

Generations

SPECIAL EXPANDED EDITION

The Official Publication of the National Ataxia Foundation

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Summer 2015



International Ataxia Awareness Day (IAAD)

— Friday, September 25, 2015 —

Chances are that if you had stopped 100 people on the street anywhere in the world 20 years ago and asked the question, “What is ataxia?” not one would have had an answer. From that question, a new initiative was born ... International Ataxia Awareness Day (IAAD). IAAD is an international effort from ataxia organizations around the world to dedicate September 25 as International Ataxia Awareness Day.

The first IAAD occurred on September 25, 2000 and was the first time ataxia organizations throughout the world declared and recognized September 25 as IAAD. Through IAAD,



Inside This Issue

- **International Ataxia Awareness Day** events and fundraisers are highlighted on pages 1-11
- Updated information about the **2016 Ataxia Annual Conference** is on page 12
- Read a touching article about **Children with Ataxia** on pages 24-25
- **More ‘Pearls of Wisdom’** can be found on page 25
- What’s happening near you? Find out on the **Calendar of Events** on pages 49-54

NAF Chapters, Support Groups, Ambassadors, and members have created ataxia awareness throughout the United States, better informing tens of thousands of people about ataxia.

Continued on page 3

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Membership Topics

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Creating Ataxia Awareness

The goal of IAAD is for everyone to participate in some activity to help create awareness about ataxia by sharing your story with one other person who has never heard of ataxia, educating others by speaking at a school or civic group, getting in touch with your local media, or wearing ataxia awareness apparel on IAAD. Many have contacted city, county, or state government officials to receive a proclamation recognizing September 25 as IAAD. Others start or participate in an IAAD event, get involved or organize a Walk n’ Roll for Ataxia.

International Ataxia Awareness Day has grown over the years, with more ideas and more people getting involved. It will be celebrated on Friday, September 25. To find out how you can get involved, please download the IAAD Kit on NAF’s web site, www.ataxia.org, on the IAAD page under the Events Section. On NAF’s web site you will also find all the IAAD events near you on the Events Calendar under the Events Section.



Awareness Tools

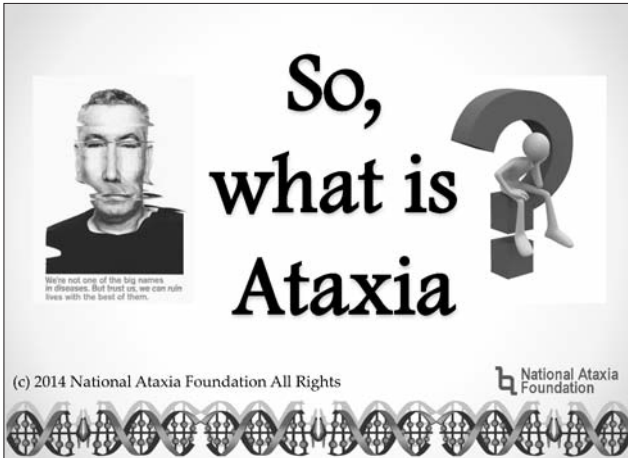
To help you get the word out about ataxia, NAF offers a variety of tools to support your awareness efforts. Public Service Announcements (PSAs) are available on the foundation’s website – www.ataxia.org/events/international-ataxia-awareness-day.aspx – and on NAF’s YouTube Channel – <https://www.youtube.com/user/NatlAtaxiaFound> – for you to post and share or include with a press release.



2015 IAAD PSA



What Is Ataxia? PSA

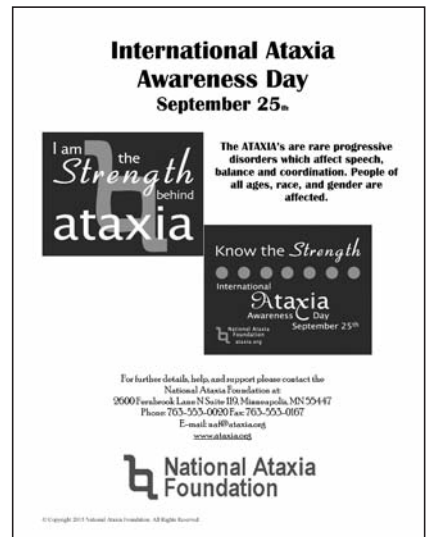


A presentation about ataxia can be found on NAF's website to use during your talk about ataxia, to prepare for a talk you are giving about ataxia, or to share with others who may be interested in learning more about ataxia.

NAF Ataxia Presentation



In the IAAD Kit you will find a sample Press Release to aid you in sharing your story with media outlets. A sample IAAD Proclamation is also available to submit to state or local officials to declare September 25th as International Ataxia Awareness Day in your city or state. There is also an IAAD poster in the IAAD Kit that you can print, copy, and distribute. Copies of these materials can also be requested by contacting the NAF office.



Thumbnails are available on NAF's Facebook page – www.facebook.com/ataxia_foundation – for you to use to update your social media profile picture in recognition of IAAD.



Ataxia awareness items are available for purchase through NAF's Store. Available awareness items include t-shirts, wristbands, magnets, and bags. To purchase ataxia awareness apparel or items, visit the NAF's online store at <http://tinyurl.com/nafstore>.

International Reach

IAAD helps create ataxia awareness, but IAAD also creates a way to raise much needed funds. Funds raised through NAF Walk n' Rolls and other NAF IAAD events have helped support vital ataxia research studies not only here in the United States, but also throughout the world. The International Ataxia Awareness Day impact is international. Without the involvement of NAF Chapters, Support Groups, Ambassadors, and members, many of these important ataxia research studies would have gone unfunded.

IAAD Activities

Currently Underway or Planned

- **Missy's PCT Ataxia Hike** – Missy is hiking the Pacific Crest Trail to raise awareness for ATAXIA & in Memory of Allen Prather.

<https://naf.myetap.org/fundraiser/hike4ataxia/>

- **National Bike Challenge – Team NAF** – Hop on your bike or trike and join Team NAF in The National Bike Challenge!

<https://nationalbikechallenge.org/team/6929>

- **Team KR Endurance** – is a virtual run event to support the important work of the NAF! Visit the event website to register for a virtual 5K, 10K, or 13.1-mile run. Registration is free. Participants that raise \$30 or more receive a complementary t-shirt.

<https://naf.myetap.org/fundraiser/15nafrun/aboutEvent.do>

- **The Ataxia Hoedown at the Seton Corral** – September 19 from 5-10 p.m. at Elizabeth Ann Seton Hall, Bear, DE. This event is a Country Hoedown featuring Chuck Wagon Buffet, DJ & Line Dancing. In lieu of an Admittance fee or Gifts donations are requested in support of NAF. We're also having a Chinese Auction For more information contact Joe and Cathy DeCrescenzo at (302) 369-9287 or cdecres@verizon.net.

<https://naf.myetap.org/fundraiser/15hoedown/>

- **Tour de Shunk – Go On 3!** – On

September 20 Mike Cammer is entering the "Tour de Shunk" for the second year in a row to ride the entire 102 miles!

<https://naf.myetap.org/fundraiser/15GoOn3/>

- **AZ Shop Till You Drop Craft & Vendor Fair** – October 3 from 9 a.m. to 12:30 p.m. at the Disability Empowerment Center, 5025 E. Washington, Phoenix, AZ 85034. At this event you will find Health & Wellness vendors, a Chinese Auction, 50/50 Raffle, and Kids Games and Prizes. Snacks and bottled water will be for sale. This is a FREE event. Donations accepted. All proceeds benefit the National Ataxia Foundation. For more information about attending or exhibiting, contact Angela Li at (847) 505-4325 or angelali1010@gmail.com or Mary Fuchs at (480) 212-6425 or mary11115@msn.com.

- **Tea Time for Ataxia** – October 10 at the Aubrey Rose Tea Room, La Mesa, CA. Due to the overwhelming popularity of this tea, this year you will again have a choice of sitting from 11:00 a.m. to 1:00 p.m. or 1:30 to 3:30 p.m. Please help us fill the tea room at both sittings. Ask your friends to join you, and plan now to attend. Cost is \$35 per person. All proceeds benefit the National Ataxia Foundation. For more information contact Jane Jaffe at (619) 286-9745 or sicilianmother@cox.net.

- **Bosco's Friends Helping Friends** – On October 20 Bosco's Department Store will again be hosting the popular FRIENDS HELPING FRIENDS special shopping day. 25% discount shopping passes are available for \$5 to use on this special shopping day. The \$5 from your shopping pass purchase entirely goes to benefit the National Ataxia Foundation. To purchase your shopping pass contact Mike Cammer at (610) 996-5814 or michael.cammer62@hotmail.com.

- **Warriors4Awareness** – Warriors4Awareness is the name for the team of race car drivers that have committed to race in support of the National Ataxia Foundation by donating and challenging their fans to match the donations.

The Warriors4Awareness are asking their fans to match donations according to their finish, the donations go to help fund research for a cure.

<https://naf.myetap.org/fundraiser/warriors4awareness/>

- **World Spinners** – #ataxiapinchallenge was created to raise awareness of a non-curable non-treatable disease ... ataxia. On the event website you can learn about “The Challenge,” register and/or start a team to share your story, and challenge others.

<https://naf.myetap.org/fundraiser/15spinners/>

Other exciting IAAD events planned may include “Jeans Day” where on September 25



employees are allowed by their employer to wear jeans at work on that day with a donation to NAF. Various restaurants are donating a percentage of sales to NAF during IAAD, group and family picnics, information tables, and many others bringing the word “ataxia” to local communities throughout the country.

Many of the IAAD Events and fundraisers are printed in the Calendar of Events listing located in the back of this issue of *Generations* (starting on page 49).

For the most current event information, details and links, please visit the NAF Events Calendar at www.ataxia.org.

How Did You Participate in IAAD?

Tell us how you recognized International Ataxia Awareness Day (IAAD) this year. Share a photo with us for a future issue of *Generations*. Please e-mail your story/photo to joan@ataxia.org or mail to the National Ataxia Foundation, Attn: Generations Editor, 2600 Fernbrook Lane, Suite 119, Minneapolis, MN 55447-4752.

Thank You

Thank for creating ataxia awareness on IAAD and throughout the year. ❖

International Ataxia Awareness Day (IAAD) Get Involved in IAAD Events and Planning

— Friday, September 25, 2015 —

“International Ataxia Awareness Day” (IAAD) is an international effort from ataxia organizations around the world to recognize September 25 as International Ataxia Awareness Day. IAAD has grown over the years, with new ideas being implemented and more people getting involved.

To find out how you can get involved, please download the IAAD Kit on the National Ataxia Foundation’s website, www.ataxia.org, on the IAAD page under the Event Section. On the website you will also find all the IAAD events near you on the Event Calendar under the Event Section as they become available.

Please let the Foundation know about your IAAD event by contacting Lori Shogren at lori@ataxia.org or (763) 553-0020.



Walk n' Roll for Ataxia

The ultimate finish line ... a cure for ataxia

What is Walk n' Roll for Ataxia?

The Walk n' Roll for Ataxia program is the National Ataxia Foundation's largest national grassroots fundraising event held in recognition of International Ataxia Awareness Day (IAAD).

Walk n' Roll, which began in 2007, is held in cities across the U.S. Walk n' Roll for Ataxia has raised more than \$1,200,000 thanks to the support and tireless commitment from walkers, rollers, runners, volunteers, donors, and sponsors.

Why Walk or Roll?

Thousands of families, friends, co-workers, neighbors, and communities come together each year to support NAF's fight to improve the lives of people affected by ataxia and their families.

How Can I Participate?

For more information, or to start a Walk n' Roll in your community, please contact Lori Shogren, NAF Special Projects Coordinator at (763) 553-0020 or lori@ataxia.org.

2015 Walk n' Roll Events

Walk for Dave

Liverpool, NY – August 8

Contact: Marc Alessi – pianoman345@hotmail.com

<https://naf.myetap.org/fundraiser/15walk4dave/>

Concord Walk n' Roll

Concord, CA – September TBD

Contact: Brian Petersen – smileypetersen@yahoo.com

www.ataxia.org/walk/concord

Northern CA Walk n' Roll

Lafayette, CA – September TBD

Contact: Joanne Loveland – joanneloveland@gmail.com

www.ataxia.org/walk/lafayette

Minnesota Walk, Stroll n' Roll

St. Louis Park, MN – September 12

Contact: Terry Sweeney – mnataxiawalk@yahoo.com

www.ataxia.org/walk/minnesota

New England Walk n' Roll

Auburn, MA – September 12

Contact: John Mauro – john@ataxia.org

www.ataxia.org/walk/auburn

Denver Run, Walk n' Roll

Denver, CO – September 13

Contact: Charlotte DePew – cldepew77@comcast.net

www.ataxia.org/walk/denver



Continued on page 8

Walk n' Roll for Ataxia
Continued from page 7

Atlanta Walk n' Roll

Duluth, GA – September 19

Contact: Greg Rooks – atlantaataxia@gmail.com

www.ataxia.org/walk/atlanta

OC/LA Walk n' Roll

Orange County, CA – September 26

Contact: Cindy DeMint – cindyocataxia@gmail.com

www.ataxia.org/walk/ocla

Utah Walk n' Roll

Salt Lake City, UT – September 26

Contact: Jenny Durrant – jenny@utahataxia.org

www.ataxia.org/walk/utah

Western PA Walk n' Roll

South Park, PA – September 26

Contact: Donna Eiben – donnaeiben@ataxia.org

www.ataxia.org/walk/wpa

Michigan Walk n' Roll

Ann Arbor, MI – October 31

Contact: Elizabeth Sullivan – elizabethsull@umich.edu

www.ataxia.org/walk/michigan ❖



For more information on
Walk n' Roll for Ataxia events
and locations, please visit
www.ataxia.org/events/walk_n_roll.aspx

Macy's 'Shop for a Cause'

Purchase a "Macy's Shop for a Cause" discount card today for \$5 and help the National Ataxia Foundation. Your special discount card gives you access to a special one-day-only sales event at Macy's stores nationwide on Saturday, August 29. Just in time for "Back to School" shopping! For the first time, Macy's will be offering 30% off all-day on SELECT regular, sale and clearance merchandise throughout the store to those customers with a Shop for a Cause discount card. Specifically, the pass will be good for:

- 30% off all-day on SELECT regular, sale and clearance merchandise;
- 25% off all-day on select designer apparel collections for him and her, Impulse, designer handbags, men's shoes, Wacaol, Tumi, Wustoff, Henkels, Kate Spade home & All Clad; and
- 10% off all-day on furniture, mattresses,

rugs, electrics/electronics. Exclusions apply.

