**
by Henry J. Schut \$8.75
- There's Nothing Wrong with Asking for a Little Help ... and Other Myths**
by Dave Lewis \$15.95
- Recipes and Recollections**
by Kathryn Hoefler Smith \$10
- Cooking for a Cause**
by Julie Karjalahti for FRDA research \$12

VIDEO/CD

- Ballads of a Family Man CD** \$5
- Together There is Understanding** VHS \$20 DVD \$25

SHIRTS/MISCELLANEOUS

- Original NAF IAAD T-Shirt** \$10
- NAF Baseball Cap (White or Blue)** \$10

- International Ataxia Awareness Day T-Shirt** \$10
Available in youth L, and adult S to XXXL (XXL out).
- Past Annual Membership Meeting (AMM) T-Shirts**
\$1 each while supplies last!
- NAF Polo Shirts** \$25
Mens – Royal blue w/white NAF logo in M to XXXL.
Womens – Light blue w/ navy NAF logo in S to XXL.
- NAF Denim Shirt** w/ white embr. NAF logo. \$27.50
- “Ataxia is Not a Foreign Cab” T-Shirt** \$10
White. New design. Sizes S to XXXL.
- “Ataxia is Not a Foreign Cab” Long-Sleeve T-Shirt**
Blue. Sizes S to XXXL. \$15
- “Ataxia is Not a Foreign Cab” Sweatshirt**
White. Sizes S to XXXL. \$20
- NAF 50th Anniversary Coffee Mug** \$3
- “Ataxia is Not a Foreign Cab” Magnet** \$1
- Window Cling or Bumper Sticker** \$1 ea. or 6/\$5
- NAF Ataxia Awareness Band Blue** One size. \$2
- NAF Ataxia Awareness Ribbon Magnet** \$4
- Reusable Grocery Bag w/ NAF and Cab Logos** \$5
- “Know Ataxia” Backpack 20”x16”** \$5
- NAF Grip n’ Sip Water Mug** \$5
- NAF Lapel Pin** \$5
- Magnetic Power Clip** \$3
- NAF Shoulder Bag** \$10

To place your order, call (763) 553-0020, fax (763) 553-0167, mail a copy of this form to National Ataxia Foundation, 2600 Fernbrook Lane, Suite 119, Minneapolis, MN 55447 or visit <http://tinyurl.com/nafstore>

ORDER FORM

Description	Qty.	Size	Each	Total
SUBTOTAL:				
Shipping within U.S.:			Add \$5.00	
Shipping outside U.S.:			Add \$15.00	
ORDER TOTAL:				

NAME: _____

ADDRESS: _____

CITY: _____ **STATE:** _____ **ZIP:** _____

PHONE: _____

E-MAIL: _____

*For credit card orders, please fill out the following information (you **must** include phone number and signature):*

PLEASE CIRCLE ONE: Visa Mastercard Discover

NAME ON CARD: _____

CARD #: _____

EXP DATE: _____ **CVV #:** _____

SIGNATURE: _____

PLEASE ALLOW 4-6 WEEKS FOR DELIVERY

An Adventure

Submitted by Tim Gillilan

This is written from the perspective of a person dealing with ataxia and its aftermath. If you're reading this I can only presume you or a family member or perhaps an acquaintance has been diagnosed with this condition. I don't pretend to have all the answers but wanted instead to take this opportunity to share some of my experiences with the hope that someone reading it might in some way benefit from it.

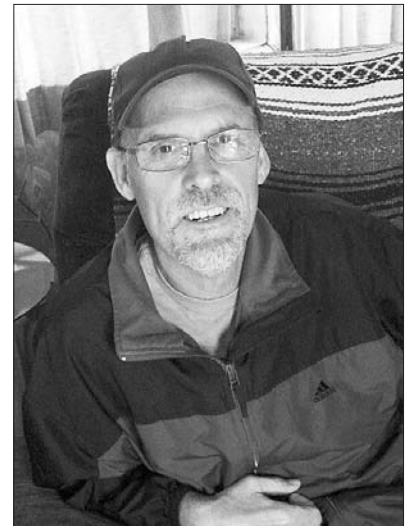
I first received a diagnosis in April of 2013 after struggling for some two or three years to get my medical provider to tell me why it was that I was having certain problems. My chief complaint, as doctors like to say, was having a problem with my balance and my speech. I had seen my primary care doctor a number of times and graduated to specialists, including neurologists, an ear, nose and throat doctor, which included having various tests performed that included MRI's and blood tests and the best that I could come up with from them was to be told I had an inner ear problem, although I knew that something more serious was happening.

