

Generations

EXPANDED EDITION

The Official Publication of the National Ataxia Foundation

Volume 44, Number 2

Summer 2016



Get Ready for the Walk n' Roll Season!

Well, it's time to tighten down the laces and oil up the wheels as the 2016 Walk n' Roll season is HERE! That's right, the National Ataxia Foundation's nationwide effort in support of the NAF mission is here and the question needs to be asked, "Have you registered your team for this year's event?"

With events from New England to Orange County and from Atlanta to Minneapolis and Denver, there are regional sites across the country that you can be part of. Walk n' Rolls provide a fantastic opportunity for family, friends, students, co-workers, and colleagues to come together in support of those living with Ataxia. Select the site closest to you and register today.

If there is not a Walk n' Roll event near you, the virtual "International Walk n' Roll" is the way to go and was developed with you in mind. It is an easy and fun way to make a difference by raising funds online for the National Ataxia Foundation. Visit www.ataxia.org/walk/virtual for more information.



Denver's 2015 Run, Walk n' Roll was a huge success

Now, the sooner you get started, the better results you'll get. And when you create your fundraising page be sure to make it personal. Tell your story! Remind readers why you're participating. Provide some pictures or even perhaps a video that tells your story. All of this will certainly help you in your efforts. Sharing your fundraising page with as many people as you can,

Inside This Issue

- **International Ataxia Awareness Day** is highlighted on pages 3-8
- **'From the Desk of...'** on page 13 is a farewell from Michael Parent
- **'Stem Cells: Fact-Fiction-Future'** has important information and begins on page 14
- New National Development Director **Joel Sutherland** is featured on page 22

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**CFC
 #10752**

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Walk n' Roll Season...
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is the #1 one most effective and efficient way to raise money for your team.

However, while the Walk n' Roll events are an impactful way to raise funds, they're also much more than that. They serve as a great reason for all of us to come together for one day and have some fun. Many of our walks feature music, food and beverages and other entertainment to insure that all those who attend have a wonderful time.

So identify the Walk n' Roll nearest you and register your team today. Set an achievable goal

and start fundraising to support the mission of finding treatments and a cure for Ataxia. This is the one event each year where we all need to come together with one goal in mind; to raise as much money as we can, as fast as we can. These Walk n' Roll events allow us to have a great time doing it as well.

If you need help setting up your fundraising page, just reach out to the NAF for assistance by calling (763) 553-0020 or e-mailing Lori Shogren at lori@ataxia.org.

For the current listing of the upcoming Walk n' Roll events, please see pages 7-8 or visit our website, www.ataxia.org. ❖

International Ataxia Awareness Day (IAAD)

— Thursday, September 25, 2016 —

“What is Ataxia?” 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 that Ataxia organizations throughout the world declared and recognized September 25 as IAAD. Through IAAD, National Ataxia Foundation Chapters, Support Groups, Ambassadors, and members have created Ataxia awareness throughout the world, better informing tens of thousands of people about Ataxia.

Creating Ataxia Awareness

The goal of IAAD is for everyone to participate in some activity to help create awareness about Ataxia. Share your story with one other person who has never heard of Ataxia, educate others by speaking at a school or civic group, get in touch with your local media, and wear 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



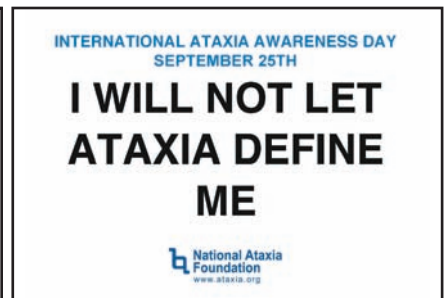


Walk n' Roll to Cure Ataxia, or participate in a global online Walk n' Roll.

International Ataxia Awareness Day has grown over the years, with more ideas and more people getting involved. It will be celebrated on Thursday, 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.