Card holders are also eligible to register to win a \$500 Macy's gift card.

Macy's will not be reprinting the passes and all current Shop for a Cause savings passes will be honored. The 30% discount will be given at the register for any and all applicable merchandise.

To purchase your discount card today you can order online through NAF's online store, by mail by sending a check made payable to the National Ataxia Foundation to 2600 Fernbrook Lane, Suite 119 Minneapolis, MN 55447 (write "Macy's Card" in the memo line). You may also call the NAF office at (763) 553-0020 to place an order or for more information. All Macy's Card orders must be received by August 21. All proceeds benefit the National Ataxia Foundation.

For more information, visit www.ataxia.org/macyscard.

Recent Fundraisers

Raising money for the important work of the National Ataxia Foundation and awareness of ataxia takes on many forms. From sports tournaments and events to dress-up days to product sales, there are an amazing number of ways that clever, caring folks have gotten the job done. The following are just a few recent fundraisers. The NAF is truly grateful to all of you for your hard work.



Virginia Middle School 80's Dress-up Day was a hit!

'80s Dress-up Day

Submitted by Betsy Turnbull

The Virginia Middle School in Bristol, VA recently held an '80s Dress-up Day fundraiser and awareness event.

Colton Walsh helped organize the event, which raised over \$650 in honor of his younger sister who was recently diagnosed with ataxia. Everyone had fun dressing-up and supporting a great cause.

Students and faculty paid a minimum of \$1 to dress up; students also donated through their PE classes to earn an extra game day for the week. Each student who donated received an Ataxia Awareness bookmark.

The event was held on Friday, March 27 and was tremendous fun.



KML Chargers with Barry Washburn, coach since 1984

KML Soccer Tournament

Submitted by Barry Washburn

The Kettle Moraine Lutheran Chargers (KML) of Jackson, WI played against the Winnebago Lutheran Academy (WLA), both of the Flyway Conference of the WIAA, on May 15.

KML won against WLA, a huge rival of KML in girls' soccer, giving them a share of the conference title. This is the fourth year the team has had an ataxia game in honor of their previous coach Barry Washburn. The girls wore blue armbands to represent ataxia and a donation table was set-up by the bleachers where attendees could make a donation or purchase a baked goodie to benefit the NAF. Everyone who attended received information about ataxia reprinted on the back of the roster using the pamphlet provided by the NAF. The event raised almost \$300.

For more information please contact Barry Washburn at ewashburn@nconnect.net.

Thank you to all of you who have so graciously raised funds and awareness!

Continued on page 10

Juniper Hills Fundraiser

A charity event was held at Juniper Hills Golf Course by the Juniper Hills Women's Golf League on June 16. The event raised \$2,500.

Pampered Chef Party Fundraiser

Friends of Ed Schwartz hosted a Pampered Chef party in his honor and as a fundraiser for the National Ataxia Foundation (NAF). The event was held April 11 at Trinity United Methodist Church in McMurray. The event raised over \$700.

Because of the wide range of symptoms that may be experienced and the irregular pattern of occurrence, diagnosis is very difficult. It took Ed 20 years to achieve a diagnosis. Ed is starting an aggressive program to share his experience hoping that he can help someone else with his symptomology. Ed is a member of the Western PA Support Group which is seeking others in and around Pittsburgh who have ataxia or know someone who does. If you are interested he may be reached at (724) 986-8088 or via e-mail at smsllc@comcast.net.

Gunning's Run for Ataxia 2015

Kurt Gunning was diagnosed with SCA in 2004. Samantha Gunning, Kurt's daughter, participated in the Fargo Marathon to raise money and awareness for SCA in honor of her father. Samantha completed the full marathon, held at the FargoDome on May 9, while her family and friends participated in the 5K and half marathon events. The event raised almost \$9,000.



Kurt & Mykin Gunning

O's American Kitchen Fundraiser

The O's American Kitchen offered 20% off and all proceeds to be donated to the NAF when you presented their flyer at the time of purchase during the hours of noon to 8 p.m. The fundraiser had about 50 guests attend on April 12. The event raised almost \$350 for research.



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

Travel expenses reimbursed.

**Contact: Diane Hutter
(612) 625-2350
hutte019@umn.edu**





Neddroy “DJ HeadBussa” Bent (fourth from left) and friends at the Strike Out Ataxia event

Strike Out Ataxia

Submitted by Neddroy Bent (DJ HeadBussa)

The Fourth Annual Strike Out Ataxia Charity Bowling Event was held on May 3rd at PinChasers in Tampa, FL. Neddroy Bent (aka “DJ HeadBussa”) partnered with the National Ataxia Foundation to host the event to bring awareness to ataxia and in honor of his mother.

Chuck and Duck Dodgeball Tourney

Submitted by Andrew Haluska

Charlton Heights Elementary School held their Sixth Annual Chuck and Duck Dodgeball Tournament on April 24.

The event continues to get bigger and better each year and the students, staff and community look forward to the tournament.



This year’s event raised almost \$5,000 in honor of Jacob Van Buren, a past Charlton Heights student who has Friedreich ataxia.

Luke Haluska (left) and Keller Casey prepare to do battle

Brain Health Fair

Submitted by Mike Cammer

I had the pleasure of manning the National Ataxia Foundation table at the Brain Health Fair in Washington, D.C. on April 18, along with Carolyn Davis, Jenean McKay and Libby Labash.

We had a steady flow of visitors to our table throughout the day despite the beautiful spring day outside. We had NAF logo crayons and “Ataxia is not a Foreign Cab” and brain coloring sheets for the kids (and adults too).

I was especially impressed by one young man, Soren Christensen, who was able to name all 12 sections of the brain! I talked more with Soren and found out that he was the winner of the 2015 National U.S. Brain Bee, quite impressive for a high school freshman.

We also got to meet fellow NAF Facebook friend Colleen Brooks Thomas, who was taking in the event, and a couple newly diagnosed



Left to right: Carolyn Davis, Mike Cammer and Jenean McKay

ataxians who stopped at the table for more information about ataxia.

Next year’s Brain Health Fair will be held in Vancouver, British Columbia, I encourage all of you living in the northwest to go visit. ❖

THE NAF BOARD OF DIRECTORS ALONG WITH THE NAF
SOUTHEAST REGION WOULD LIKE TO INVITE YOU TO ATTEND

THE MAGIC OF A CURE

DREAM IT.
HOPE IT.

National Ataxia Foundation
Annual Ataxia Conference
April 1-3, 2016 ★ Orlando, Florida
Hosted by the Southeast Region



The Caribe Royale Orlando is pleased to provide the facilities for the 2016 Annual Ataxia Conference (AAC)

Room Reservations-Begins November 4

Room reservations for all room types at the Caribe Royale will be made available starting November 4. Please note all ADA rooms must be reserved through the NAF office starting on **November 4 at noon CST** by contacting (763) 553-0020 or lori@ataxia.org. Calls or e-mails prior to noon CST on November 4 to reserve an ADA room cannot be honored.

Reservations at group rate will be available until February 27, 2016.

The NAF group rate starts at only \$149 +tax for Standard Rooms.

Meeting Registration-Begins November 4

Registration for the 2016 NAF AAC will open on November 4. You are encouraged to register before February 12, 2016 to receive the early registration discount rate. In addition, members of the NAF pay a lower registration fee to attend the Annual Ataxia Conference. If you are not currently a member of the Foundation go online at www.ataxia.org or call the NAF office at (763) 553-0020 to become a member or renew your membership. For the latest information on conference registration, program schedule, and area information keep checking the NAF's website www.ataxia.org.

2016 NAF Annual Ataxia Conference "Support Our Conference" Campaign

Help support the 2016 ACC by donating online. <https://naf.myetap.org/fundraiser/16AMM/>

For more information on Orlando visit <http://www.visitorlando.com/>

VisitOrlando.

From the Desk of the Executive Director

There is much happening at the National Ataxia Foundation this summer. Plans are underway for the 2016 Annual Ataxia Conference which will be held in Orlando, Florida on April 1- 3, 2016. The name of the meeting has been changed from the Annual Membership Meeting to the Annual Ataxia Conference to better reflect what the conference has evolved into – a conference for the ataxia community.

Plans have also begun for the NAF's Sixth Ataxia Investigators Meeting (AIM) being held just prior to the 2016 Annual Ataxia Conference. Leading ataxia scientists and clinicians from around the world will gather together to share their cutting-edge ataxia research to help accelerate worldwide ataxia research efforts.

The NAF Annual Membership Drive continues, and we are truly grateful to all who have become new members or have renewed their membership. A warm welcome to our new members and for our renewing members, a heartfelt thank you for your continued support! Membership support is vital in providing funding for important programs for ataxia families. Thank you for making a difference. This is still time to renew or become a member, just go to www.ataxia.org and click on the "Donate Now" button.

We are very excited by the interest from researchers around the world in the NAF's five research funding programs for the funding cycle which will occur in late December of this year. Last year, the NAF received 107 ataxia research proposals from 19 countries. Much of the funds to support the NAF's research programs are through our generous donors who support the NAF Annual Ataxia Research Drive. This year's drive will begin on October 15th. Additional

information on this important drive will be forthcoming.

The NAF, in partnership with Sanford Research, is pleased to announce that a new and improved CoRDS Ataxia Patient Registry has been launched. The new system offers a variety of improved functionality for our participants. All currently enrolled participants have received an email from CoRDS with a link to the new portal and their new username and password.

For those who have not yet registered on the CoRDS Ataxia Patient Registry, you can begin your enrollment by completing a screening form. Once the form is submitted, you will receive an e-mail from CoRDS with a link to the login page. Once you login to the portal, you will be able to complete the questionnaire to finish your enrollment. You can find the link to the CoRDS Ataxia Patient Registry on NAF's web site, www.ataxia.org or to go

directly to CoRDS at <https://cords.connect.sanfordresearch.org/BayaPES/sf/screeningForm?id=SFSFL#>.

International Ataxia Awareness Day, September 25, is just around the corner. Many events and activities are being planned in recognition of this very special day. Walk n' Rolls for Ataxia have been scheduled throughout the country for this Summer and early Fall to raise ataxia awareness and funds to support the important work of the National Ataxia Foundation. Thank you to our amazing volunteers, event organizers, sponsors, donors, and participants. Don't forget to tell a friend, neighbor, or co-worker about ataxia on International Ataxia Awareness Day and to wear your ataxia apparel.

Thank you.



Michael Parent

NAF's Travel Grant Program Needs Your Support

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

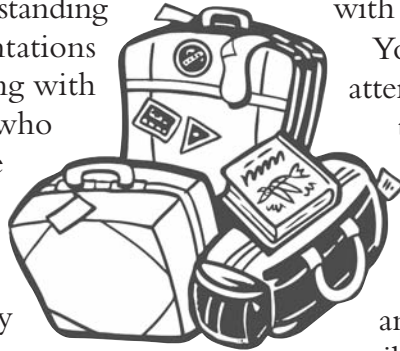
The National Ataxia Foundation's Annual Ataxia Conference (AAC) connects the ataxia community. The conference program is designed to foster learning and understanding by providing informative presentations about ataxia research and on living with ataxia. Connecting with those who understand and face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

Traveling to an Annual Ataxia Conference can be financially difficult. To help those with ataxia

who are unable to financially attend the AAC, the NAF established an AAC Travel Grant Program to help with some of the costs associated with attending the AAC.

You can help someone with ataxia attend the AAC by making a donation to the NAF AAC Travel Grant Program. Your gift to the AAC Travel Grant Fund will make an immense difference in someone's life. Thank you for your support and for making the AAC experience possible for an individual affected by

ataxia who would not have been able to attend without your help.



Quotes from Past Travel Grant Recipients:

"It gave me an opportunity to be part of the NAF."

"Thank you for providing me the opportunity to attend this year's AMM. I am grateful."

"Many, many heartfelt thanks to all who donated so I was financially able to attend this meeting, where I fit in. Thank you so much!"

"It is one of the few times that being disabled is normal & expected. Attending is so affirming – good for my self-esteem."

"Being around other people with ataxia at the meeting helps me feel less alone. I know that even though they might have different symptoms, they still understand what I face."

"Attending enables me to network and mingle with ataxians from around the country. I feel my experience helps with issues that face us. I am constantly looking for new information to help the ataxia community through support and advocacy and to strengthen my relationship with NAF" ❖

Vehicle Donation

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

To donate your car, truck or motor home, call

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The National Ataxia Foundation

58th Annual Membership Meeting

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Implications of Genetic Testing and Ataxia on Families

Presented by Melissa Gibbons, MS, CGC, a genetic counselor at the Children's Hospital in Denver at the 2015 National Ataxia Foundation Annual Membership meeting in Denver, CO. Melissa works with Dr. Abigail Collins, the Director of the Ataxia Clinic at the University of Colorado Hospital. Her presentation was edited for publication in Generations.

Genetic Counselors

Genetic counselors are individuals who have a Master's Degree specifically in genetic counseling. It's a two-year, intensive program, with clinic rotations on all subspecialties of genetics. Course work is heavy on the sciences, but it's also very focused on how to actually talk to individuals, interact with people and how to share important information in a way that people can understand.

Certified Genetic Counselors are individuals who have graduated from an accredited program, sat for the American Board of Genetic Counseling certification exam and maintain education over time. This is very important because the field of genetics is changing so rapidly. It's not something where you get a degree and not keep up with emerging information because you'll be so far behind within a week.

What we truly do is that we are educators. It's not our job to tell you what to do. It is our job to give you all the information so that you can make a well-informed choice that is right for you and your family. The term we use is that we are "non-directive." Unlike medical professionals who tell you, "I think you should have this surgery," or "You need this blood test to look for diabetes," we give you all your options, help talk through it with you so that you can make your own choices.



Melissa Gibbons

Common Reasons to See a Genetic Counselor

Common reasons that people typically see a genetic counselor are because:

- They have a family history of a certain health condition and they want to know if they are at-risk for inheriting it.
- They are planning a pregnancy or are pregnant.
- If they are symptomatic, they want to have an answer as to why they're having the symptoms they're having.
- They want to learn about inheritance and whether they can pass this on to additional family members.
- They are seeing us because their child is having some concerns, which is my most common situation as a pediatric genetic counselor.

The Right Test for the Right Patient at the Right Time

Our mantra is, "The right test, for the right patient, at the right time." We are reminded to slow down, think about why the family is approaching us, and what is the best thing for that family.

There are different types of genetic testing:

Diagnostic testing is the most common and involves identifying current disease states. This is

Implications of Genetic Testing...
Continued from page 17

the test where you are having signs or symptoms and you are testing to identify why.