Looking back even further, maybe several years, I wonder now why it was that a formerly very active person such as myself was suddenly having occasional problems with little things like the dragging, briefly, of a foot, or recovering from an off-balance situation that would previously have been no trouble for me at all. I tried to ignore these problems and, true to the accepted wisdom of the experts, though, my condition progressed to the point and I could no longer ignore them. I had an experience with falling and it was while being treated for the fall, in which fortunately I was not seriously hurt (but could have been), that I realized that I needed to find out what the root of my "problem" was.

Thus started my adventure, sometimes in frustration in feeling my condition was not getting

the attention it deserved and dealing with what I felt to be at times to be an indifferent medical bureaucracy, to other times in fear, in gradually losing a physical ability that was at one time very robust. It turns out that I was diagnosed with a rare condition that was not readily apparent to the medical establishment in which I found myself.

I felt very alone at times in my quest to understand what was happening to me and it was only an inner strength and the picking up of friends along the way, and of course member of my extended family,



Tim Gillilan

that has carried me through. Some people also look to a faith in a higher power to cope also.

I'd gone all too quickly from being an independent provider for others and to myself to a person that depends on others to help me perform what were once routine tasks, which was not an easy but ultimately necessary process. Gradually, I came to understand that nearly everyone I encountered wanted to do a good job, and would if given the chance. I learned that it does me no good to dwell on the negative aspects of this condition.

If I felt that the medical bureaucracy I was dealing with was challenging, I was not prepared for the shock of navigating the maze that is the

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*An Adventure**Continued from page 41*

Social Security Administration. Initially promising, my “claim” for disability as it is known, has languished in what I can only describe as application purgatory, a real exercise in frustration that required oceans of patience.

I learned some months later, only after I had submitted my application, that the condition that I have is listed, along with many others, on the Social Security Administration Compassionate Allowance web site. This program was set up by Congress to speed the process of filing for disability. Surely, I thought, the person from the Social Security Administration assigned to my case would have informed me of the existence of this program. But no, that was not the case. It was only after attending a meeting of my local chapter of the National Ataxia Foundation that I learned of its existence. I of course made sure that my Social Security Analyst knew that I was filing under that program.

I’ve had the good fortune of being directed by the NAF to an advocate of the disabled that has helped me in understanding the workings of the disability process and has also been a source of comfort to me. Almost uniquely, I felt that I was talking to someone that got it. While the outcome is not yet decided, I have more confidence in the eventual outcome.

If I can provide any advice, know without a doubt that it is so important to maintain a posi-

tive outlook. I’ve been told by many people that I’ve met along the way of this adventure of the value in maintaining a positive disposition. Granted, at times it is very difficult to do, but I think it is so important to maintain one and to keep the fires of hope burning. It might help you to know that there are some very positive developments taking place that are yielding encouraging developments. Not a cure I’m told, mind you, but a treatment nonetheless.

Having a supportive network of friends and family has been so important to my well being it cannot be overstated. I am very fortunate to be in what I feel to be a good place; it definitely has taken a load off my mind. Realize also that, although your life has drastically changed, you are a valued member of the human family and are deserving of love, respect and dignity.

Not playing a passive role in your care, I feel, is also something that will first of all keep you occupied, which in my opinion is a positive. What do I mean by that? Some examples are educating oneself by reading material available on the web site of the National Ataxia Foundation, which I will admit can be a bit daunting and in all honesty I’ve not completely digested. Nonetheless, I think that it is important to gain a broader understanding of the issues you face and interacting from that base of knowledge with your medical care givers.

Having a doctor knowledgeable in, and the treatment of, ataxia is also important. An experienced physician will know what to do and when. A list of doctors can be found on the web site of the NAF.

Finally, and know that there is no special order here, is participating in the closest local chapter of the National Ataxia Foundation. Aside from the camaraderie of meeting people with your condition, you can gain immeasurably from a pool of knowledge from people that have gone through many of the same issues and problems you face. Just realize that you are not so alone.

I humbly welcome inquires at: timgillilan@gmail.com.



Share Your Story

Generations is published quarterly by the National Ataxia Foundation. Personal stories from our readers are an important part of the publication. Stories submitted should be no longer than 1,200 words. Please include a picture. Submit stories to joan@ataxia.org to be considered for publication. The deadline for the upcoming Spring 2014 issue is Friday, March 7, 2014.