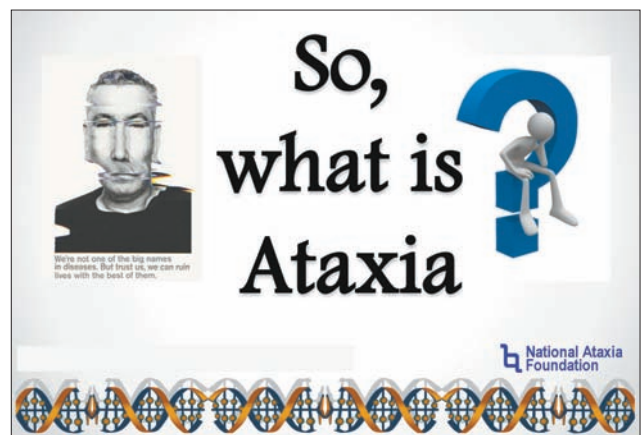
Awareness Tools

To help you get the word out about Ataxia, NAF offers a variety of tools to support your awareness efforts. Ataxia awareness messages are available on NAF website for you to share by taking a photo or video of yourself or your group with your message(s). Be sure to share your pictures and videos with us by e-mailing naf@ataxia.org. Hard copies of these messages can be requested by contacting the NAF at naf@ataxia.org or by calling (763) 553-0020.



What Is Ataxia? PSA

Public Service Announcements (PSAs) are available on NAF's website at <http://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.



NAF Ataxia Presentation

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

Proclamation - copyright 2015 Michael Peter Parson, All rights reserved.

International Ataxia Awareness Day
September 25, 2016

WHEREAS, the National Ataxia Foundation strives to meet the goal of:

- 1) Location of and make early and
- 2) Increased research available to the public;
- 3) Preservation of individuals and
- 4) Research that is designed to be based upon the best available scientific information.

WHEREAS, an entire nation:

WHEREAS, ataxia is a speech:

WHEREAS, ataxia is a:

WHEREAS, there is a:

NOW THEREFORE,

INTERNATIONAL ATAXIA and support those who:

IN WITNESS WHEREOF,

For Immediate Release

Michael Parson
Executive Director
michael@ataxia.org
(763) 553-0020

Theresa Morsell

SEVENTEENTH ANNUAL INTERNATIONAL ATAXIA AWARENESS DAY

Chosen are that you have never heard of ataxia. That is why the National Ataxia Foundation and other ataxia organizations throughout the world have declared September 25, 2016 as "International Ataxia Awareness Day" to help get the word out about ataxia.

Ataxia is a group of rare and often fatal degenerative neurological disorders. An estimated 150,000 people in the United States are affected by ataxia. Symptoms are progressive and often impact coordination, hearing, vision, and speech. Ataxia affects both children and all ages, but one often ataxia strikes children and young adults. At this time, there is no effective treatment or cure for ataxia.

"The National Ataxia Foundation was established in 1972 and is dedicated to serving ataxia families through research, education, and support services," says Michael Parson, the Executive Director of the National Ataxia Foundation. Parson continued, "Ataxia can affect anyone at any time and is caused by either a mutation or dominant gene. There are also sporadic forms of ataxia which have no known genetic link or family history."

In the dominant form of ataxia, each child born has a 50/50 chance of developing the disorder. In the case of recessive forms, each child born has a 25% chance of being affected, a 50% chance of being a carrier, and only 25% chance of not being affected at all. In the recessive form of ataxia, many times people do not know that they carry an ataxia gene until their child begins to display signs of the condition.

Please share your personal story on how ataxia has impacted you and your family as part of this press release!

To find out more about ataxia, visit the National Ataxia Foundation's website at www.ataxia.org. You may also write the Foundation at 2000 Facebook Lane, Suite 119, Minneapolis, MN 55447 4752, email at info@ataxia.org, or call (763) 553-0020.

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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 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.

International Ataxia Awareness Day
September 25th

I am the Strength behind ataxia

The ATAXIA's are rare progressive disorders which affect speech, balance and coordination. People of all ages, race, and gender are affected.

Know the Strength

International Ataxia Awareness Day September 25th

For further details, help and support please contact the National Ataxia Foundation at:
2000 Facebook Lane N Suite 119, Minneapolis, MN 55447
Phone: 763-553-0020 Fax: 763-553-0807
E-mail: info@ataxia.org
www.ataxia.org

National Ataxia Foundation



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



Ataxia Awareness Merchandise

Ataxia awareness items are available for purchase through NAF's Store. Awareness items available include t-shirts, wristbands, magnets, and bags. To purchase Ataxia awareness apparel or items, check out the NAF Merchandise listing on page 43 of this issue of *Generations*, or visit NAF's online store at <http://ataxia.donorshops.com/>.