Carrier testing is for conditions that an individual can pass on to future generations but may not have symptoms.

Predictive testing is used when a person is at-risk for developing a genetic condition but does not yet have symptoms.

Prenatal testing is offered during pregnancy to identify if the fetus has a certain disease.

Preimplantation genetic diagnosis is either a screening test depending on what you are doing or a diagnostic test to determine if an embryo has the disease before it is implanted.

Newborn screening is a screen that is performed at birth for diseases that need quick intervention in order to help eliminate symptoms or help to manage symptoms better. Many people know this as the PKU test, although that is only one of the diseases. Some people don't realize that this is done in all the states, unless you opt out.

Why get Genetic Testing?

Everybody has a different reason for why they might explore genetic testing and no two people are going to have the same reason. You'll also notice that some of reasons to have or not to have genetic testing are listed on both slides (see slides

below). Family planning and lifelong goals are on both; it would depend on your viewpoint as to whether the reason would be a pro or a con to genetic testing.

Some individuals may want to have the answer to the question: "Why?" Others may be thinking about family planning. In certain genetic conditions a diagnosis can impact your disease management because there may be certain drugs or therapies that are more beneficial. Access to services is one reason often seen in the pediatric population. Having a name of the disease instead of a summary of symptoms can actually improve access in schools and with healthcare services. The results may inform you of your ability to do things in the future so it may speed up your timeline for doing some of the things you really want to do, like travel or retire.

On the flip side, there are just as many reasons why someone may choose not to get genetic testing. A significant reason is that genetic testing, and some of you may have experienced this, can actually raise more questions than answers. Genetic test results are not always black and white; there is a lot of gray. Sometimes it can lead to more confusion. Many individuals are concerned that a diagnosis may lead to discrimination. They may feel that their control is taken away from them, because now their diagnosis is in control. One reason that I have heard from families is there is a certain amount of guilt associated with having a genetic change and ►►

Why Get Testing?

- Might explain the symptoms I am having
- Family planning
- A diagnosis may lead to better treatment**
- Information for other members of the family
- I just want to know
- Financial Planning
- Control**
- The results could alter my Retirement/Travel Plans
- Answers
- Access to Services
- Research Opportunities

Why Not To Get Testing?

- Might raises more questions than answers
- Family planning
- A diagnosis may lead to discrimination**
- other family members do not want to know
- I am not sure I want to know
- Financial Planning
- Lack of Control**
- The results could alter my Retirement/Travel Plans
- Guilt over passing on a faulty gene

passing it on, even though none of us have control over our genes and what they are doing in our bodies.

Discrimination

The Genetic Information Nondiscrimination Act (GINA) was passed in 2008. It is a federal law that protects people from genetic discrimination in health insurance and employment. This does not apply to things such as life insurance or long-term care or disability. Basically it states that you can seek genetic testing or counseling without fear that there will be genetic discrimination on behalf of your insurance company. However, this does not apply to everyone. It does not apply if you have “TriCare” which is the military insurance, if you have the Indian Health Service or if you are a federal employee. There is a separate law that provides the exact protection. You may still experience some discrimination based on your symptoms under a health plan. They can’t use the actual genetic diagnosis, but they can use the medical concerns that you have. This means that by getting genetic testing you are not increasing your risk of discrimination over what was already there just by having symptoms. There have been some new laws put into place recently that help protect people from pre-existing conditions.

There are some hurdles on the path to genetic testing. The first is finding a provider who can put it altogether and recommend the appropriate genetic testing, not just some generalized test that they don’t know how to interpret. Unfortunately, once you have the provider in place, you need to deal with the insurance company. Genetic testing is not something that is standardly covered across all insurance plans. Each plan is very different and some insurance plans actually have exemption clauses where they do not cover genetic tests at all and unfortunately right now, genetic testing is quite expensive ranging from a couple of hundred dollars all the way up to several thousand dollars. You really have to work with someone who can go through

all those insurance steps with you and make sure you do not end up having a really large, out-of-pocket, cost. Some labs do offer patient protection services which can help cut down on the cost as well, but you need to know which labs offer those protections for the family.

The biggest hurdle is the interpretation of the results. Anyone can order a genetic test, but not everyone knows what those results mean. I have had many families that have a result and were told one thing or were just handed or mailed the results, and have not had any actual explanation. Genetic test results are not straight forward. They require someone to look through the results, look at what the genetic change is, and interpret whether or not it is the cause of the change. We have had families who thought they had a diagnosis for years and they came to see us and it turned out that someone had misread their report and they were given the wrong diagnosis. That can be really important because different diagnoses come with different therapies and a different prognosis which will cause a family to attack it very differently.

So you get through all these hurdles. Now what? Genetic testing that confirms a diagnosis can often give us information that can guide management, and more importantly provides risk information to families, and allows for connection to others who may have a similar diagnosis through things like this annual meeting. However, it’s not always clear cut, and many times families are left with more questions. Additionally, genetic testing doesn’t result in what everybody wants when they come in which is the *crystal ball prognosis*: “How does this impact me, specifically?” That’s the hard part about genetics, because we don’t know all those answers. We may be able to find an underlying genetic change, but we still don’t have a great idea on how all of our genes work together, how environment or lifestyle changes play into that. So we can give some guidelines and general

Implications of Genetic Testing...
Continued from page 19

information but sometimes families do walk away feeling like they didn't get many more answers and that can be a very unsettling feeling for them.

Once we do have the results, then it becomes a family affair. One thing I stress is: "Yes, your genetic tests belong to you, but in genetics, the results are information that the whole family is impacted by." The biggest challenge that I come across in a family is how do they go about sharing these genetic testing results? Much of it is based on family dynamics, how the family interacts with each other, how members share things, and in some cases, how they don't share things. Some families might not have open discussions with family members about what's going on from a health standpoint. It is something to put a great deal of thought into.

I have families do it different ways. A favorite of mine was a family of a pediatric patient who hosted a party and invited all of their family and friends who they wanted to know the results and they told everyone all at one time. They made it more like a celebration versus feeling like they were sharing negative news with everybody. Other individuals like to do it by letter or by one-on-one conversations with family members. One thing genetic counselors do is talk about how to share the results with the family and how to anticipate the reactions that may come. I've mentioned family dynamics and one of the things we have to think about is that some family members may decide that they don't want to hear this information. That can be really hard when you feel like they should have the information. So how do you go about navigating that of telling some family members who want to know but then those family members that don't is: to let it be.

The impact on family members is a little different than when you get your genetic testing

results because you're having signs or symptoms. For a family member who is not symptomatic, their approach to testing is going to be very different because they are not trying to answer the question, "Why am I having these symptoms?" They are trying to answer the question of, "Whether I am going to get the symptoms or if I could pass it on?" This decision may differ if one already has children or are still in the family planning process or thinking about expanding the family. Other family members may already be having symptoms but are not ready to deal with them yet so when you get your diagnosis, then they may have the understanding, "Oh, wait, that's probably why I've been having X, Y and Z symptoms." This may accelerate the acceptance process of their symptoms. Other individuals may not find **themselves** at-risk, because they decide to have genetic testing, but they may be at-risk for passing it on. Many of the disorders that we talk about today are ones where the gene can expand over generations so they get their test results and find out that they are probably not going to have symptoms but now they need to think about how that affects their children and future grandchildren. How you interpret and accept the results really depends on where you are in your own lifecycle.

The impact on family planning is a little different than it was years ago. We have technology now that sometimes sounds like science fiction. When we are talking about reproductive options, the first thing we always talk about is that you can choose to do absolutely nothing and that is an okay decision. You approach it like you had never known the genetic condition exists in your family.

Some individuals may choose to use a donor. That can be either a sperm or egg donor. That child is then not related biologically to one of the parents but it decreases the chances of having the same condition. A very hot topic right now is: preimplantation genetic diagnosis. This is when a couple goes through invitro-fertilization ►►

which is a process where they stimulate mom to create more eggs than she typically would, retrieve those eggs, then match them with sperm to create embryos outside of the body. They can then actually do genetic testing on the embryos and look to see if an embryo has the genetic condition. Only the embryos that do not have the genetic condition are implanted. This is the most expensive of all the options, and on average is \$20,000 plus, depending on the center you are using. Also it requires quite a bit on behalf of the mom. Right now, insurance companies are tending to not cover this, although there are starting to be some exceptions (see story on page 32).

The other option is prenatal diagnosis. These are techniques that have been around for quite a

while. They include: Chorionic Villus Sampling (CVS) which is taking a sample of the placenta early on because the placenta and the baby have similar genetic information, or Amniocentesis which is taking a sampling of the fluid surrounding the baby later in pregnancy. Both of these can be used as a diagnostic test. Another choice is adoption as an option for expanding a family.

Each family is so different and there is no way to address every situation, however, there are some great resources about genetics and genetic testing on the National Ataxia Foundation's website at this link: www.ataxia.org/links/ataxia-biology.aspx.

Thank you. ❖

DNA Structure in Health and Disease (DSHD)

FRDA Conference – AIIMS
New Delhi – April 11-13, 2015

Submitted by Chandu Prasad George (SAMAG)

As an FRDA patient and Ataxia Patient Advocacy Group Leader, the conference has thrown much light and better understanding of new therapeutics and new research work being done in treating FRDA. More importantly the conference gave a clear understanding of physiotherapy approaches, the use of balance vests to treat some symptoms associated with FRDA. We found this information valuable and very helpful for all FRDA patients.

Dr. Achal Srivastava, Professor Neurology AIIMS, devoted every Saturday of his working time to attend ataxia patients in his Ataxia Clinic. Dr. Agarwal elaborated on different approaches such as physiotherapy and assistive devices in improving the quality of life of ataxians.

International researchers like Dr. Sanjay



FRDA Conference in India

Bidichandani, Scientific Director of the FARA-USA Scientific Advisory Board, and Dr. Barbara Schreiber-Mojdehkar, Vienna, Austria, gave presentations on new research therapeutic models of FRDA. This conference was partly funded by FARA-USA.

Lastly our special mention of thanks to Dr. Rajeswari Moganty, Organizing Secretary of the DSHD 2015 Conference and Professor in the Department of Biochemistry at All India Institute of Medical Sciences, New Delhi who successfully organized this meeting and also declared an annual FRDA meeting inviting international researchers as well as FRDA patients.

For more information about SAMAG, e-mail india.ataxiagroup@gmail.com or visit our website, www.ataxia.in. ❖

NAF Attends Largest Meeting of Neurologists

Submitted by Sue Hagen, NAF Patient Services Director

In 2011, the American Academy of Neurology (AAN) began their annual meeting with the first public outreach education event in AAN history. “The Brain Health Fair” was created as an event to connect patients who have a brain disease and their family members with care givers, information, experts in the field and resources. The National Ataxia Foundation was at the first Brain Health Fair and has had a presence at every fair since.



Soren Christensen from Thomas Jefferson H.S. for Science and Technology, Alexandria, VA and Mike Cammer

This year the Brain Health Fair was on Saturday, April 18 in Washington, D.C. Local volunteers staffed the exhibit table and provided information about ataxia to the attendees. New this year at the NAF exhibit table were boxes of NAF-branded crayons with coloring sheets of the brain and NAF’s Foreign Cab. Thank you to Mike Cammer, Jenean McKay and Carolyn Davis for distributing materials during the day and educating the public about ataxia.

Mike Cammer had the pleasure of meeting Soren Christensen at the Brain Health Fair. Soren is a 9th grader who won the 2015 National

U.S. Brain Bee. He filled out all the parts of the brain that were on the brain coloring sheet without looking at the answers on the back! We can only hope that he chooses to study ataxia in the future.

Following the Brain Health Fair the next week, the AAN Annual meeting began with the Presidential Plenary Session. Dr. Stefan Pulst, a member of the National Ataxia Foundation’s Medical Research Advisory Board, gave the George C. Cotzias Lecture titled, “Degenerative Ataxias: From Genes to Therapies.” In this lecture Dr. Pulst described his lab’s research in SCA2 to the neurologists who were in attendance. The 2015 AAN meeting broke records with well over 13,000 in attendance.

Throughout the four days of the AAN meeting, the National Ataxia Foundation staffed a booth in the exhibit hall. Neurologists from around the world stopped at the booth to gather information about ataxia and information about NAF’s services and research programs for their patients. Thank you to Diane Paige, Carolyn Davis and Mike Cammer for volunteering to staff the table at different times throughout the AAN meeting. ❖

Matching Gifts

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

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

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

Together There is Understanding VHS \$20 DVD \$25

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"Ataxia is Not a Foreign Cab" Long-Sleeve T-Shirt
Light blue sizes S to XXXL \$15

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Children with Ataxia

Most of the spinocerebellar ataxias and sporadic ataxias have an adult-onset of symptoms, however, there are forms of ataxia that affect young and adolescent children. The National Ataxia Foundation wants to share the stories of some of those children.

In 2011 NAF published a booklet that was distributed at a medical conference of pediatric neurologists. The booklet provided “Faces of Childhood Ataxia” to the doctors and researchers in attendance. The booklet became very popular for other venues and audiences and was reprinted in 2013. NAF recently updated the booklet and added new stories of children with ataxia. We asked for stories of the challenges that a child with ataxia and the parents or other family members struggle with daily. We received stories of the courage which with many children face this disease. We also included stories in memory of children who have lost their battle with ataxia. We are grateful for the generous contributions from parents and family members to provide this booklet. Please contact the National Ataxia Foundation if you are interested in receiving copies of this booklet for your fundraising or ataxia awareness-raising event.

Below you will read the story of Angela, who is now 23 years old. Her story appeared in the first edition when she was 19.

Angela’s Story

Story provided by Angela’s Mom and Dad

We have three children, all beautiful girls; Angela is our middle daughter. Our world was turned upside down when Angela was diagnosed with Spinocerebellar Ataxia type 17. I can still

recall how the oxygen left my brain and the sick feeling in my stomach on that painful day. A wonderful nurse had taken Ang for a walk in the hospital as we sat numb in the doctor’s office while being told the devastating news of our daughter’s future. The doctor told us to be strong in front of our children and cry at night when they were in bed.

Angela was 15 years old when she diagnosed with SCA 17, today she is 23. She does not seem that old though. The progression has caused her to no longer be able to do most things. It’s almost as if her life stopped in its tracks. Angela cannot walk anymore, she is in a wheelchair that we push because she is not able to operate it. Harness straps are necessary at all times. Ang cannot support herself sitting or standing. A headrest must always be in place otherwise her head falls backwards and she is not able to lift it up on her own. Choking occurs quickly.