Chapter and Support Group News

from Around the Country

Alabama Ataxia Support Group

Submitted by Becky Donnelly

Our summer social was held at the Gunter'sville State Lodge on June 22, with a great attendance, excellent food, and good fellowship.

Our October meeting and luncheon was held at Covenant Presbyterian Church with 19 members present. Our speaker was Leanne Messner, Business Development Coordinator at Brookdale Place in Homewood. She gave a comprehensive overview of senior living and care costs of facilities in our community and surrounding areas. Sandee Mackinaw provided a delicious luncheon for us. Juanita Dorroh, our inspirational leader, sparked discussion by giving out personality scoring sheets for members to fill out and return in January when results will be determined. This activity's intent is to make those with ataxia, as well as their caregiver, understand the differences in personalities which will help them understand and appreciate one another.

We held our December social at the Red Lobster in Vestavia Hills, with the group's three sisters – Rita Dean, Ann Smith and Regina Hildredth – as social planners.

Greater Atlanta Ataxia Support Group

Submitted by Dave Zilles and Greg Rooks

Lynn Robinette, due to work and other commitments, has decided to step down as co-leader. For many years she was a key contributor to our success. Lynn felt her schedule would not be slowing soon and another support group member could better serve as co-leader. We thank Lynn for her devotion and all that she has done for our support group. It has been a pleasure and honor to work with her.

We had a good crowd and a great meeting. A very special welcome to our first-time attendees. Dr. Wilmot dropped by unexpectedly with some exciting news.

We reported on results of the Walk n' Roll. The video from the Walk n' Roll has been completed and posted to YouTube here: <http://youtu.be/Ijr7ylTNbsA>.

We talked about the Ataxia Research Drive and donating to the general Research Fund so the funds can be directed to the most promising ataxia research projects.

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Members of the Greater Atlanta Ataxia Support Group

Chapter and Support Group News
Continued from page 43

We also discussed the New Ataxia Patient Registry and recommended that all members join. Plans were also made for our annual Christmas party.

In November our support group elected four support group leaders. For several years there have been no changes. With Lynn’s resignation there was one replacement this year and we added an additional person. Dave and Greg were still willing to serve and were nominated and elected. We also elected Lealan LaRoche and Brean Underwood.

Delaware Ataxia Support Group

Submitted by Joe DeCrescenzo

The Delaware Support Group held its Fall meeting on October 19. Our featured speaker was Carol Barnett from the State of Delaware Aging and Disabled Adults Resource Department. Carol has over 30 years of experience dealing with aging and adults with physical disabilities issues. Carol spent over an hour explaining the many, and varied, resources available to us through the State of Delaware. She also distributed literature on how to find the various resources. One of the topics covered was the many home-assistive devices set-up for physical testing through the Easter Seals.

Denver Ataxia Support Group

Submitted by Charlotte DePew

The October 19 meeting was both frustrating and rewarding. The frustrating parts were audio-visual and computer issues. The rewarding part was the laptop going into hibernation while we watched the physical therapy presentation (online) given in Detroit in March 2013. The host hospital’s computer system “kicked us out” just as the online speaker reached the point where she discussed exercises for strength, balance, etc. Ann Valentine, PT, DPT, NCS, a Physical Therapist at UCH Rehabilitation Medicine, was present to answer questions. She skillfully took over describing and demonstrating the exercises diagrammed in the speaker’s handout. Several members commented that this was among the best and most helpful talks we have had at our meetings. Ultimately, having Ann finish the program was better than following slides.

The second fortunate event was that David Garcia, from the Phoenix Support Group, unexpectedly attending our meeting while visiting Denver for the weekend. Because of his help, we were finally able to get audio to the overhead speakers so we could get the first half of the online talk.

Don Stanosheck, our 98-year-old ataxia member, recited a beautiful poem from memory: “When Man Knows How to Live.” ▶▶



Members of the Denver Ataxia Support Group

The program topic for our next meeting on January 18, 2014 will be on genetic testing by Athena Diagnostics and a genetic counselor.

Central New York Ataxia Support Group Luncheon and Quilt Raffle

Submitted by Mary Jane Damiano

The Central New York Ataxia Support Group met on September 28 for the final meeting of the season. We enjoyed a delicious lunch. The refreshments were donated by Wegmans Food Markets.