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

★ **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>

★ **Tour de Shunk – Go On 3!** – September 18 Mike Cammer is entering the “Tour de Shunk” for the third year in a row to ride the entire 102 miles! All proceeds benefit the National Ataxia Foundation. <http://ataxia.donorpages.com/2016GoOn3TourdeShunk/>

★ **Arizona Ataxia Awareness Extravaganza** – September 24 from 10 a.m. to 2 p.m. at St. Xavier University, 92 W. Vaugh Ave., Gilbert, AZ 85233. Enjoy local artists, health and wellness vendors, silent auction, raffle, and children’s activities. This is a FREE event. Donations accepted. All proceeds benefit the National Ataxia Foundation. For more information about attending or exhibiting contact Angela Li, (847) 505-4325 or angelali1010@gmail.com or Mary Fuchs, (480) 212-6425 or mary11115@msn.com.

★ **Tea Time for Ataxia** – September 24 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 at 11 a.m. to 1 p.m. or 1:30 p.m. 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.

★ **Boscov’s Friends Helping Friends** – On October 18, Boscov’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.

★ **Other events** – 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.

Some of you may want to do something different, but you’re just not sure what to do. If that’s the case, ask yourself, where do I find my passion? If you love to camp, may we suggest a Camp-A-Thon? If you and your family are trying to scale back or eliminate the clutter maybe a neighborhood garage sale might be best. For families with bowlers, golfers or runners, pledge programs for games bowled, holes played or miles run can be fun ways to raise money for NAF and/or your Walk n’ Roll team.

Many of the IAAD Events and fundraisers are printed in the Calendar of Events listing 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 address on the inside front cover.

Thank You

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



Walk n' Roll to Cure Ataxia

The ultimate finish line ... a Cure for Ataxia

What is Walk n' Roll for Ataxia?

The Walk n' Roll to Cure 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 to Cure Ataxia has raised more than \$1,885,000 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.

— 2016 Walk n' Roll to Cure Ataxia Events & Contact Information —

International Walk n' Roll to Cure Ataxia – Virtual Event

www.ataxia.org/walk/virtual

Walk for Dave to Cure Ataxia

Liverpool, NY – August 6

Marc Alessi pianoman345@hotmail.com

www.ataxia.org/walk/walk4dave

Northeast Ohio Walk n' Roll to Cure Ataxia

Parma, OH – August 14

Susan Kresnye susan.kresnye@ataxia.org

www.ataxia.org/walk/cleveland

Michigan Walk n' Roll to Cure Ataxia and Symposium

Ann Arbor, MI – August 27

Elizabeth Sullivan elizsull@umich.edu

www.ataxia.org/walk/michigan

Tri-State Walk n' Roll to Cure Ataxia

Jersey City, NJ – August 27

Kathy Gingerelli kgingerelli@msn.com
www.ataxia.org/walk/tristate

Minnesota Walk, Stroll n' Roll to Cure Ataxia

St. Louis Park, MN – September 10

Terry Sweeney mnataxiawalk@yahoo.com

www.ataxia.org/walk/minnesota

New England Walk n' Roll to Cure Ataxia

Bristol, RI – September 10

Jeannette Viveiros jeannette@ataxia.org

www.ataxia.org/walk/newengland

Denver Run, Walk n' Roll to Cure Ataxia

Denver, CO – September 11

Charlotte DePew cldepew77@comcast.net

www.ataxia.org/walk/denver

OC/LA Walk n' Roll to Cure Ataxia

Orange County, CA – September 17

Continued on page 8

Walk n' Roll for Ataxia
Continued from page 7

Cindy DeMint cindyocataxia@gmail.com
www.ataxia.org/walk/ocla

**Atlanta Walk n' Roll
to Cure Ataxia**

Duluth, GA – September 24

Greg Rooks atlantaataxia@gmail.com
www.ataxia.org/walk/atlanta

**Concord Walk n' Roll and Swim
to Cure Ataxia**

Concord, CA – September TBD Brian
Petersen smileypetersen@yahoo.com
www.ataxia.org/walk/concord

**Western PA Walk, Run n' Roll
to Cure Ataxia**

South Park, PA – September 24

Ed Schwartz eds@ataxia.org
www.ataxia.org/walk/wpa

Utah Walk n' Roll to Cure Ataxia

Layton, UT – October 1

Jenny Durrant jenny@utahataxia.org
www.ataxia.org/walk/utah

For more information, visit
[www.ataxia.org/events/
walk_n_roll.aspx](http://www.ataxia.org/events/walk_n_roll.aspx)

Create or Join a Walk n' Roll Team

brought to you by:

Invite others to
Join or Support
your Team

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

— Thursday, September 25, 2016 —

“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 each year.

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.