Angela

Vomiting had become a very serious problem for Angela. We tried for months to figure out why this was happening. We were scared. Losing Angela certainly crossed our minds during this difficult time as she dropped down to 69 pounds. We eliminated foods, added foods but nothing stopped the vomiting. We decided to take Angela off all medications, the weaning process took quite some time but eventually the vomiting completely stopped! She now also sleeps through the night or is at least peaceful.

Unfortunately a large pressure wound near her tailbone opened up causing Angela great distress. The wound became infected. We added an air pressure mattress to her bed, a ROHO pad to ►►

her wheelchair, tissue nutrients to her diet and Angela was repositioned every 30 minutes. It took a little over a year for the pressure wound to completely close up and heal. This was an incredibly painful time for Angela and also for her family.

It is necessary for us to feed Angela. Each meal generally takes one and a half hours. The food needs to be chopped up very fine and have a high calorie count. Every morning her dad gives her yogurt, cereal with whole milk, Juven (which promotes tissue growth and strength), Karo syrup and, of course, ice cream. Every single morning without fail he does this. We need to be diligent in our efforts to feed her so she can at least maintain her low weight which is now in the 80's.

On a really good day Angela is able to say one word, it tends to be a one syllable word. This does not happen very often, to say once a month might be exaggerating. Angela will try her best to nod for us. But there are times when she's just

not able to do that and times when we are not able to tell if it's a yes or a no. Angela's losing her ability to talk has been one of the hardest things. Is she hungry? Is she in pain? Is she cold? Is she sad? Is she scared? We can only hope that she knows that we are trying our very best to give her what we think she needs and wants.

Angela is now very stable, she is tough, she's a fighter. Better yet, she is happy and likes to be near us. Her smile is as beautiful as ever! We continue to wait for a cure for Spinocerebellar Ataxia. We are so fortunate to have so many loving and dedicated doctors, nurses, counselors, researchers and all of the others who tirelessly provide their time and talents to help make life better for others ... to find a cure. Please don't give up, please don't be discouraged. When you find that cure, our daughter will be able to again say the words that we so long to hear, "I love you."

Thank you from the bottom of our hearts,

— Angela's Mom and Dad ❖

More 'Pearls of Wisdom'

Submitted by Martha Elliot (docelliott268@gmail.com)

At 84 I've had over 40 years of SCA, and much of the time felt like a voice crying in the wilderness trying to figure out what was going on with a body that increasingly was difficult to manage. I'm one of a family of 10 or 12, depending on how one counts, with varying manifestations of SCA, and find it very difficult to determine what is permanent and what is not. I'm not in a support group as I no longer drive and my husband still works, so I don't have input from others, but I'd like to add a little to what you've so kindly offered.

Grab bars, vertical, can substitute for poles. You may have to let go of all modesty in the bathroom. In fact when we moved to a retirement home, we took out half of one wall so I could access the bathroom. Still haven't figured

out how to take a bath, since the legs are not able to get into the tub, and the room is too small for a second person to help.

When it comes to falls, I found that when I was still stressed from a fall, I thought I was calling for help, but I made no sound at all, so a whistle would have helped.

My previous kitchen had everything within reach – drawers, micro, oven, sink – but in this kitchen I cannot reach any of them, so I eat a lot of cold meals. ADA planning would help.

An apron is helpful. Cut off the top just above the ties and the bottom a little below the pockets. Adding tissues and a cordless phone can be handy.

See if there is anything available for home-bound. My librarian not only brings books, she is helping me learn to use my Kindle! ❖

Ataxia: Little Known Disorder Perplexes Doctors and Patients

By Kristin Emery

Kristin Emery is a contributing writer for the Observer Publishing Company, Washington, PA.

Ed Schwartz remembers when he first started having problems with his balance.

“This started close to 20 years ago,” remembers Schwartz, 71, who lives in Venetia. “I would get up at night to go to the bathroom and fall.”

Doctors first told him his inner ear was out of balance and affecting his equilibrium. Through the years, other changes emerged. “It started out being one thing and then another and we treated each one of these things,” he says. “The restless legs, the lack of sleep, the breathing. All of those we treated individually and not until about two years ago did we see them as a single entity.”

That’s when Schwartz finally got a diagnosis that solved the medical mystery that had been vexing him for two decades. The diagnosis was ataxia, which comes from the Greek word for disorder. The National Ataxia Foundation says it’s a term used to describe a group of neurological disorders that cause problems with balance and coordinated movement. It may also affect vision, swallowing and speech. NAF Executive Director Michael Parents says, “An estimated 150,000 Americans are affected by different forms of ataxia which can be hereditary, sporadic or caused by trauma. Ataxia can strike anyone at any time regardless of age, gender, or race. Unfortunately, getting a proper diagnosis can take years.” Parent says that

process involves a complete neurological examination, MRI, family history and gene testing.

What Causes Ataxia?

Ataxia can be a symptom of a number of neurological conditions or caused by an injury or environmental factors. NAF research shows about 50 percent inherit the condition with a gene defect or mutation, another 25 percent can attribute their disability to a known cause such as a stroke or head trauma and the remainder may never know the cause for their condition.

Schwartz fits into the last category and says the final clue to his condition came with an MRI which confirmed atrophy of his cerebellum. “Walking is difficult,” he admits. “I walk with a wide gait. I fall regularly. I wear a special vest that is designed to

help me counteract problems.” That vest holds 10 pounds of weights specially designed to counterbalance him.

Neuropathy contributes to his unsteadiness and has also weakened his grip. The retired engineer is still productive in his garage workshop but has had to make adjustments. “I used to like to work on cars,” he says. “There’s no way I could reach under a fender and try to turn a nut now.”

Other symptoms include difficulty sleeping and sleep apnea, which he’s controlling with a ►►



Ed and his wife Linda

C-PAP breathing machine. All of this has been a challenge for Schwartz and his wife, Linda, who will celebrate their 50th wedding anniversary this summer. But both are avid researchers and found evidence that many ataxia patients also suffer from gluten intolerance. Schwartz eliminated gluten from his diet and says he noticed immediate improvement in digestion and his restless leg syndrome.

Providing Resources and Support

For those who are diagnosed, the NAF provides help and support.

“Not only does the Foundation support worldwide ataxia research to help find treatments and ultimately a cure,” says Executive Director Parent, “but it offers ataxia publications for physicians as well as attends various medical conferences to help better inform the medical community about ataxia.”

The Foundation offers support groups for families including one here in Western Pennsylvania. Donna Eiben of South Park started the local chapter two years ago. “We have less than 10 members in our group and Ed was the first member,” she says. Hereditary ataxia runs in Eiben’s family and five members have been affected.

“It has been a very difficult life for me and as far as I know I am not affected,” says Eiben. “There was no support group in my area and I decided

we needed one here. It has been helpful for me and others in the group to share our experiences and feelings and feel that we are not alone.”

For Ed Schwartz, finally having a correct diagnosis has given him peace of mind. He gets physical therapy twice weekly to focus on eye exercises, balance and walking. His dietary changes have also helped alleviate symptoms.

“I’ve gotten so I can stand now, I can walk now and that is so significant,” he says.

“Thank goodness I know what it’s about now,” says Schwartz. “I don’t like it but I know what it is and I’m learning more and more all the time. I have set a personal mission to tell as many people about this as I possibly can.”

Schwartz advises others to be their own advocates and wants to increase ataxia awareness. “I want to somehow get into the medical community and let these people understand what the symptoms are and what to look for so that when someone comes in with this they can recognize it and start helping them.”

More information is available online at www.ataxia.org.

A special thanks to Linda Ritzer for allowing us to reprint this article.

The article originally appeared in the Observer-Reporter Newspaper’s Total Health magazine June 2015 edition. ❖

CoRDS Registry
Coordination of Rare Diseases
at Sanford

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

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

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

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

Helpful Resources

The National Ataxia Foundation does not endorse products, services, or manufactures. 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.

The National Ataxia Foundation Website

The following resource links can be found on the National Ataxia Foundation Website. For the most current information and additional resource links, please visit www.ataxia.org.

Genetic Information

<http://www.ataxia.org/links/ataxia-biology.aspx>

Neurological Resources

<http://www.ataxia.org/links/neurological-resources.aspx>

Caregiver Resources

<http://www.ataxia.org/resources/caregivers.aspx>

NAF provides a variety of ways to connect with others affected by ataxia:

<http://www.ataxia.org/connect/default.aspx>

American Red Cross

Emergencies can happen at a moment's notice. Tips providing people with disabilities and their

caregivers with guidance in managing communications, equipment, pets and home hazards.

<http://www.redcross.org/prepare/location/home-family/disabilities>

Center for Disease Control and Prevention

Provides many different topics and resources related to disabilities and accessibility.

<http://www.cdc.gov/ncbddd/disabilityandhealth/index.html>

Directory of Centers for Independent Living and Associations

Provides five core services:

- Information and referral
- Independent living skills training
- Individual and systems advocacy
- Peer counseling
- Transition – Transition from nursing homes and other institutions to community-based residences; assisting individuals to avoid institutional placement; and transition of youth with significant disabilities after completion of secondary education to postsecondary life.

<http://www.ilru.org/projects/cil-net/cil-center-and-association-directory> ▶▶

Individuals with SCA 1, 2, 3, 6, 8 Needed

Adults with SCA1, SCA2, SCA3, SCA6, and SCA8 are needed to participate in a research study of cerebellar function. Testing will involve a 90-minute MRI of the brain, neurological testing, and cognitive (thinking and mood) testing.

The cerebellum is an integral part of the brain that controls balance, coordination, and eye movements among other vital functions.

However, many questions about its structure and function in cerebellar syndromes remain unanswered. Through our studies, we hope to

gain a better understanding of the normal functions of the cerebellum as well as its contribution to ataxia. Your participation in this research will help build our understanding of ataxia and cerebellar function. Thank you for the gift of your time.

Subjects will be paid \$25 for MRI scan and \$25 for cognitive testing.

Contact Ann Fishman (Research Coordinator) at (410) 502-5816 or ataxiaresearch@jhu.edu for more information.

Disability★gov

Disability.gov directs you to information that may answer your questions about disability benefits and other types of assistance.

<https://www.disability.gov/getting-help-community/>
Home Modifications to Promote Independent Living

<https://www.disability.gov/resource/home-modifications-to-promote-independent-living/>

Disabled Sports USA

Providing adaptive sports opportunities for people with disabilities to develop independence, confidence and fitness through sports

<http://www.disabledsportsusa.org>

HomeAdvisor

Useful tool to help plan and budget for disability accommodation projects.

<http://www.homeadvisor.com/cost/disability-accommodation/>

Move Forward

Search their national database of physical therapists.

<http://www.moveforwardpt.com/Default.aspx> or
<http://www.moveforwardpt.com/symptomsconditions/detail.aspx?cid=1bb9c784-a874-43b1-976f-d0de03c19f99#.VVUZ85PmUTk>

National AMBUCS, Inc.

It is a non-profit service organization consisting of a diverse group of men and women who are dedicated to Creating Mobility and Independence for People with Disabilities.

<http://www.ambucs.org/general-info/>

National Center on Health, Physical Activity and Disability (NCHPAD)

A public health practice and resource center on health promotion for people with disability.

<http://www.nchpad.org/index.php>

Next Step – Program for Youth Living with Rare Genetic Diseases

A program for youth living with rare genetic

diseases helps these individuals develop life skills, find community and become self-advocates so they can move beyond their challenges to become strong, independent, productive adults.

<http://www.nextstepnet.org/our-programs/rare-genetic-diseases>

Social Security

Do you have a question about Compassionate Allowances? Check out their CAL FAQs page to find answers.

<http://www.socialsecurity.gov/compassionate-allowances/>

Tetra Society

Dedicated to assisting people with disabilities to achieve an independent and fulfilling life, one assistive device at a time.

<http://www.tetrasociety.org/>

United Way 2-1-1

A free and confidential service that helps people across North America find the local resources they need 24/7.

<http://www.211.org/>

Did you know that Generations is available electronically to members? Having Generations sent electronically allows you to save your issues and easily access links inside the issue with a simple click.

If you are interested in having your issue of Generations sent electronically, please contact Joan at joan@ataxia.org, call (763) 553-0020. ❖

Friedreich Ataxia Tissue Donation

If you have Friedreich Ataxia and you are interested in the Tissue Donation Program, please contact Dr. Arnulf Koeppen at (518) 626-6377 or arnulf.koeppen@va.gov.

Improving Your Brain Health Through a Healthy, Balanced Diet

Submitted by Dana Mauro

The following is submitted for information purposes and is not intended to serve as medical advice. Check with your doctor or medical professional when making any significant changes to your diet. If you have any questions, please contact Dana Mauro at danamauro63@msn.com.

Did you know ...

The brain uses the carbohydrates from your diet, for fuel? The best type are complex carbohydrates, because they release energy slowly and help the brain to function in a stable way. Complex carbohydrates can be found in starchy foods like wholegrain bread, pasta and brown rice.

For better concentration and mental performance, choose whole grain foods (like whole grain bread) instead of refined versions (like white bread). Avoid sweets and sugary foods.

Did you know ...

The brain needs essential fatty acids like Omega 3 and Omega 6? The body cannot make these, so they have to come from your diet.

Omega-6 is found in foods such as poultry, eggs, avocado and nuts.

Omega-3 is found in oily fish like salmon, herring and mackerel. Plant sources include seeds, especially flax seeds, and nuts, especially walnuts.

Processed foods, like cakes and biscuits, contain trans fats, also known as partially hydrogenated oils. For optimal brain health avoid trans fat as they stop essential fatty acids from doing their work effectively.

Did you know ...

Amino acids make neurotransmitters in the

brain, which affect our moods? Some of these amino acids come from what we eat and drink. For a good night's sleep, choose food and drink rich in tryptophan – such as a milk drink before bed. (Note: This can be helpful for some ataxia sufferers, but not for those with migraine symptoms. It is important to brush your teeth after drinking milk before retiring because it can cause

tooth decay. If the issue is disturbed sleep, you may talk to your doctor about trying 3-5 mg of melatonin. – Lyle Brecht, lbrecht@gmail.com)

Did you know ...

Vitamins and minerals are really important for the functioning of your whole body?

A vitamin or mineral deficiency can affect your mood, as well as other brain functions. Get a balanced diet by eating a variety of foods, including plenty of fruit and vegetables.



Dana Mauro

Did you know ...

The brain is about 80% water? Drinking lots of fluids will keep it functioning properly. Not getting enough fluids can affect mood and concentration. We lose water every day through our sweat, breath and urine.