We celebrated Saul Beckman’s 92nd birthday, he is the oldest member of our group.



A quilt was raffled off by the Central New York Ataxia Support Group

A quilt donated by the Pompey Pincushions, a local sewing group, was raffled off to benefit NAF. We raised \$125 for ataxia research. The winner of the raffle was Tess Oliver of the MDA. She will donate it to the MDA to be used for fundraising.

Central PA Ataxia Support Group

By Chris Rakshys

We had our third meeting on October 26 at the Muhlenberg Library in Laureldale. We were very fortunate to have Ms. Jennifer Millar from Johns Hopkins come up from Maryland to

spend time with us and to speak on the topic of physical therapy. A special thank you to our member, Ms. Donna Klotz, for suggesting her!

The presentation was packed with very useful information and focused on physical therapy catered to an ataxian. At the Johns Hopkins clinic, a thorough evaluation usually takes about 90 minutes and covers posture, strength, range of motion, endurance and safety considerations. When a physical therapy treatment is later given to the patient as a take-home piece, it is a comprehensive individualized program which may include cerebellar and vestibular adaptation exercises (eye head coordination exercises), vision therapy (tasks to encourage eyes to move together), balance training (standing/static tasks, walking/dynamic) and functional mobility and gait training (mobility strategies).

Personally, what I thought was the most interesting point of her presentation was the inclusion of Vestibular Therapy as part of the Physical Therapy program. Unfortunately, a lot of local physical therapists don’t incorporate these types of exercises (eye head coordination) into a regular session with an ataxian, but I feel that it is such an important component for many of us.

Afterwards, we decided to hold off for the winter and to have our next meeting in April, 2014. We look forward to hearing from Mike, Harry, and Kathy at the NAF AMM in Las Vegas. Hope to see you then!

Tri-State Ataxia Support Group

Submitted by Kathy Gingerelli

Our meeting on September 12 started off with everyone going “around the table” and making introductions for our new attendees. After that we talked about what had been going on with each of us since our last meeting.

Starting off our discussion was the Balance Wear Vest. The website *www.motiontherapeutics.com* is the place for patient testimonials, videos,

Chapter and Support Group News
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and contact information. Please remember, the vest is NOT a cure and results (or lack of) are going to vary for each individual.

We also spoke about the Ataxia Center at Johns Hopkins, www.hopkinspdmd.org. I handed out a copy of the *Ataxia Digest*, which is the newsletter of the Johns Hopkins Ataxia Center, and encourage everyone to check out the site and gather any information pertaining to studies going on.

With the cold weather moving in everyone was encouraged to keep busy and stay active, daily, with exercise and volunteer work.

Everyone was reminded to become a member of NAF and enroll into the CoRDS registry.

Submitted by Patty Hanley

I would like to share with everyone what the Arthritis Foundation has to offer. Having ataxia makes it difficult to exercise but the classes that the foundation offers I feel could benefit us all. They offer Aquatic, Exercise and Tai Chi classes. I ask you all to look at the Arthritis Foundation website www.arthritis.org, as I know how important exercise is.

Middle Tennessee Ataxia Support Group

Submitted by Vicki Tyler

The Middle Tennessee Ataxia Support Group met Saturday, November 16. We had 22 attendees. We had a good time visiting with each

Vehicle Donation

Donation of your vehicle to the National Ataxia Foundation will help support the important work of the Foundation. To donate your car, truck, motorcycle or motor home, please call 1-800-240-0160 or visit www.donateacar.com.



Members of the Middle Tennessee Ataxia Support Group and guests enjoying lunch.

other, eating lunch, and hearing from Laura Morefield about her new balance vest. She has seen improvement in both her balance and coordination. For example, her handwriting seems to be improved, in addition being able to walk with more control. Another member, Donna Roysdon, has ordered a balance vest, so we are excited to be able to hear from both of them as time goes on.

Our next meeting will be in February on a Saturday at Amerigo restaurant in Cool Springs. The exact date is yet to be determined.