Recent Fundraisers



The kids get ready to rumble at the Seventh Annual Chuck and Duck Dodgeball Tourney

Chuck and Duck Dodgeball Tourney

Submitted by Andrew Haluska (ahaluska@bhbl.org)

Charlton Heights Elementary School held their Seventh Annual Chuck and Duck Dodgeball Tournament on Thursday, April 14.

It was another amazing year! What a great night. We had record crowds for this year's event and had to change the venue to the high school so we had more space. This year we were also able to increase our media coverage. Our local NBC affiliate came and did a story on the event.

The Albany *Times Union* and the Schenectady *Gazette* also covered the event.

This year's event raised \$4,939 in honor of Jacob Van Buren, a past Charlton Heights student who has Friedreich Ataxia.

University of Pittsburgh Chapter of Triangle Fraternity Rent-a-Gent Fundraiser

Submitted Brendan Stack

This past spring, the University of Pittsburgh chapter of Triangle Fraternity raised over \$850 in the first annual Rent-a-Gent auction benefiting the National Ataxia Foundation.

Due to the recent diagnosis of a Triangle alumni living in the Pittsburgh region, the group decided to take a stand against this condition. The event featured brothers of the fraternity being auctioned off for various services and events, such as home-cooked meals, convertible rides and guitar lessons. Overall, there was an incredible turnout of over 150 students from all

Continued on page 10

New York Metro Abilities Expo

By Kathleen Gingerelli

The weekend of April 29 to May 1 featured the Abilities Expo held at the New Jersey Convention Center in Edison, NJ. For the three days, members of Tri-State Ataxia Support Group, along with John Mauro from the Massachusetts group, manned the NAF booth meeting people, educating many about Ataxia and exploring all the new products the Expo had to offer.

The Expo was packed with over 200 vendors and exhibitors showing the latest products to assist people with all types of disabilities in everything from diet and exercise to assistance animals, and there were workshops and events

every day highlighting sports, dance and much, much more. Many products were offered for sale, at a discount, to make it worth your while.

Ian Bouras (from the Tri-State group) brought his guitar on Saturday and showed off his unique musical talent at our booth. Ian was one of the many members from Tri-State group to volunteer their time during the weekend.

This was an eye-opening weekend, meeting all inspirational people and learning about all the products and services that are out there to help us in our everyday lives and even planning for the future.

Recent Fundraisers
Continued from page 9

across campus coming together to contribute to this great foundation. Having such great success, the fraternity has already begun planning next year's event in hopes of continuing to grow the support in Pittsburgh.



Neddroy "DJ Headbussa" Bent (Middle) and friends at the Strike Out Ataxia event

Strike Out Ataxia

Submitted by Neddroy "DJ Headbussa" Bent

The Fifth Annual Strike Out Ataxia Charity Bowling Event was held on May 1 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.

<https://www.youtube.com/watch?v=WC7kz1YxA&feature=youtu.be>

Concert to Aid the National Ataxia Foundation

Submitted by Ed Schwartz

The Western Pennsylvania Ataxia Support Group held a concert Sunday, May 22, at the Trinity United Methodist Church in McMurry, PA. The concert was the idea of the musicians in their church who approached Linda and Ed.

It featured The Hobbs Sisters, who have been singing in the church since the girls were five years old. Now that they are out of college they are trying to "break-into-Nashville" with country



The Hobbs Sisters perform at the Concert to Aid the National Ataxia Foundation

western ballads. They write some of their own music, are currently cutting their second album and will open for Lady Antebellum this summer at the Clearfield (PA) County Fair.

The Reverend Mark Stewart writes most of his own music and has been captivating congregations for 40 years with his music, limited by the number of keys on the piano.



Rev. Mark Stewart

And finally, Cross Vision performed. They are a contemporary religious rock group that also writes some of their own music and has recordings "on the charts."

Admission was free, but freewill offerings were accepted and we had a great turnout. The event raised \$2,500. All proceeds benefit the National Ataxia Foundation. ▶▶



Members of Cross Vision



Sandy Stein (front center with Coke bottle) with members of the “Widow to Widow” group, who raised \$150 in coins.

Change for Change Fundraiser

Sandy Stein has a goal of raising \$10,000 to support the National Ataxia Foundation through her “Change for Change” fundraising initiative in honor of her son, Dave, who has Ataxia. Sandy has already raised more than \$3,000 in the first few months of her fundraiser. Sandy has received an overwhelming amount of support from friends, family and groups she is connected with.