Drink about 6 to 8 cups of non-alcoholic fluids every day. Optimal beverage choices are water, milk and fruit juice. Tea and coffee are okay but don't get all your fluid from caffeinated drinks. Sugary drinks should be avoided. ❖

John Mauro Named 2015 Myra Kraft Community MVP Award Winner

The Kraft family and New England Patriots Charitable Foundation's Myra Kraft Community MVP Awards place a spotlight on those who give their time to help others and exemplify leadership, dedication and a commitment to improving their communities through volunteerism. Each year, the Kraft family and the New England Patriots Charitable Foundation host the awards program as part of the ongoing Celebrate Volunteerism initiative in honor of Myra Kraft's example of being a lifelong volunteer.

John Mauro, NAF Board Member and Support Group Leader for the Central Massachusetts Support Group, was selected as a 2015 Myra Kraft Community MVP Award winner. He has shown an incredible commitment to volunteering and a dedication to his community that had not gone unrecognized by his peers. He was one of 26 volunteers who were recognized at the Putnam Club at Gillette Stadium on June 9. www.patriotledger.com/article/20150605/BLOGS/150607497/2000/NEWS

The day of the awards was a great day. Here is a quote by John on what it means to be selected as a winner and why volunteering is important to him: "I am humbled and honored by this recognition, but cannot accept this great honor for myself, but rather on behalf of all who struggle each day with ataxia. As a volunteer, it's about making strides to create awareness of a life altering disease that affects thousands of people here in New England and 150,000 across the United States."

"I decided a long time ago that I would not be a victim of my circumstance. I am a fighter and am meeting this challenge head on by proving to 'ataxia' that it cannot keep me down. As a volunteer and advocate, I can offer an insider's perspective on the subject of ataxia. I cannot sit

idly by in silence, so I raise my voice for those who are unable to speak."

"There have been many friends I have met through this journey who have been impacted by ataxia, each one has enriched my life and made me a better version of myself. I volunteer for them and accept this award on their behalf."



Patriots Chairman and CEO Robert Kraft, John Mauro, and Patriots and Pro Football Hall of Famer Andre Tippett

The following are videos showing the event:

<https://youtu.be/UkBgCYtfOe0>

<https://youtu.be/THLIEUNFTE8>

<https://youtu.be/MnTuxvndCgE>



GoodSearch

Did you know that donating money to the National Ataxia Foundation can be as easy as changing your search engine? GoodSearch.com donates 50 percent of its revenue to charities designated by its users.

To get started, simply go to the site and follow the easy steps to make NAF your charity of choice. Then use GoodSearch as you would any other search engine. This simple change will make a difference in the lives of those with ataxia!

Reproductive Options: My Story

By Jessica Oberlin

As I approach the celebration of my twin girls' first birthday, I reflect on the journey it took to bring them into the world. This journey was filled with emotional highs and lows and a roller-coaster of events which spanned nearly two years until we reached our ultimate goal, to have a healthy baby (which for us resulted in two)!

My story begins October 2012 when my dad sat me down to tell me that he carries a genetic disease called Spinocerebellar Ataxia Type 3. He had chosen this moment in time to tell me about ataxia because he knew my husband and I wanted to start our family soon. He explained that I have a 50/50 chance of also carrying the disease and if I did have it, the odds were the same for my children. He went on to tell me there are options now to prevent passing the gene on to the next generation.

As you can imagine this was a LOT to take in. Not only did I have concern for my father (whose symptoms were not obvious at the time), but also for myself, my three siblings (who shortly thereafter also learned of the disease), along with my future children. Here I was, ready and excited to become pregnant, when everything was put on hold.

Soon after, my husband and I met with a genetic counselor who was wonderful at explaining the disease and helping us to have a clear understanding of our options if my DNA test came back positive. The options were to either go ahead and get pregnant the old fashioned way, go through the process of pre-implantation genetic diagnosis (PGD) with in vitro fertilization (IVF), not have children, or adopt. He did not guide us whatsoever in one direction or the other, and assured us that no

matter which option we would ultimately choose, it is only up to us, and will be the right decision for our family.

Well, my test unfortunately came back positive. Although I had not yet decided which path I wanted to take in regards to reproduction, I quickly scheduled an appointment at a nearby reproductive clinic which was recommended by our genetic counselor. Our reproductive doctor explained what takes place in PGD through IVF. Following is my high level overview.

The process begins with sending a cheek swab DNA sample to the PGD laboratory. It takes about four months for this company to create what they call a probe which they will later use to test the cell samples for the genetic mutation. Once the probe is created you can then start the IVF process. One round of IVF typically lasts about eight weeks, requiring the mother to take multiple daily injections with the goal of creating as many eggs as possible. Once the eggs have matured they are retrieved from the mother and immediately fertilized in a test tube with the father's sperm. The medical term for the fertilized egg is 'embryo,' which after three days includes about eight cells. One cell is extracted from each embryo and shipped to the PGD lab to test for the genetic mutation. This is completed within 24 hours. One or more unaffected embryos is then implanted into the mother, typically five to six days after the eggs were retrieved. The first pregnancy test is usually taken two weeks after the implantation.

After receiving all of this information I felt EXTREMELY overwhelmed. Not only did this process sound like quite the opposite of what I had in mind for getting pregnant, but I was ►►

also still uncertain about the decision. There was a part of me that wondered if this was the “right” thing to do or if we would be messing with nature and God’s plan. It took several meetings with the counselor at the reproductive clinic, long talks with my husband and family, and a lot of praying to finally feel confident and know in my heart that this process would be the right decision for me and my family. I wanted ataxia-free children, and found peace in knowing all future generations would not have to worry about this ever again.

At this point it was already February 2013 and we mailed my cheek swab so my genetic probe could be created over the next four months. As I was battling depression during this time I had to force myself to pass the time with work and new hobbies. I started art classes and took a couple weekend trips with my husband.

May 2013 we were told the probe was finally ready and we could begin the IVF process. From someone who hates needles I was surprised to find the series of injections were not as bad

as I expected. Like most things, you quickly adapt and I found most of the pain with receiving a shot is in your mind. I was very lucky to have my mom and husband not hesitate when asked to give me my shots. The egg retrieval process also has a reputation for being painful as it is done while awake, but I found the procedure to be fast and not nearly as bad as I thought it would be. I was given pain relieving medication and a local anesthetic which made the experience tolerable.

After the retrieval I ended up with three eggs that could be fertilized. One cell from each was sent off to be tested and resulted in two unaffected embryos and one affected embryo (each ‘embryo’ includes about eight cells). I was disappointed that we had such a small number of

embryos to work with but still hopeful that if we implanted the two unaffected at least one would be successful. The preliminary results were positive and I was becoming more and more excited as each day passed. However, two weeks later I was informed the pregnancy had failed. I will never forget the moment I learned this. The ache in my heart and feeling of disappointment could not have been stronger. Not only did the pregnancy not work, but we also did not have any additional embryos to implant.

It is now July 2013. I took my mom’s advice and jumped right back into it. I couldn’t let the disappointment consume me and give up. I had a clear goal in sight and decided to dive into

another round of IVF. My doctor recommended increasing the amount of hormones in my injections and boy, did it work! I produced 22 eggs. Thirteen of those were successfully fertilized and tested for the genetic mutation. Of those, three were affected, six were unaffected and the remainder were not viable. We had two of the unaffected embryos transferred October 5, 2013,

which resulted in a successful pregnancy. My husband and I became the proud parents of two baby girls on May 29, 2014.

You may be wondering what happened to the remaining embryos. Two of the four remaining unaffected embryos were able to be frozen for our later use (hopefully, more babies!). The affected embryos were donated to the University of Michigan (MStem Cell Laboratories) where researchers were able to create the very first SCA3 disease-specific embryonic stem cell line which is now being used in ataxia research.

As I reflect, there are a few additional points I want to pass along:



Jessica, Matt, Lydia (left) and Avery (right) Oberlin

Reproductive Options: My Story
Continued from page 33

• **It is important to me that everyone reading about my journey understands there are options.** Whichever path chosen to have a child – whether conceiving naturally, through IVF, or adopting – it is a very personal decision and your decision is the best choice for you.

• The process may be physically and emotionally challenging, but there is support out there. I recommend meeting with a genetic counselor along with someone (like me) who has gone through this experience. It can be overwhelming and you are not alone.

• The cost of the PGD portion is around \$3,800 for each round and the IVF portion can exceed \$17,000 per round. I learned that very few insurance companies will assist in the cost of these procedures. However, you should always

check with them first. Based on your family household income, you may qualify for financial assistance through infertility grants and scholarships.

• I was concerned what others may say or think of my decision. Although I don't go around telling the general population my story, I have found that those I have shared it with have responded overwhelmingly in support and praise of my decision.

In conclusion, as I prepare for my daughters' first birthday, I know that my decision was the right one for my family. God has blessed us with two beautiful little girls. I am also thankful that our donation may benefit the ataxia research community in finding a cure for and prevention of this disease.

If anyone is interested in learning more about my story or is in need of support as they go through this process, please do not hesitate to contact me at oberlin.jessica@gmail.com. ❖

One Ataxian's Experience with HBOT

Submitted by Ed Biniek

My name is Ed Biniek. I am a 42-year-old male with ataxia. I use a walker for balance. I decided to try hyperbaric oxygen therapy (HBOT) last November. I have noticed some improvements. Better balance, sleep quality, vision, hearing, feeling or touch, speech, writing, mood, bladder and bowel functions, almost no throat seizures when eating or drinking, hands not so shaky, mind is clearer, no cramps, more energy, a lot better manual dexterity or control of hand movements. Some improvements aren't huge, just better.

I read a book on HBOT by Dr. Harch, the doctor giving me the treatments. Usually the first round is 40 treatments, a few months break, then 50 more treatments. I did 39 treatments, short break, and am on treatment four of 50.

If you have questions about my experience with HBOT, you may contact me at edwardbiniek@gmail.com.

Thank you for reading my story.



❖ **Ed Biniek**

Live Audio Looping at the NAF Booth

Submitted by Ian C. Bouras

My name is Ian C. Bouras. I was diagnosed with ataxia a few years ago, and have been developing my own brand of audio looping as a result (see *Generations*, Spring 2014, page 36).

Both John Mauro and Kathy Gingerelli were gracious enough to let me perform at the NAF booth at the New York Abilities Expo held May 1-3 at the New Jersey Convention and Expo Center in Edison, New Jersey.

It was such a fun experience, and meant a lot to me that my first live looping was at the NAF booth since I developed it because of ataxia. I am grateful to the NAF, John, and Kathy for the opportunity. It was a wonderful experience and I hope I helped draw some people to the booth to help spread awareness of ataxia.

Here are some links I hope you find interesting:

<http://guitarpr.com/guitarist-ian-c-bouras-transcends-rare-neurological-disorder-with-unique-musical-style/>

<https://www.youtube.com/watch?v=duUc57u26V4>

<https://www.youtube.com/watch?v=fahYBqeMkzo>



Ian C. Bouras

https://www.youtube.com/watch?v=UfDaSFC_bIw
www.sdmrecords.com (sdmrecords@gmail.com) ❖

Weill Cornell Medical College FRDA Study

A new Institutional Review Board (IRB)-approved study at Weill Cornell Medical College on Friedreich Ataxia (FRDA) is recruiting patients between 18 and 30 years old.

The purpose of the study is to compare different tests and procedures and to evaluate their usefulness in assessing the cardiac manifestations of FRDA. The study requires a two-day, overnight stay in New York City.

For more information, contact Gerardine Rodriguez at (646) 962-4537 or ger3001@med.cornell.edu.

'The Ataxian' Film Debuts

The world premiere of "The Ataxian" was held at Hollywood's "Dances with Films" festival on June 6. The festival is host to inspiring filmmakers who want their voices heard.

The film is a documentary on Kyle Bryant, who lives with Friedreich ataxia and works hard to create awareness on the disease.

For more information, visit www.theataxianmovie.com or www.examiner.com/article/dances-with-films-18-the-ataxian-is-one-awesome-documentary.





PROFILE

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1-(877)-638-3375
www.metlife.com/specialneeds

Our mission is to help families secure lifetime care & quality of life for special needs dependents. Established in 1998, MetLife Center for Special Needs Planning extends MetLife's traditional commitment of public service to families with dependents of any age, from infant to senior, who have a disability. Through a dedicated network of Special Needs Planners, the Center helps families through the maze of legal and financial complexities surrounding planning for the future of dependents with special needs.

Nearly 1 in 5 people
have a disability
in the U.S.²

The Need

69% of caregivers are very concerned about being able to provide lifetime care for their special needs dependent¹

48% of caregivers are *not* familiar with the planning steps for lifetime financial assistance for their special needs dependent¹

The Center has established working relationships with several leading advocacy groups such as, The Arc, Autism Society, National Down Syndrome Congress, Huntington's Disease Society of America, Tuberous Sclerosis Alliance, and United Cerebral Palsy.

MetLife's Vital Statistics MetLife, Inc. is a leading global provider of insurance, annuities and employee benefit programs, serving 90 million customers. Through its subsidiaries and affiliates, MetLife holds leading market positions in the United States, Japan, Latin America, Asia, Europe and the Middle East. For more information, visit www.metlife.com.

For more information or to be referred to a local MetLife Special Needs Planner, please call

1-877-638-3375, or visit
www.metlife.com/specialneeds

Source: ¹"The Torn Security Blanket"; MetLife, October 2011 Study

²"Nearly 1 in 5 People Have a Disability in the U.S., Census Bureau Reports", U.S. Census Bureau, July 25, 2012, URL: <http://www.census.gov/newsroom/releases/archives/miscellaneous/cb12-134.html>

MetLife does not provide tax or legal advice. We will work with your tax and legal advisors regarding your specific situation.



Chapter and Support Group News

from Around the Country

Central PA Ataxia Support Group

Submitted by Chris Rakshys

Our first meeting of 2015 took place on Saturday, April 11. There were just six of us, and our guest speaker was none other than “Mr. Shoulder-Shrug Ataxia” himself, our very own co-leader – Mike Cammer! He got a second shot at presenting his personal story that he previously shared at the NAF AMM in Denver in March. It was very nice to hear from one of our own, and we plan to have a different support group member speak as much/as little as he/she likes at future meetings. We hope this will make members, both old and new alike, feel more comfortable and at home with the group.

We also spent some time talking about future activities and fundraisers. Mike will look into the possibility of attending a Reading Phillies baseball game as a group. He will be participating in the Tour de Shunk Go On 3 bike ride in September in recognition of IAAD. The NAF will make a webpage for his event, so please be on the lookout for this wonderful opportunity to donate. We are planning to have a support group picnic for IAAD as well.

We are in the process of creating and distributing support group brochures. Hopefully, this will help in spreading ataxia awareness and recruiting new members from the area.