Central Massachusetts Ataxia Support Group

Submitted by John Mauro

It is our goal is to have four states attend the Walk n' Roll and double our fundraising goal in the near future. We are currently working with other support groups to form the "New England Chapter." This could be done by joining all the support groups together. This group of people would drive all the media in Massachusetts, New Hampshire, New York, Connecticut, and soon Rhode Island. This consolidation could make the northeast a stronger ataxia community. This year the group helped New Hampshire get their resolution signed and are working on a bill for them. The group is also working on three more states to do the same thing by September 2014.❖

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 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

NAF CHAT ROOM

Moderator – Della (ddpokernut@yahoo.com)

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

NAF FACEBOOK GROUP

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

NAF FACEBOOK FANS

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

NAF YOUTUBE CHANNEL

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

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Charlotte DePew

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

Matching Gifts

Many employers will match your gift to the National Ataxia Foundation. 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 ask your employer if they have a Matching Gifts Program, and encourage your co-workers to contribute to the important work of the Foundation. Thank you.

Enroll in the Ataxia Patient Registry Today

There has been a wonderful response to the upgraded patient registry that was launched in July 2013. Over 900 people have begun the process of enrollment.

Everyone who has any form of ataxia or who is at risk for ataxia is encouraged to enroll in the CoRDS/NAF ataxia patient registry. If you have started the process but have not yet completed the Ataxia Questionnaire, please log-in so that you can fully enroll.

To register in the CoRDS ataxia patient registry, go to www.ataxia.org and click on "Ataxia Patient Registry."

Step 1: Complete the single-page CoRDS Registry Screening Form. It is important that you indicate on this form that you would like to complete the disease-specific registry of the National Ataxia Foundation. Once you have completed this step, you will receive an e-mail with your unique username and password and a link to the CoRDS secure portal.

Step 2: Log in to the secure portal to read and agree to the Informed Consent Form. After agreeing to the consent form on-line, you will be taken directly to the final step.

Step 3: Complete the Ataxia Questionnaire. After completing the questionnaire and clicking submit, the enrollment process is complete ... you are now fully registered!

Please indicate on the Informed Consent Form that you give permission to provide your information to the National Ataxia Foundation which will be used for research and educational purposes only.

If you prefer to enroll by postal mail, contact CoRDS personnel at (605) 312-6423 or e-mail CoRDS@sanfordhealth.org. Thank you for participating in this important research tool.

Calendar of Events

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

SUPPORT GROUP MEETINGS

– Saturday, December 28, 2013 –

Detroit Area Ataxia Support Group Meeting

Time: 1 – 4 p.m.

Location: The Barbara Ann Karmanos Cancer Institute at Wayne State University in the Warts Classroom, 4100 John R St., Detroit, MI 48201

Details: For more information contact Tanya Tunstall at (313) 397-7858 or tinyt48221@yahoo.com.

New Hampshire Ataxia Support Group

Lunch Meeting

Time: 11:30 a.m.

Location: Puritan Back Room, Manchester, NH.

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

– Thursday, January 9, 2014 –

Tri-State Ataxia Support Group

Meeting and Potluck Dinner

Time: 6:30 – 8:30 p.m.

Location: Bethel Israel Medical Center, Phillips Ambulatory Care Center (PACC), Second Floor Conference Room (Room 3), 10 Union Square East, New York, NY 10003

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

– Saturday, January 11, 2014 –

North Texas Ataxia Support Group Meeting

Time: 10 a.m. – noon

Location: Las Colinas Cancer Center, 7415 Las Colinas Blvd., Irving, TX 75039. The parking is free and the building is handicap accessible (behind the Regions Bank).

Details: For more information contact David Henry Jr. at cheve11e@sbcglobal.net.

– Saturday, January 18, 2014 –

Denver Area Ataxia Support Group Meeting

Time: 1 – 4 p.m.

Location: The Spruce C meeting room at the Swedish Medical Center, 501 E. Hampden Ave., Englewood, CO 80113.

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

– Saturday, January 25, 2014 –

Alabama Ataxia Support Group Meeting

Time: 10 a.m. – 2 p. m.

Location: Covenant Presbyterian Church, Homewood, AL

Details: For more information contact Becky Donnelly at (205) 987-2883 or donnely6132b@aol.com.

New Hampshire Ataxia Support Group Meeting

Time: 10 a.m. – noon

Location: Hannafords at the Bedford Shopping Mall, 5 Colby Ct., Bedford, NH 03110, (603) 625-5431.

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

– Saturday, February 8, 2014 –

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 or clarkstone9348@sbcglobal.net.

– Saturday, February 15, 2014 –

Orange County Ataxia Support Group Meeting

Time: 2 – 4 p.m.