Party Lite

Submitted by Lisa Cole

I hosted a PartyLite Jar Candles fundraiser in March. PartyLite donates 40% of the sales to the organization chosen by the party hostess. The event raised over \$200 to help find a cure or assist others who have Ataxia.



Lisa Cole

Pet a Service Dog

Submitted by Mary Jane Domiano

Due to the heat this year, when we held the Pet a Service Dog fundraiser, there were not too many people out. The event still raised \$40 to benefit the National Ataxia Foundation. I still plan on holding the event again next year.

Thank you to everyone who raised funds to support the NAF! ❖

Brain Donation Program

If you have **Friedreich Ataxia** and are interested in helping Ataxia research by donation of your brain and tissue after death, please contact Dr. Koeppen for information and details.

Arnulf Koeppen, MD

Professor-Emeritus of Neurology
Professor of Pathology,
Albany Medical College
Research and Neurology Services
Stratton VA Medical Center
113 Holland Ave., Albany, NY 12208
(518) 626-6377 Fax: (518) 626-6369
E-Mail: Arnulf.Koeppen@va.gov

If you have **any other form of Ataxia** and are interested in helping Ataxia research by donation of your brain and tissue after death, please contact the NAF at (763) 553-0020 or susan@ataxia.org.

Study of Cardiomyopathy in Friedreich's Ataxia Patients

A new IRB-approved study at Weill Cornell Medical College on Friedreich's Ataxia is recruiting patients between 18 to 30 years old who have genetic confirmation of diagnosis and are capable of completing all study tests and procedures. 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, please contact Michelle at (646) 962-2672 or miy2006@med.cornell.edu.

Canada and the United States Partner for the Brain Health Fair

Submitted by Sherry McLaughlin

The 2016 annual meeting of the American Academy of Neurology was held in the beautiful city of Vancouver, British Columbia, Canada in the oceanfront Convention Centre. Preceding the meeting of the neurologists was a one-day Brain Health Fair public event, sponsored by the American Brain Foundation, which drew an equally international crowd.



(Left to right) Brenda Dixon and Sherry McLaughlin at the Brain Health Fair

NAF was represented by Sherry McLaughlin (Western Washington Support Group leader) and Brenda Dixon, (President of Ataxia Canada, Western Branch and member of the BC Ataxia

Society). Canadian Erin Heesaker was the third member of our group and a super support person.

Here comes the best part of this story. Person after person told us they drove many miles and paid big city parking rates because they saw the National Ataxia Foundation on the exhibitor list. They made the trip specifically to see us and we were there to greet them and welcome them into our supportive family. This is what happens when volunteers from the NAF answer the call to represent our community at public events.

Of course, hundreds of people not affected by Ataxia also stopped by to ask a few questions about our group. We did our best to attract the crowds with our giveaways and our hourly dinosaur raffle. By the end of our day, Brenda had signed up six new Canadian members and I had an American. Wow! Getting six new members in one day is a support group leader's dream.

As you would expect, Brenda, Erin and I ended our day with a good Canadian burger and a glass of American wine. ❖

North Atlanta Mobility Show

The 2016 Mobility Show was held in North Atlanta on Friday and Saturday, 9 a.m. – 6 p.m., April 15-16 at the North Atlanta Trade Center in Norcross, GA.

The National Ataxia Foundation's booth was manned by members of the Greater Atlanta Support Group over the two-day period.



(Left to right) Teri Kemper, Louise Estabrook and Greg Rooks at the North Atlanta Mobility Show

From the Desk of the **Executive Director**

This summer has been a time for reflection and anticipation. With the 2016 NAF Annual Ataxia Conference (AAC) concluding in April 2016, NAF has been busy planning for the 2017 60th AAC to be held in San Antonio, Texas on March 10-11. Just prior to the 2016 AAC, the Sixth Ataxia Investigator Meeting (AIM) was held March 29 – April 1, with nearly 170 participants from 12 countries on four continents. The AIM, a premier scientific conference on Ataxia, saw the largest number of scientists this year as well as the largest number of sponsors. Many of these sponsors were pharmas who are showing an interest in Ataxia.

We are beginning to receive Letters of Intent from researchers around the world for the five NAF research programs. Last year, the NAF received more than 100 quality research applications and we anticipate that number will reach more than 100 again this year. Funding for the most promising Ataxia research studies will occur in late December this year, so please support the Fall Annual Ataxia Research Drive which will begin on October 15. More research donations through this important drive means more research studies funded in bringing us closer to ending Ataxia.