Support Group Member Goes Above and Beyond

Co-leader Mike Cammer and I received a phone call the week of May 11 from a mother of a NAF member who lives on our state. She explained that her son, who was diagnosed with Friedreich Ataxia at age 12, was recently admit-

ted to a rehabilitation hospital in Pittsburgh. She wanted to know if we could please reach out to him, help him with his current challenges and give him some encouragement, guidance and friendship.

Mike shared an e-mail with a couple of the group’s members. Although this is not in our area of central/eastern PA, Ed Schwartz and his wife Linda (Ed no longer drives) drove the 35 miles to visit this man and be there for him. This is a true example of what a support group is all about!

Greater Houston Ataxia Support Group

Submitted by David Brunnert

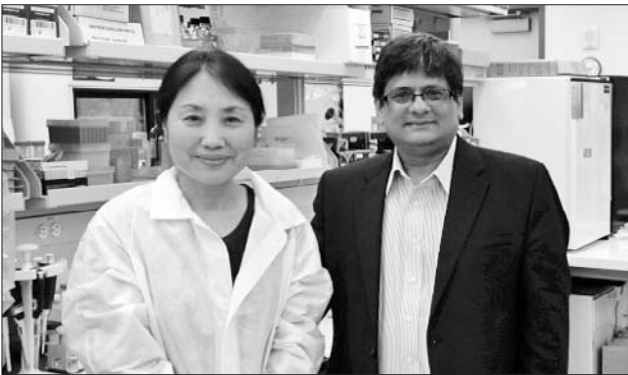
We held our meeting on April 26 at The Women’s Hospital of Texas with 27 in attendance. Bonnie Sills gave us a brief overview of the AMM that was held in Denver in March.

We had a guest speaker, Dr. Partha Sarkar, UTMB Galveston, who gave an informative presentation on a group of ataxias caused by “repeat” sequences in DNA. His team recently published the results of some critical research. The research validates previous research that shows a correlation between a protein called ATXN3 and ataxia. However, Dr. Sarkar’s research shows the negative effects of ataxia aren’t caused by ATXN3 directly. Instead, the ATXN3 protein attaches itself to the PNKP enzyme and renders it ineffective. This is important because in normal cells, the PNKP enzyme is continually repairing it. So ATXN3 isn’t causing damage, per se, its preventing normal repair.

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Chapter and Support Group News
Continued from page 37

This leaves two potential “targets” for treatment: 1) Prevent the ATXN3 from attaching to the PNKP, and 2) produce a surplus of PNKP. My understanding is that there are drugs, already in clinical testing for cancer patients, that are known to do these two things. (Note, it’s not certain they would have the same affect in ataxia patients. Nevertheless, it’s encouraging!) Finally, Dr. Sarkar indicated that these results would probably apply to several different SCAs as well as Huntington’s disease.



Dr. Rui Gao, MD (left), and Partha S. Sarkar, PhD, Department of Neurology, Neuroscience and Cell Biology, University of Texas, Medical Branch)

Everyone was impressed by Dr. Sarkar’s technical knowledge. However, what really excited everyone was learning how passionate he and his team are to make a difference in our lives.

The Abilities Expo will be held in Houston on

July 31–August 2. Our support group will be staffing the booth along with the North Texas Support Group.

Because pediatric patients sometimes have special needs that require extra attention from their caregivers, we have decided to schedule a special get-together for pediatric patients prior to our next regular meeting.

Also discussed was fundraising. There is a broad willingness to support fundraising activities and we will be working on this in the future.

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Northern California Ataxia Support Group

Submitted by Joanne Loveland

We are so excited to have our own website. Brian Wong has built this to our delight! Please check it out at <https://norcalataxia.org>. We had our second NCASG meeting on Saturday, April 11. A summary of the AMM in Denver was passed out at the meeting. The quarterly Newsletter (edited by Alan Acacia), the Local Area Contacts (organized by Shirley Hanks) and now our own website (built by Brian Wong) are ALL creating much better communication with our members. We are all seeing an increase in inquiries about our SG. With this new momentum people are volunteering because Alan has been reaching out and asking members to sign up to help our SG. We have new people who are willing to help with fundraising – which is next on our list of objectives. Woohoo! ▶▶



Members of the Greater Houston Ataxia Support Group

India Ataxia Support Group

Submitted by Chandu Prasad George

Returning from the NAF AMM in Denver, we were given a hero's welcome. It was all a great feeling and at the same time I was a bit nervous with all the attention.



Chandu Prasad George returns to India to a hero's welcome

Tri-State Ataxia Support Group

Submitted by Kathy Gingerelli

The Abilities Expo at the New Jersey Convention and Expo Center on May 1-3 was great. Members of our group showed up to help out which was very much appreciated. I had fun and met a lot of new people and learned new and helpful information.

What a great turnout we had for our March

meeting. Everyone spoke of how they got through the winter.

We covered a lot of topics including the fact that our group is now merged with the North East Area Ataxia Support Group Chapter, which includes the Central Massachusetts, Boston Area, New Hampshire, Rhode Island and Maine Support Groups. Being on an e-mail blast with all these groups will make it easy to share ideas and even come up with new things to discuss at future meetings.

One of these ideas we talked about and will implement is splitting up for a 15-20 minute interval between caregivers/family members and ataxia patients.

Another topic discussed was that Athena Labs is the go-to for genetic testing and more insurance plans are covering than before. Also, the lab will work with each individual as far as payments go. Remember, sometimes getting a diagnosis can benefit future family members.

Tarheel Ataxia Support Group

Submitted by Ron Smith

Our support group had a great turnout on Saturday, May 2. About 30 people came to the White Deer Park Nature Center for our group picnic.

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Members of the Tarheel Ataxia Support Group

Chapter and Support Group News
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Chesapeake Chapter – 32nd Annual Medical Meeting

Submitted by Carolyn Davis, President, Chesapeake Chapter

The Chesapeake Chapter's 32nd Annual Medical Meeting was held April 25 in Washington DC, and led by Joe DeCrescenzo as Master of Ceremonies. The annual meeting of the American Academy of Neurology ended that day, and three ataxia clinicians/researchers attending and speaking at the meeting graciously agreed to address our group. All are members of NAF's Medical Research Advisory Board.

Dr. Tetsuo Ashizawa addressed the identification of the SCA's, now numbering 36. He also

gave an example of differences in treating the symptoms vs. finding a cure – the ultimate goal is finding the cure. There is emphasis on documenting the natural history of the SCA's in order to assess the efficacy of potential treatments and cures. Dr. Ashizawa is Professor of the Department of Neurology at the University of Florida, Gainesville; Co-Director of the Ataxia Center of Excellence there; and Executive Director of the McKnight Brain Institute.

Dr. Massimo Pandolfo, having discovered the FA gene, is a leading researcher of Friedreich Ataxia. He spoke of progress towards a therapy for FA, as clinical trials are ongoing. Requirements for trial design include tools to assess the progression of the disease and biomarkers to determine the effects of the therapies. Dr. Pandolfo continues his research as Chair of the Department of Neurology at Universite Libre ►►

Genes in Inherited Neurologic Disorders Study #HUM00041414

Dr. Burmeister at the University of Michigan is recruiting individuals with ataxia for the research study Genes in Inherited Neurological Disorders. This study is designed to find what and how changes in the genetic material (DNA) cause inherited neurologic disorders, such as ataxia. We are recruiting individuals with inherited ataxia, their affected relatives (such as a brother or sister, a cousin, or a parent), and their unaffected family members, where possible. We are currently recruiting persons with an unknown form of ataxia, so at least one affected in your family should first be tested for the most common known causes of ataxia and found to be negative. We are recruiting both subjects with or without other affected family members.

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

The lab has already identified several novel ataxia genes, and additional cases with newer known ataxia genes as well as mutations in genes causing other diseases involving ataxia and other, seemingly unrelated, symptoms such as tooth problems, although most subjects in our study have ataxia as main symptom.

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

If you would like further information or are interested in participating, please contact:

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de Bruxelles-Hopital Erasme in Belgium.

Dr. Brent L. Fogel has a research lab at UCLA and was recognized last year for his use of exome sequencing in diagnosing cerebellar ataxia. He spoke of ataxia as a symptom, not a disease, and of the need to rule out causes of ataxia other than genetics when making diagnoses. Dr. Fogel is Assistant Professor of Neurology at the University of California, Los Angeles, and Director of the Ataxia and Neurogenetics Biobank Program.

Bailey Vernon, Health Educator for the Ataxia Center at Johns Hopkins and Leader of the Mid-Atlantic Ataxia Social Group, had a dual assignment – to report on NAF’s Annual Membership Meeting and on the Ataxia Center. Johns Hopkins has assembled a team of physicians and other health professionals to treat patients with ataxia. Bailey referred us to *ataxia.org* to view the presentations made at NAF’s 2015 AMM and encouraged all to attend NAF’s 2016 Annual Membership Meeting in Orlando, FL.

Two chapter members addressed the group, telling of their personal journeys with ataxia. Mike Cammer, Co-Leader of the Central Pennsylvania Ataxia Support Group, spoke of what he had to give up as the ataxia progressed but what he is still able to do because of determination and adaptation. John Cernosek, an Ambassador for the Friedreich’s Ataxia Research Alliance and a Leader of the Mid-Atlantic Young Ataxia Social Group, spoke of the importance of having a support system around you – a strong community of those affected by ataxia, as well as friends and family.

During the meeting Libby Labash made a plea for all of us to support research with our time and our money. In attendance from Johns Hopkins were Ann Fishman, Research Coordinator, and Dr. Chiadi Onyike, Principal Investigator, for a research study of cerebellar function.

Over 50 people attended the meeting, which afforded an opportunity to socialize before and after as well as during the lunch break.

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Alabama Ataxia Support Group

Submitted by Becky Donnelly

The Alabama Ataxia Support Group held its March 28th meeting at Covenant Presbyterian Church in Homewood, AL. Our speaker, Steve Bailey of the Alabama Elder Care Council and Bailey Law firm, gave an update on Alabama’s elder care laws, especially regarding long-term care coverage. There was much interest and Steve answered many questions posed by the group. He encouraged our members to call him with their questions and concerns. A great time of fellowship and a delicious lunch was enjoyed by the 20-plus members present.

Our May 23rd social was held at the Red Lobster in Vestavia Hills, AL, with 23 members in attendance. Members remembered with sadness the passing of a beloved member, Mike McLain of Camden, AL, and Doug Mason, spouse of Susan Mason and father of Chandler Abel.

A flyer advertising our support group to be displayed in doctors’ offices was discussed and an updated one will be created by Becky and distributed.

We looked forward to our September 26th awareness event to be held in north Alabama, our October 24th meeting and luncheon in Homewood, where we will have a disability judge as a speaker, and our December 12th social in Birmingham.

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New Hampshire Ataxia Support Group

Submitted by Jill Porter

The New Hampshire Support Group met on Saturday, May 30th. There were five members in attendance with some members sending their regrets at being unable to attend. We appreciate RSVPs from our members as it helps in planning the agenda and it is also an opportunity to ask for a subject to be placed on the agenda.

Chapter and Support Group News
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This meeting focused on sharing time and covered many topics, one being the benefit for a caregiver to seek out long-term care insurance.

We will continue to meet on the fourth Saturday of each month at the Hannaford Market in Bedford, NH. Newcomers, friends and family are always welcome. If your travels take you near us on one of our meeting dates, we invite you to attend our meeting too.

Arizona Ataxia Support Group

Submitted by Mary Fuchs

The Arizona Ataxia Support Group had a table at the Fifth Annual D-Backs Disability & Human Services Day on Sunday, June 7. The Disability Expo began at 11:30 a.m. and ran until the seventh inning. We had 12 people help at the booth. Included with the table fee we received free tickets to the game. We had fun and there was good traffic and lots of questions about ataxia.



Left to right: Mary Fuchs, Tony Troutt (son) Frank & Jack Fuchs (husband and grandson) and Matia Troutt (granddaughter) at the Fifth Annual D-Backs Disability & Human Services Day

Northeast Area Ataxia Support Groups

Submitted by John Mauro

At our meeting in April we had 85 people attend which is the largest yet.

Dr. Jeremy Schmahmann, Director of the

MGH Ataxia Unit, spoke about how he has been creating awareness about the cerebellum. He recently did an interview on National Public Radio to discuss Jonathan Keleher, one of a handful of people who have lived their entire lives without a cerebellum.

You can listen to the interview here: <http://www.npr.org/sections/health-shots/2015/03/16/392789753/a-man-s-incomplete-brain-reveals-cerebellum-s-role-in-thought-and-emotion>.

Adam Burch, is a chiropractor who treats individuals with joint and back pain. Adam demonstrated some exercises to improve strength and flexibility using common items found around the house (bath towel and a belt or strap from a duffle bag). Regularly doing these exercises will help with one's balance, gait and coordination.

You can also view these exercises on line: <https://www.youtube.com/playlist?list=PL3EBDE86D65ED5747>.

Adam is in the process of creating a video of all the demonstrated exercises which will be completed at the end of the year.

Dave Kulis is a Senior Research Assistant at the Anderson Lab, Woods Hole Oceanographic Institution. He also is the organizer of the New Balance Falmouth Road Race fundraiser benefiting MindLink (Dr. Schmahmann is the founder). Dave's two children were diagnosed with AOA2 at age 17. The Kulis family want to support MindLink as it leads the way in studying the causes and clinical manifestations of disorders of the cerebellum, and how the brain is wired. up to enable motor control, intellect and emotion. This work has shed new light on the ataxias and related disorders, and has changed the way that doctors and scientists think about the brain and manage patients with neurological disease.

With the upcoming Walk n' Rolls for IAAD, we talked about the need to get active members to create awareness and how to draw more people this year. ▶▶

Wisconsin Ataxia Support Group

Submitted by Jenny Mathison

We had a great turnout for our May meeting, especially considering it was held on a holiday weekend. Bill Sweeney, the NAF’s new president, came down for the meeting and we had some good conversation about what the NAF can do to help support the support groups and the ataxia community in general.



Left to right: Martin & Jenny Mathison and Kim & Rob Rosario of the Wisconsin Ataxia Support Group

We came away with some good topic ideas for future meetings, including traveling with disabilities and helpful equipment to have. Organizing some fundraising and ataxia awareness is another hot topic that Kory and I will brainstorm on. We hope to get some more speakers in the future, including Dr. Gomez.

One of the struggles I have with being support group “leader” is that I’m not much of a leader. With everyone so spread out over the state, it’s hard to organize a meeting that will accommodate everyone who wants to come, setting an agenda that makes it worthwhile for people to attend, and having meetings frequently enough that they would benefit our members.