Location: The Orange Coast Memorial Medical Center, Breast Center Building, Room 1A, 9900 Talbert Ave., Fountain Valley, CA 92708

Details: For more information contact Daniel Navar at (323) 788-7751 or danieln27@gmail.com.

Twin Cities Ataxia Support Group Meeting

Time: 10 a.m.

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

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

– Saturday, February 22, 2014 –

New Hampshire Ataxia Support Group Meeting

Time: 10 a.m. – noon

Location: Hannafords at the Bedford Shopping Mall, 5 Colby Ct., Bedford, NH 03110, (603) 625-5431.

Details: For more information contact Jill and ►►

Ken Porter at (603) 626-0129 or jilleporter@comcast.net.

– **Thursday, March 13, 2014** –

Tri-State Ataxia Support Group Meeting

Time: 6:30 – 8:30 p.m.

Location: Bethel Israel Medical Center, Phillips Ambulatory Care Center (PACC), Second Floor Conference Room (Room 3), 10 Union Square East, New York, NY 10003

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

– **Saturday, March 15, 2014** –

Twin Cities Ataxia Support Group Meeting

Time: 10 a.m.

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

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

– **Saturday, March 29, 2014** –

New Hampshire Ataxia Support Group Meeting

Time: 10 a.m. – noon

Location: Hannafords at the Bedford Shopping Mall, 5 Colby Ct., Bedford, NH 03110, (603) 625-5431.

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

– **Saturday, April 12, 2014** –

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 or clarkstone9348@sbcglobal.net.

– **Saturday, April 19, 2014** –

Orange County Ataxia Support Group Meeting

Time: 2 – 4 p.m.

Location: The Orange Coast Memorial Medical Center, Breast Center Building, Room 1A, 9900 Talbert Ave., Fountain Valley, CA 92708

Details: For more information contact Daniel Navar at (323) 788-7751 or danieln27@gmail.com.

Denver Area Ataxia Support Group Meeting

Time: 1 – 4 p.m.

Location: The Spruce C meeting room at the Swedish Medical Center, 501 E. Hampden Ave.,

Englewood, CO 80113.

Details: Topic: Report from the Las Vegas NAF Annual Membership Meeting. For more information contact Charlotte DePew at (720) 379-6887 or cldepew77@comcast.net.

Twin Cities Ataxia Support Group Meeting

Time: 10 a.m.

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

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

– **Saturday, April 26, 2014** –

Alabama Ataxia Support Group Meeting

Time: 10 a.m. – 2 p. m.

Location: Covenant Presbyterian Church, Homewood, AL

Details: For more information contact Becky Donnelly at (205) 987-2883 or donnely6132b@aol.com.

INFORMATIONAL AND AWARENESS EVENTS

– **Monday, January 27, 2014** –

Ataxia Awareness Cruise

Time: Departs January 27, 2014

Location: Ft. Lauderdale, FL

Details: Join the West Central Florida Ataxia Support Group on Royal Caribbean International's "Liberty of the Seas." Travel from Ft. Lauderdale to Jamaica and Labadee, Haiti and back. Due to the limited number of fully accessible cabins, please e-mail us immediately to check on availability. A \$100 per cabin deposit MUST be made at the time of booking. Book early! For more information contact Cindy Steever-Ziegler at (239) 878-3092 or csteever@msn.com.

– **Saturday, February 22, 2014** –

Ataxia Caregivers Conference

Time: 9:00 a.m. – 3:00 p.m.

Location: Grace Fellowship Church at 9505 Deereco Road, Lutherville-Timonium, MD 21093

Description: This event is for family and friends who care for those with ataxia. There will be several presentations and facilitated discussions on coping skills, future planning, communication, and strategies for providing care.

RSVP: Pre-registration is required by February 18. Bailey Vernon, Health Educator, (410) 616-2811 or bvernon1@jhmi.edu

Calendar of Events
Continued from page 53

– **Friday, February 28, 2014** –

Rare Disease Day

Details: Rare Disease Day is an international advocacy day to bring widespread recognition of rare diseases as a global health challenge. The day has been established as a grassroots advocacy day and we encourage everyone to participate in some way! <http://rarediseaseday.us/>

– **Friday, February 28 - March 2, 2014** –

Los Angeles Abilities Expo

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

Location: Los Angeles Convention Center, Los Angeles, CA

Details: Admission is free. <http://www.abilitiesexpo.com/losangeles/index.html>

– **Friday, March 14-16, 2014** –

Atlanta Abilities Expo

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

Location: Georgia World Congress Center, Hall C4

Details: Admission is free. <http://www.abilitiesexpo.com/atlanta/index.html>

– **Tuesday, March 18-21, 2014** –

5th Annual Investigators Meeting (AIM)

Time: Tuesday 5:15 p.m. – Friday noon

Location: Bally's Las Vegas

Details: This meeting is intended for physicians and researchers who are actively involved in ataxia research. For registration information please contact Sue Hagen at susan@ataxia.org or call (763) 553-0020.