In April 2016 the National Ataxia Foundation's Board of Directors approved a three-to-five-year strategic plan to guide us as we move forward in our efforts to better serve the Ataxia community and to help accelerate

world-wide Ataxia research. Thank you to our members who helped us with this strategic plan by participating in various member surveys. Your input was invaluable in this vital process. Thank you!

In closing, it is bittersweet to announce that I will be retiring this summer. I am leaving with a wealth of wonderful memories and friendships I will always treasure. I first became involved with the NAF in 1982 and in

2004 became the Executive Director, a position that has been extremely rewarding and challenging, both professionally and personally. I thank you for your support and trust over the years, it has truly been a privilege and an honor to be part of this exceptional organization.

Over those years, I have had the opportunity to meet thousands of people across the United States and from

around the world. It has been truly humbling to see the courage of so many who bear the unbearable. I give thanks to all of our stunning volunteers, amazing members, incredible donors, remarkable staff, dedicated board, and committed researchers. I will truly miss you all and in leaving I am confident that NAF will continue to move forward in providing a bright future for those with Ataxia.

I wish you all a heartfelt farewell as my wife Renae and I turn the page in a new chapter in our lives, filled with anticipation and new adventures. Thank you!



Michael Parent

Stem Cells: Fact-Fiction-Future

The following article was a presentation given at the 2016 Annual Ataxia Conference in Orlando, FL by Henry Paulson, MD, PhD and Lauren Moore, MS, researchers at University of Michigan, Ann Arbor, MI.

Here is the link to the stem cells presentation video: https://www.youtube.com/watch?v=NFQhN_GE2NI

Dr. Henry Paulson presentation...

Many of you wonder about stem cells. What are they? Can they be a therapy for my form of Ataxia? How are they currently being used and how can they be used in the future? In this talk we address these and other questions.

What is a stem cell? It is an undifferentiated cell that can give rise, indefinitely, to more cells of the same type, and from which certain other kinds of cells arise by differentiation, the process in which an unspecialized cell turns into a highly specialized cell (such as neuron). Stem cells can differentiate into many different types of cells. The ultimate stem cell is a fertilized egg. It is something that is totipotent and can make all kinds of tissues.

There are several terms we use when we talk about stem cells.

- **Totipotent stem cells:** can produce all types of cells and even generate a full organism. They have the capacity to generate all types of cells.

- **Pluripotent or multipotent stem cells:** can produce many, but not all, types of cells.

There are three sources of stem cells we will talk about today.

- **Adult mesenchymal stem cells** are found in many tissues of the body (e.g. bone marrow, umbilical cord, adipose tissue, placenta, muscle, fat.) We don't know exactly what various roles they play, but they likely play a role in normal tissue repair.

Many stem cell trials involve mesenchymal stem cells that are either derived from the same person, termed autologous, or derived from some other person. Have there been successes

with stem cell therapy for any disease? In a sense, the answer is clearly yes. Bone marrow transplant is essentially a stem cell therapy. People who have cancer will undergo procedures like radiation, chemotherapy or a combination of both, which essentially kills off the immune system. Placed back into such persons are their own stem cells or those from a bone marrow donor. These stem cells can reconstitute the immune system in those persons.

While bone marrow transplant is a clear stem cell success, it's not the brain nor does it apply to neurological disorders like the Ataxias. But it does show you the power of a cell that can differentiate into different tissues and replenish something in a human being.

- **Induced pluripotent stem cells (iPSC)** are most often derived from skin cells, but also can be generated from blood cells. Many scientists use iPSCs to study disease pathways and find drugs or compounds that can help in disease processes. Scientists can take a skin cell or a blood cell and supply certain molecules that allow these cells to de-differentiate and take-on stem cell-like properties. Then, when provided appropriate factors, they can be induced to differentiate into various types of cells, for instance neurons. The great benefit is that scientists can take skin or blood cells from anyone and generate an iPSC line – young people or old people. It's easy to do and is widely used by scientists around the world.

There are some limitations to iPSCs, however. It can be difficult for them to differentiate into certain types of tissues, and there is variability from cell line to line. Scientists prefer not to study a single iPSC line. Instead they prefer to draw conclusions from studying several ►►

iPSC lines and appropriate control lines, particularly if they are investigating how a particular mutation might cause disease. Let's say you're studying SCA1, a dominantly inherited, and you have the SCA1 mutation in a particular iPSC line. You're going to want to compare results to a control line derived from the same cell in which the mutation has been reverted to the normal configuration.

- **Embryonic stem cells** are stem cells that come from an early embryo and are truly totipotent cells.