We’ve had two meetings and I am hopeful by the number of people who have attended. We plan on starting each meeting with a meet-and-greet. I strongly encourage you to keep in contact with members that live in your area for a closer support network between meetings, and possible carpooling for future meetings. The e-mail chain can be a support group in itself. It may be beneficial to hold meetings in different areas and have members who live there host and set up the meeting.

I’d love to hear from others on any ideas for future meetings: *mjmathison@att.net*.

Greater Atlanta Ataxia Support Group

Submitted by Dave, Greg and Lealan

It was a great day, great food and great friendship at the Greater Atlanta Ataxia Support Group Spring Picnic at Lake Lanier. ❖



Members of the Greater Atlanta Ataxia Support Group

NAF Directory of Chapters, Support Groups, Social Networks and Ambassadors

The National Ataxia Foundation has a large network of volunteers who serve as support group leaders, chapter presidents, and ambassadors for our organization. These volunteers help identify important local resources and professional care for people with ataxia and their families.

If you or a family member or friend has been newly diagnosed with ataxia, please contact the NAF leader nearest you. If there is not a group in your area, we encourage you to visit our online social networks. You may also consider starting a support group in your area or becoming an NAF ambassador. If you are interested in these volunteer positions please contact Lori Shogren at lori@ataxia.org or (763) 553-0020.

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

Social Networks

NAF BULLETIN BOARD

Moderator – Atilla and Bear

www.ataxia.org/forum/toast.asp

NAF CHAT ROOM

Moderator – Della (ddpokernut@yahoo.com)

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

NAF FACEBOOK GROUP

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

NAF FACEBOOK FANS

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

NAF YOUTUBE CHANNEL

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

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CFC Number

The National Ataxia Foundation's Combined Federal Campaign (CFC) number is 10752. This program provides a convenient way to donate to the Foundation, and provides a great benefit to those with ataxia.

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E-mail: dsmith@sa-pr.com

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

(513) 284-2865

E-mail: jenmu@yahoo.com

Julia Soriano – Cincinnati, OH

(513) 899-1195

E-mail: julia@epivision.com

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

(216) 272-5588

E-mail: willowpier@roadrunner.com

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

(503) 502-2633

E-mail: wolfer.jason@gmail.com

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

(610) 395-6905

E-mail: cpa.ataxia@rcn.com

Michael Cammer – Downingtown, PA

(610) 873-1852

E-mail: michael.cammer62@hotmail.com

Facebook Group:<https://www.facebook.com/groups/1475283086068548/>www.ataxia.org/chapters/CentralPA/default.aspx**POSITIVE PEOPLE IN PA SUPPORT GROUP LEADER****Liz Nussear** – Norristown, PA

(610) 272-1502

E-mail: lizout@aol.com

www.ataxia.org/chapters/SEPennsylvania/default.aspx**WESTERN PA SUPPORT GROUP LEADER****Donna Eiben** – South Park, PA

(412) 655-4091

E-mail: dawn.eiben@verizon.net

S.G. Website:

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

(401) 297-8627

E-mail: azevedo_anabela@yahoo.com

www.ataxia.org/chapters/Rhodelsland/default.aspx**— SOUTH CAROLINA —****AMBASSADOR****Brad Forth** – Greenville, SC

(864) 415-8147

E-mail: bradf@photoforth.com

www.ataxia.org/chapters/Greenville/default.aspx**— TENNESSEE —****MIDDLE TN AREA SUPPORT GROUP LEADER****Vicki Tyler** – Nashville, TN

(615) 646-3024

E-mail: tylerv2@comcast.net

www.ataxia.org/chapters/TN/default.aspx**— TEXAS —****GREATER HOUSTON AREA SUPPORT GROUP LEADER****David Brunnert** – Cypress, TX

(713) 578-0607

E-mail: david.brunnert@sbcglobal.net

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

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

E-mail: cheve11e@sbcglobal.net

www.ataxia.org/chapters/NorthTexas/default.aspx**AMBASSADORS****Dana LeBlanc** – Orange, TX

(409) 883-5570

E-mail: tilessal@yahoo.com

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

(915) 329-0721

E-mail: debrawhitcomb@hotmail.com

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

*NAF Directory**Continued from page 47***– UTAH –****UTAH SUPPORT GROUP LEADERS****Grant Beutler** – Salt Lake City, UT
E-mail: grant.beutler@gmail.com**Jenny Durrant** – North Ogden, UT
E-mail: jenny@utahataxia.org**Lisa Ord, PhD, LCSW** – Salt Lake City, UT
(801) 587-3020
E-mail: lisa.ord@hsc.utah.edu**Facebook Page:** www.facebook.com/utahataxia
S.G. Website: www.utahataxia.org
www.ataxia.org/chapters/Utah/default.aspx**– VIRGINIA –****CHESAPEAKE CHAPTER PRESIDENT****Carolyn Davis** – Vienna, VA
(703) 759-2008E-mail: ccnafpres@gmail.com
www.ataxia.org/chapters/Chesapeake/default.aspx**– WASHINGTON –****SEATTLE AREA SUPPORT GROUP LEADER****Milly Lewendon** – Kirkland, WA
(425) 823-6239E-mail: ataxiaseattle@comcast.net
www.ataxia.org/chapters/Seattle/default.aspx**AMBASSADOR****Linda Jacoy** – Spokane, WA
(509) 482-8501E-mail: linda4727@hotmail.com
www.ataxia.org/chapters/Spokane/default.aspx**Sherry McLaughlin** – Port Townsend, WA
(360) 344-2445E-mail: ccherilynmc@yahoo.com
www.ataxia.org/chapters/McLaughlin/default.aspx**– WISCONSIN –****WISCONSIN SUPPORT GROUP LEADER****Jenny Mathison** – Madison, WI
(608) 285-5285E-mail: mjmathison@att.net
www.ataxia.org/chapters/Wisconsin/default.aspx**International
Support Groups & Ambassadors****– CANADA –****OTTAWA SUPPORT GROUP LEADER****Prentis Clairmont** – Ottawa, Ontario
(613) 864-8545E-mail: prentis.clairmont@gmail.com **Facebook Group:**
<https://www.facebook.com/groups/1468963499991380/>
www.ataxia.org/chapters/Ottawa/default.aspx**– INDIA –****INDIA SUPPORT GROUP LEADER****“Seek a Miracle Ataxia Group” (SAMAG)****Chandu Prasad George**

Hyderabad, Secunderabad, India

Mobile: 0091-9989899919, 0091-9885199918

E-mail: sam_ataxiaindia@yahoo.com

S.G. E-mail: india.ataxiagroup@gmail.com

Facebook Group: <https://www.facebook.com/ataxiain>S.G. Website: www.ataxia.inwww.ataxia.org/chapters/Chandu/default.aspx**– PAKISTAN –****AMBASSADOR****Sajjad Jaider** – Sindh, Pakistan

0092-(300) 8221850

E-mail: sajjadhaiderb@hotmail.com

**PATIENTS with EARLY SYMPTOMS of
FRIEDREICH'S ATAXIA****age 10 and above needed for an MRI study to
evaluate the chemistry and connectivity of the
brain and spinal cord in Friedreich's ataxia****at the Center for Magnetic Resonance Research
at University of Minnesota****You will lie in the scanner for ~1.5 hour while listening to the
music of your choice. Reimbursement for travel expenses is
available and you will be compensated for your time.****Please note that we cannot scan you if you have Harrington rods,
and we cannot scan people with diabetes at this time.****If you are interested or have questions, please call****Diane Hutter @ (612) 625-2350 or e-mail hutte019@umn.edu.**

Calendar of Events

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

SUPPORT GROUP MEETINGS

– **Saturday, July 18, 2015** –

Denver Area Ataxia Support Group Meeting

Time: 1 – 4 p.m.

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

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

Greater Atlanta Ataxia Support Group Meeting

Time: 1 p.m.

Location: Emory Center for Rehabilitation Medicine, 1441 Clifton Rd. NE, Rm. 101, Atlanta, GA 30322

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

NCASG – New Sacramento Area Location Meeting

Time: 10 – 11:45 a.m.

Location: Pocket Library, 7335 Gloria Dr., Sacramento, CA 95831

Details: Attending a “Fall Prevention 101” workshop. For additional information contact Teresa Bredberg at tbredberg@sbcglobal.net.

Twin Cities Ataxia Social Group Meeting

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

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

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

– **Sunday, July 19, 2015** –

Chi-town Ataxia Friendship Group Meeting

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

Location: Good Samaritan Hospital (White/Blue Oak Rm.), 3815 Highland Ave., Downers Grove, IL 60515

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

– **Saturday, July 25, 2015** –

Central PA Ataxia Support Group Meeting

Time: Noon – 2 p.m.

Location: Muhlenberg Community Library, 3612 Kutztown Rd., Laureldale (Reading), PA 19605

Details: For additional information contact Chris Rakshys at (610) 395-6905 or cpa.ataxia@rcn.com or Mike Cammer at (610) 996-5814 or michael.cammer62@hotmail.com.

New Hampshire Ataxia Support Group Meeting

Time: 10 – Noon

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

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

– **Saturday, August 1, 2015** –

Boston Ataxia Support Group Meeting

Time: Noon – 2 p.m.

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

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

– **Saturday, August 8, 2015** –

Central Minnesota Ataxia Support Group Meeting

Time: 9:45 – 11:45 a.m.

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

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

Kansas City Ataxia Support Group Meeting

Time: 2 – 4 p.m.

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

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

North Texas Ataxia Support Group Meeting

Time: 10 a.m. – Noon

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

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

Continued on page 50

Calendar of Events
Continued from page 49

– **Wednesday, August 12, 2015** –

Willamette Valley Ataxia

Support Group Meeting – Albany

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

Location: 400 NW Hickory, Albany, OR 97321

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

– **Thursday, August 13, 2015** –

St. Louis Area Ataxia Support Group Meeting

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

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

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

– **Saturday, August 15, 2015** –

Orange County Ataxia Support Group Meeting

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

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

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

Twin Cities Ataxia Social Group Meeting

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

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

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

– **Sunday, August 16, 2015** –

Greater Houston Area Ataxia Support Group Meeting

Time: 2 – 4 p.m.

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

Details: For more information contact Bonnie Sills at (713) 944-5183 or texasnow@aol.com or David Brunnert at (713) 578-0607 or david.brunnert@sbcglobal.net.

– **Saturday, August 22, 2015** –

New Hampshire Ataxia Support Group Meeting

Time: 10 – Noon

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

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

– **Sunday, August 30, 2015** –

Willamette Valley Ataxia Support Group Meeting – Portland

Time: 3 – 4:30 p.m. every 6th Sunday

Location: Public Library at 10723 SW Capitol Highway, Portland, OR

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

– **Wednesday, September 9, 2015** –

Willamette Valley Ataxia Support Group Meeting – Albany

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

Location: 400 NW Hickory, Albany, OR 97321

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

– **Thursday, September 10, 2015** –

St. Louis Area Ataxia Support Group Meeting

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

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

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

Tri-State Ataxia Support Group Potluck Meeting

Time: 6:30 – 8:30 p.m.

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

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

– **Saturday, September 12, 2015** –

Central Minnesota Ataxia Support Group Meeting

Time: 9:45 – 11:45 a.m.

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

Details: For additional information contact ►►

Marsha Binnebose at (320) 248-9851 or e-mail mbinnebose@hotmail.com.

North Texas Ataxia Support Group Meeting

Time: 10 a.m. – Noon

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

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

Positive People in PA Ataxia Support Group Meeting

Time: 10 – 11:30 a.m.

Location: Mercy Suburban Hospital, Second Floor Walk-up Room.

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

– **Saturday, September 19, 2015** –

Twin Cities Ataxia Social Group Meeting

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

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

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

– **Sunday, September 20, 2015** –

Chi-town Ataxia Friendship Group Meeting

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

Location: Good Samaritan Hospital (White/Blue Oak Room), 3815 Highland Ave., Downers Grove, IL 60515

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

– **Thursday, October 8, 2015** –

St. Louis Area Ataxia Support Group Meeting

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

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

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

– **Saturday, October 10, 2015** –

Central Minnesota Ataxia Support Group Meeting

Time: 9:45 – 11:45 a.m.

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

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

Kansas City Ataxia Support Group Meeting

Time: 2 – 4 p.m.

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

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

North Texas Ataxia Support Group Meeting

Time: 10 a.m. – Noon

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

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

Northern California Ataxia Support Group Meeting

Time: 11:30 a.m. – 2 p.m.

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

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

Tampa Bay Ataxia Support Group Meeting

Time: 12:30 – 3 p.m.

Location: Morsani Center, 13330 USF Laurel Dr. #1013, Tampa, FL 33612

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

– **Wednesday, October 14, 2015** –

Willamette Valley Ataxia Support Group Meeting – Albany

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

Location: 400 NW Hickory, Albany, OR 97321

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

INFORMATIONAL, AWARENESS, AND IAAD EVENTS AND FUNDRAISERS

Thursday, July 16, 2015

KML 3 vs. 3 Soccer Tournament

Time: 6 – 8 p.m.

Location: Kettle Moraine Lutheran High School,

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3399 Division Rd., Jackson, WI 53037

Details: Tournament benefits the National Ataxia Foundation (NAF). For more information contact Barry Washburn at ewashburn@nconnect.net.

– **Sunday, July 26, 2015** –

25th Anniversary of ADA

Details: July 26th is the 25th anniversary of the signing of the Americans with Disabilities Act! <http://adaanniversary.org/>

– **Friday, July 31 – Sunday, August 2, 2015** –

Houston Abilities Expo

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

Location: NRG Center (Formerly Reliant Center), Hall E

Details: Admission is free.
www.abilities.com/houston

– **Saturday, August 8, 2015** –

Walk for Dave

Time: 9 a.m. – Noon

Location: Ononsaga Lake Park, (Bay View Tent at Willow Bay), 7199 Onondaga Lake Park Trl., Liverpool, NY 13088

Details: Registration is \$10 per participant. This walk is dedicated to the memory of David Alessi. Visit the website to register. For additional information please contact Marc Alessi at (615) 622-3976 or pianoman345@hotmail.com. All Proceeds to benefit the National Ataxia Foundation (NAF). <https://naf.myetap.org/fundraiser/15walk4dave/>

– **Saturday, August 29, 2015** –

Macy's "Shop for a Cause"

Details: Just in time for "Back to School" shopping! One-day-only sales event at Macy's stores nationwide. Card holders receive a 30% discount on regular, sale, and clearance items, including home. Even save on most brands usually excluded. Card holders will also save 10% on electronics, watches, furniture, and rugs. Exclusions apply. Card holders are also eligible to register to win a \$500 Macy's gift card. All Macy's Card orders must be received by August 21. For more information please contact NAF at (763) 553-0020. All proceeds benefit the National Ataxia Foundation (NAF). <https://www.ataxia.org/macyscard>

– **September or October TBD, 2015** –

**Northern CA Walk n' Roll for Ataxia
IAAD Event and Fundraiser**

Location: TBD

Details: All proceeds benefit the National Ataxia Foundation (NAF). For more information contact Brian Petersen at smileypetersen@yahoo.com. www.ataxia.org/walk/concord

– **October TBD, 2015** –

**Concord Walk n' Roll for Ataxia
IAAD Event and Fundraiser**

Location: TBD

Details: All proceeds benefit the National Ataxia Foundation (NAF). For more information contact Joann Loveland at joanneloveland@gmail.com. www.ataxia.org/walk/lafayette

– **Saturday, September 12, 2015** –

**Minnesota Walk Stroll n' Roll for Ataxia
IAAD Event and Fundraiser**

Time: Social Hour 9 – 10 a.m., Walk and Program at 10 a.m.