– **Thursday, March 20, 2014** –

Investigator/Patient and Family Poster Session (AIM)

Time: Thursday 5:15p.m. – 6:15 p.m.

Location: Bally's Las Vegas

Details: Registered AMM attendees are welcome to engage in this opportunity to interact with ataxia researchers.

– **Friday, March 21 - 23, 2014** –

57th Annual Membership Meeting (AMM)

Time: Friday and Saturday 8:30 a.m. – 5 p.m., Sunday 9:15 a.m. – 12:30 p.m.

Location: Bally's Las Vegas

Details: Registration fee required to attend. See page 19 for more information. <http://www.ataxia.org/events/annual-meeting2014.aspx>

– **Friday, May 2-4, 2014** –

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 Center

Details: Admission is free. <http://www.abilitiesexpo.com/newyork/index.html> ❖



SEEKING PATIENTS WITH SCA (1, 2, 3, 6, 7)

**FOR A CLINICAL TRIAL USING TRANSCRANIAL MAGNETIC STIMULATION
TO IMPROVE GAIT, POSTURE, AND MOBILITY**

at the Berenson-Allen Center for Non-invasive Brain Stimulation at
Beth Israel Deaconess Medical Center, Boston MA

You will be asked to come in for daily treatments (M-F) for 4 weeks, 30 minutes a session.

You will be compensated for your time.

If you are interested or would like more information, please contact

Natasha Atkinson at 617-667-0258 or email natkinso@bidmc.harvard.edu



Memorials and In Your Honor

The National Ataxia Foundation is grateful to those who have made contributions in memory or in honor of their friends and families whose names are listed below. This list reflects contributions made in September through October 2013. 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.

Jonette Adams
 Anthony Alberico
 Roy Antonov
 David Ashley
 Sharon Baggett
 Jeffery Barberi
 Justin Bolinger
 Sharon Cable
 Roger Cooley
 Jeannette Davis
 Joe DeCrescenzo
 Bernadette DeLuca
 The DeMint Family
 Gretchen Deniger
 Denise Dudley
 Andrew Egeressy Jr.
 Ralph Even
 Shirley Even
 Trinity Falk
 Bart Ferris
 The FreiFamily
 Penny Golminas
 Steve Golomski
 Bradd Guenser
 George Guffin
 Sarah Hale

Ernie Hansel
 Randolph Hasegawa
 Harold Heikkila
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 Krista Humes
 Howard Hunnius
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 Marcella Kukelhan
 Sally Kukelhan
 Leonilla Lake
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 Kristie Logan-Guenser
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 Michael Lundquist
 Carol Marzullo
 Joe Marzullo
 Michael Massanova
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 Claire McManus
 Terrie McNabb
 Leslie Miles
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 Alfred Moline
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 Lucia Schone
 Kathryn Smithers
 Donald Snider
 LuAnn Sogge
 Leon Spears
 Joey Staiger
 Col. William Tait Jr.
 Gretchen Tressler
 Richard Tschida
 Donald Walker
 David Westrick
 Edith Whipple
 Jeffery Yeater
 Lori Zhang



Happy New Year from Everyone at the NAF Office

Julie Braun

Sue Hage

Jean Jensen



Michael Jensen

Liz Stogren

Jean Stewart



National Ataxia Foundation

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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. Thank you!

GIFT – HONOR – MEMORIAL

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

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

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

My contribution is:

- In Memory In Honor Gift Membership

Name _____

Occasion _____

Send Acknowledgment Card to:

Name _____

Address _____

City/State/Zip _____

From:

Name _____

Address _____

City/State/Zip _____

MEMBERSHIP

Yes, I want to help fight ataxia! Enclosed is my membership donation. (*Gifts in US 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

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
National Ataxia Foundation.

Total Amount Enclosed \$ _____

Credit Card: Visa MasterCard Discover

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