In fertilization a sperm and egg come together to generate the fertilized egg which then divides to generate a mass of cells called the early blastocyst. The blastocyst has a rim of cells surrounding a cluster of cells. These internal cells can be taken out and grown in a "dish" where they can form clones, or colonies, of totipotent stem cells. Then, under various conditions, they can be differentiated into numerous cell types like skin cells, muscle cells and even brain cells.

There are limitations to the embryonic stem cells, including ethical considerations. Not everyone agrees to the idea of taking a fertilized embryo that might otherwise be discarded, to generate stem cell lines. There are, in this country, NIH-certified stem cell lines that can be studied by American researchers using NIH grants. When George W. Bush was president, you may recall that he made the decision that certain existing stem cells lines could be used for research but no others could be generated for NIH certification. Since then, President Obama released the rules so that additional lines could be generated. Now there are more stem cell lines, many of them disease-specific, and that means that they were derived from an embryo that carries a particular disease mutation. These new lines include a number of Ataxia stem cell lines

that are certified and available for American researchers with NIH grants. There are some countries where scientists cannot do this, including in Europe. So there are limitations to using embryonic stem cells though the benefits include the fact that they are totipotent and can be rapidly generated into different types of tissues.

What do stem cells have to do with Ataxia?

1. They are being investigated as a potential therapy for some Ataxias and related neurological disorders.

2. The study of stem cells can provide new insights into the disease process. Let's call this "disease in a dish" that could lead to new understanding and approaches to therapy.

3. They are a good model cell system to test novel therapeutic strategies or screen potential compounds before moving into human clinical trials.

Can stem cells be used as a therapy for Ataxia?

Putting stem cells into the brain to restore lost neurons with all their connections is, at this point, an unrealized dream. But 20 years ago, who would

have imagined we would be able to generate induced pluripotent stem cells? It didn't seem conceivable we could take a skin cell and make a neuron out of it. But now we can do that. And who would have thought, even five years ago, that we could edit a gene very easily with simple molecular tricks. We can do that now.

Dreams sometimes do get realized, and there are certainly possibilities. We need to push forward to see how far we can go with stem cells in terms of understanding disease and developing therapies for disease. However, it's important to note that to date there are no well-controlled



Dr. Henry Paulson

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trials that have shown benefit from injections of stem cells in any form of Ataxia in humans. There are some successes in mouse models, but as we all know; mice are not humans. There are limitations in extrapolating from a mouse model to humans.

**Cell transplantation studies
in Parkinson Disease (PD)**

Cell transplantation studies in Parkinson Disease – not necessarily stem cells but rather cell transplantation therapies – have been going on for over 30 years. These studies offer us hope for the idea that cell replacement strategies might replenish vital cell functions or factors from brain cells in some neurological disorders. At the same time, they also provide a cautionary tale. Early claims for success in cell transplantation therapies in PD were not matched when placebo-controlled trials occurred in later years. These later well controlled trials did not show quite the robust improvements seen in earlier uncontrolled trials. It became clear from these studies that you need to transplant a large number of neurons of the right type in order to have any kind of success. I think it is very important to recognize that there are individuals who received cell transplantation of dopamine-producing neurons and now, many years later, seem to still show benefit from the transplantation. So, yes, there have been successes but we are still very much in the learning phase.

Parkinson disease is not as complex as Ataxia and arguably a more compelling target for stem cell therapy. In Parkinson disease, one major population of neurons dies out – neurons that produce the chemical dopamine. So if we could just put back in cells that produce dopamine and get the dopamine to the right spot in the brain, stem cell therapy for PD sounds plausible.

Cell replacement in Ataxia: not as easy as PD

It might be a little harder in Ataxia. Why?

The network of neurons in the cerebellum is complicated! The cerebellar Purkinje cell is just one type of neuron within the complex network of neurons in the cerebellum. It is a spectacularly beautiful neuron with massive dendrites like huge branches of a towering oak tree. Why does it have such a big network of branches? It has such a big network because it integrates signals from a vast array of other neurons connected with it. It's a tall order to ask a stem cell inserted into the cerebellum to become a Purkinje cell with all the right connections.

If that isn't complicated enough, if you look at the architecture of the cerebellum itself you'll see many other cells beyond Purkinje cells: granule cells, basket cells, other types of cells, all connecting up with Purkinje cells and each other. It's a spectacularly tall order to ask a group of stem cells, stuck into the brain, to reconstitute such an incredibly complicated network of neurons comprising the cerebellum – a biological “computer” that allows for the control of movement.