Location: Wolfe Park, 3700 Monterey Dr., St. Louis Park, MN 55416

Details: Wolfe Park is kid and pet friendly. No registration fee – donations only. All proceeds benefit the National Ataxia Foundation (NAF). For more information or to volunteer please visit the event website or contact Terry Sweeney at (612) 763-9320 or mnataxiawalk@yahoo.com. www.ataxia.org/walk/minnesota

**New England Walk n' Roll for Ataxia
IAAD Event and Fundraiser**

Time: 9 a.m. – Noon

Location: Rocketland, Auburn, MA

Details: All proceeds benefit the National Ataxia Foundation (NAF). For more information visit the event website or contact John Mauro at (508)736-6084 or john@ataxia.org. www.ataxia.org/walk/auburn
<https://www.facebook.com/events/786303194810958/>

– **Sunday, September 13, 2015** –

**Denver Walk n' Roll for Ataxia
IAAD Event and Fundraiser**

Time: Registration begins at 8 a.m.

Location: Denver City Park Pavilion, Denver, CO

Details: All proceeds benefit the National Ataxia Foundation (NAF). For more information visit the event website or contact Charlotte DePew at ►►

(720) 379-6887 or cldepew77@comcast.net.
www.ataxia.org/walk/denver

– **Friday, September 18-20, 2015** –

Boston Abilities Expo

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

Location: Boston Convention & Exhibition Center, Hall C

Details: Admission is free.

www.abilities.com/boston

– **Saturday, September 19, 2015** –

Atlanta Walk n' Roll for Ataxia

IAAD Event and Fundraiser

Time: Registration 9 a.m., Walk 10 a.m.

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

Details: All proceeds benefit the National Ataxia Foundation (NAF). For more information visit the event website or contact Greg Rooks at (404) 822-7451 or atlantaataxia@gmail.com.

www.ataxia.org/walk/atlanta

The Ataxia Hoedown at the Seton Corral

IAAD Event and Fundraiser

Time: 5 – 10 p.m.

Location: Elizabeth Ann Seton Parish Hall, 345 Bear-Christiana Rd., bear, DE 19701

Details: In recognition of IAAD and Cathy DeCrescenzo's 50+10 Birthday. Country Hoedown featuring a Chuck Wagon Buffet, DJ, Line Dancing and a Chinese Auction. In lieu of an admittance fee or gifts, donations are requested and all proceeds benefit the National Ataxia Foundation (NAF). For more information visit the event website or contact Joe or Cathy DeCrescenzo at (302) 369-9287 or cdecres@verizon.net.

<https://naf.myetap.org/fundraiser/15hoedown/>

– **Sunday, September 20, 2015** –

Tour de Shunk – Go On 3!

IAAD Event and Fundraiser

Details: I'm Mike Cammer and I have ataxia. This year on September 20, I am entering the "Tour de Shunk" for the second year in a row. I plan to ride the entire 102 miles. Please help support me on my challenge to "Go On 3! For ataxia awareness." All proceeds benefit the National Ataxia Foundation (NAF). For more information visit the event website.

<https://naf.myetap.org/fundraiser/15GoOn3/>

– **Friday, September 25, 2015** –

International Ataxia Awareness Day (IAAD)

Details: The goal of IAAD is for every individual to

participate in some activity, creating awareness about ataxia. You could share something you know about ataxia with one other person who has never heard of it, educate a group of people by speaking at a school or civic group, contact the media, or raise financial support. International Ataxia Awareness Day has grown over the years, and more ideas keep coming in. You can download the IAAD kit which contains ideas for involvement, and view the Ataxia Presentation found on the IAAD webpage and event on Facebook at <https://www.facebook.com/events/1375274836132615/>.

Tell us how you recognized International Ataxia Awareness Day (IAAD) and share a photo with us for a future issue of "Generations." Please email your story/photo to joan@ataxia.org or mail to the National Ataxia Foundation, Attn: *Generations* Editor, 2600 Fernbrook Lane, Suite 119, Minneapolis, MN 55447-4752. Your stories on how that day was recognized could live on in a future issue of *Generations*. Please send us your articles, photos, and proclamations so the entire NAF community can relive this historic day.

www.ataxia.org/events/international-ataxia-awareness-day.aspx

#ataxiaspinchallenge

IAAD Event and Fundraiser

Details: The #ataxiaspinchallenge was created to raise awareness of a non-curable, non-treatable disease ... ataxia. On the event website you can learn about "The Challenge," register and/or start a team to share your story, and challenge others. All proceeds benefit the National Ataxia Foundation (NAF). For more information visit the event website. <https://naf.myetap.org/fundraiser/15spinners/>

Central PA Support Group Ataxia Awareness Table IAAD Event and Fundraiser

Time: 5 – 9 p.m.

Location: Boscov's, Exton Square Mall, 260 Exton Square Pkwy., Exton, PA 19347

Details: We will also be selling Boscov's Friends Helping Friends shopping passes for \$5. Pass holders will receive 1–25% off shopping on October 20 at Boscov's. All proceeds benefit the National Ataxia Foundation. For more information contact Mike Cammer at (610) 996-5814 or michael.cammer62@hotmail.com.

Team KR Endurance

IAAD Event and Fundraiser

Details: Join us in this virtual run event. From this

*Calendar of Events**Continued from page 53*

site you can register for a virtual 5K, 10K or 13.1-mile run. Once you register a personal fundraising page will be generated for you. Personalize your page and let everyone know! Participants that raise \$30 or more receive a complementary t-shirt. All proceeds benefit the National Ataxia Foundation. For more information visit the website or contact KR Endurance at krendurance@gmail.com.

<https://naf.myetap.org/fundraiser/15nafrun/aboutEvent.do>

Warriors4Awareness**IAAD Event and Fundraiser**

Locations: Winder Barrow & Heartwell Speedways

Details: Warriors4Awareness is the name for the team of drivers that have committed to race in support of the National Ataxia Foundation by donating and challenging their fans to match the donations. Drivers are donating \$5 for 1st place, \$3 for 2nd thru 10th and \$1 for any other finish. All proceeds benefit the National Ataxia Foundation (NAF). For more information visit the website.

<https://naf.myetap.org/fundraiser/warriors4awareness/>

– **Saturday, September 26, 2015** –

OC/LA Walk n' Roll for Ataxia**IAAD Event and Fundraiser**

Locations: NEW LOCATION East Lake Village Community Association Club House and Parking Lot, 5325 Village Center Dr., Yorba Linda, CA 92886

Details: We will have a DJ, opportunity drawings for participants, vendors showing their product/services, children's activities and a chance to unite with others affected by ataxia. All proceeds benefit the National Ataxia Foundation (NAF). For more information visit the event website or contact Daniel Navar at (323) 788-7751 or danieln27@gmail.com, Cindy DeMint at (714) 329-4437 or cindyocataxia@gmail.com, or Lora Morn at (310) 664-8808 or Loramorn@gmail.com.

www.ataxia.org/walk/ocla

Western PA Walk n' Roll for Ataxia**IAAD Event and Fundraiser**

Time: 10:00 a.m. – Noon

Location: Check-in South Park (main children's playground), The walk will take place along Corrgan Dr., South Park, PA 15129

Details: All proceeds benefit the National Ataxia Foundation (NAF). For more information visit the event website or contact Donna Eiben at (412)

655-4091 or donnaeiben@ataxia.org.

www.ataxia.org/walk/wpa

Utah Walk n' Roll for Ataxia**IAAD Event and Fundraiser**

Location: To be determined

Details: All proceeds benefit the National Ataxia Foundation. For more information contact Jenny Durrant at (801) 721-7140 or jenny@utah.ataxia.org.

www.ataxia.org/walk/utah

– **Saturday, October 3, 2015** –

AZ Shop 'til you Drop Craft & Vendor Fair**IAAD Event and Fundraiser**

Time: 9 a.m. – Noon

Location: Disability Empowerment Center, 5025 E. Washington, Phoenix, AZ 85034

Details: Free event. Donations accepted. Health and Wellness vendors, a Chinese auction, 50/50 Raffle and kids games and prizes. All proceeds benefit the National Ataxia Foundation (NAF). For more information about attending or exhibiting contact Angela Li at (847) 505-4325 or angelali101@gmail.com or Mary Fuchs at (480) 212-6425 or mary11115@msn.com.

– **Saturday, October 10, 2015** –

Tea Time for Ataxia**IAAD Event and Fundraiser**

Time: 11:00 a.m. – 1:00 p.m. or 1:30 – 3:30 p.m.

Location: Aubrey Rose Tea Room, La Mesa, CA

Details: Cost is \$35 per person. All proceeds benefit the National Ataxia Foundation (NAF). For more information contact Jane Jaffe at (619) 286-9745 or sicilianmother@cox.net.

– **Saturday October 31, 2015** –

Michigan Walk n' Roll for Ataxia**IAAD Event and Fundraiser**

Time: Registration 8:30 – 9:00 a.m., Symposium 9:00 a.m., Luncheon 11:30 a.m., Walk 1:00 p.m.

Location: University of Michigan Biomedical Science Research Building (BSRB), 109 Zina Place, 5031 BSRB, Ann Arbor, MI 48109

Details: All proceeds benefit the National Ataxia Foundation (NAF). For more information contact Elizabeth Sullivan at (734) 232-6247 or elizsull@umich.edu or Tanya Tunstall at (313) 763-2827 or tinyt48221@yahoo.com.

www.ataxia.org/walk/michigan



Please help us keep your information and schedules up-to-date by e-mailing updates to lori@ataxia.org.

Memorials and In Your Honor

The National Ataxia Foundation is grateful to those who have made contributions in memory or in honor of their friends and families whose names are listed below. This list reflects contributions made in April through May 2015. We are sorry that we cannot separate the memorial contributions from those made in honor of someone, as sometimes the person making the contribution does not let us know if the contribution is a memorial or in honor of their friend or family member.

Chandler Abel	Ben Cantor	Kurt Gunning	Rick Moran	Cheryl Serge
Debi Adair	Sue Casey	Gary Hartsock	Robert Pacora	Michael Shears
Matthew Agostini	Abe Cavazos	Heather Hawkins	Norma Payne	Stephen Shears
David Alessi	Tiffinay Compiano	John Heimann	John Pellegrino	Kathryn Smithers
Crystal Allsopp	Janet Coyne	Krista Humes	Rita	Stafford Family
Neighborhood Charter School	Brad Dalton	Ann Hunt	Powell-Lobascio	Jack Swale
Atlanta, GA	Alex	Bonnie Huston	Allen Prather	Chris Tatti
Cheri Bearman	Detschermitsch	Marilyn Jackson	Jim Richards	John Tatti
Clair Beck	Dawn Dizon	Lisa Jaffe	Sherri Richwine	MoEng Teo
Betty Beck	Marcus Dowty	Erin Kiernan	Janet Riley	Ronald Thierfelder
Robert Bitner	Jim Drakos	Jamie Kosieraki	Ellen Rogers	Bruce Thomas
Fred Blasberg	Teresa Drakos	Michael Leader	Rocco Rotolo	Dolores Thomas
David Brown	Arlo Drury	Jennifer Leader	Christina	Patricia Tobias
Ruth Buckley	William Evens	Adrian Lund	Rozenberg	Margaret Tseng
Jen Buehler	Leslie Evens	David Mason	David Sakakura	Barry Washburn
Linda Burgher	Vincent Ferranti	Linda Meier	Don Schut	Donna Weaver
Mike Cammer	Gregson Gann	Mrs. Mendoza	Ed Schwartz	David Westrick
	Melvin Goodman	Dorothy Moetsch	Derek Semler	Rudy Yurong



Sometimes

By Dennis Cullington

I drop things all the time.

Response: Sometimes I drop things.

It takes me forever to get dressed.

Response: Sometimes I can't find a thing to wear.

Toothpaste goes all over the place.

Response: Sometimes I'm pretty sloppy.

People don't understand what I am saying.

Response: Sometimes I feel the same way.

I just want to be listened to and

Response: Sometimes I know what you mean.

I want people to acknowledge the depth and reality of my struggle.

Response: Sometimes I just have to suck it up and move on.

I have Ataxia

Response: Sometimes.....

“Oh,” What is Ataxia?

A Foreign Cab?

TM ©1990 Karen Danville



National Ataxia Foundation

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Please see page 23 or visit
our store at www.ataxia.org!

GIFT – HONOR – MEMORIAL

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

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

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

My contribution is:

- In Memory In Honor Gift Membership

Name _____

Occasion _____

Send Acknowledgment Card to:

Name _____

Address _____

City/State/Zip _____

From:

Name _____

Address _____

City/State/Zip _____

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

MEMBERSHIP

Yes, I want to help fight ataxia! Enclosed is my membership donation. (*Gifts in U.S. Dollars*)

- Lifetime membership – \$500

Annual Memberships:

- Patron membership – \$100-\$499

- Professional membership – \$55

- Individual – \$35 Household – \$55

- Addresses outside the U.S. please add \$15

Recurring Gift Membership Program:

If you wish to contribute monthly or quarterly, please consider the Recurring Gift Membership Program.

For more information contact the NAF office or visit www.ataxia.org/giving/default.aspx.

Name _____

Address _____

City/State/Zip _____

Phone _____

E-Mail _____

- Yes, sign me up for NAF e-mails

PAYMENT INFORMATION

Gifts are tax deductible under the fullest extent of the law.

- Check. Please make payable to the NAF.

Total Amount Enclosed \$ _____

Credit Card: Visa MasterCard Discover

Name on Card _____

Card # _____

Exp. Date _____ CVV # _____

Signature _____

Phone Number _____