**Neurological studies
with mesenchymal stem cells**

For this lecture we reviewed the scientific literature over the past 10 years. There are over 35 stem cell clinical trial reports in the past seven years on traumatic brain injury, spinal cord injury, ALS, stroke, multiple sclerosis and spinocerebellar Ataxia, including multiple system atrophy (MSA), a form of Ataxia. And there have been 35 clinical trial reports in humans. These studies have involved intravenous delivery of stem cells into the blood stream, direct delivery into the fluid bathing the spine, or, in rare cases, direct injection into the brain. Most have used autologous cells, that is cells derived from the very person who then has them injected back into the body.

Nearly all have been open label trials without placebo control. That's an important qualifier. Open label trials have the risk of bias. If you don't have a placebo control you can't account for the well-known placebo effect. A fascinating fact ►►

is that a placebo drug (not the active drug) will, by itself, have a positive effect in many people. An important take home from these diverse uncontrolled studies – at least our interpretation – is that the stem cells injected have been pretty well tolerated, and some of these open label studies have shown positive results.

We are going to just give you one example from the literature. In this study, the scientists took mesenchymal stromal cells, not from the actual person (autologous), but from someone else, and injected them into the fluid around the spine, four times, into people who had a dominantly inherited form of Ataxia (SCA) or MSA-cerebellar type. Then they measured Ataxia rating scales and followed-up the research participants for six to 15 months. Ten of these individuals receiving these injections remained stable for greater than six months, meaning they did not show progression in symptoms. Fourteen of the cases regressed to the pre-treatment status, on average, within three months. There are some important qualifiers to this study: open label trial, no placebo control, lack of carefully defined outcome measures, and a pretty heterogeneous or mixed group of research participants. So the study, in our view, was not statistically powered to show a significant effect.

Dongmei H, et al. Clinical analysis of the treatment of Spinocerebellar Ataxia and Multiple System Atrophy-cerebellar type with umbilical cord mesenchymal stromal cells. Cytotherapy (2011)

We Ataxia scientists and neurologists want stem cell therapy to work, but we also want it to be done with great rigor, with definitive proof that there is something worth pursuing. I (Paulson) was one of many Ataxia-ologists who provided consultation to the National Ataxia Foundation in assembling a statement on Stem Cell Research and Therapy.

The statement is available on the NAF website at www.ataxia.org or by following this link: <https://www.ataxia.org/links/ataxia-general-stem-cells.aspx>.

Selected excerpts from NAF's Statement on Stem Cell Research and Therapy:

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

"... there is promise for stem cell therapies in some neurologic disease, but for now patients need to know that currently there are no stem cells that can fix the brain, improve Ataxia or prevent the worsening of Ataxia."

"... Stem cells have great potential...but there are no shortcuts. We must use scientific principles that have been proven in the laboratory before we begin putting stem cells into people who are affected by Ataxia. We must safeguard patients from unproven treatments that may cause serious harm."

Our job, as doctors, is to do no harm. We want to advance the field and we definitely want better therapies for our patients. But we want to protect our patients when we have concerns about the operation of some of the stem cell treatment clinics around the world.

So, should the field of Ataxia pursue stem cells as a potential therapy? Absolutely. But it must be done in carefully controlled clinical trials with a sound scientific basis, based on compelling preclinical data.

We heard at this year's Ataxia Investigators Meeting, of a company doing work in Taiwan on a particular SCA, that has started a trial to see if mesenchymal stem cells benefit these individuals. We are very pleased that they are using a placebo controlled approach to the study.

What about the future?

In a sense, the future is now. We are using stem cells in Ataxia research. Lauren Moore, a gradu-

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ate student in the Paulson laboratory, is actually using stem cells to try to understand disease processes and to screen compounds for a possible cure. And here she is to talk about her work.

Lauren Moore presentation ...

I believe that I am unique among many Ataxia researchers in that I know what it is like to have one of these debilitating diseases in my family. My dad has tested positive for SCA3, which means I also have a 50% chance of carrying the mutation. So like all of you, I have a highly vested interest in finding a cure for this disease.

I would like to start off by giving some updates from the Ataxia Investigator’s Meeting that occurred earlier this week. There were about 160 Ataxia researchers in attendance and new research was presented on many of these diseases. Much of the research included stem cells. One of the very compelling talks was entitled “Transplantation of Neural Stems Cells as a Therapeutic Strategy in Machado-Joseph Disease.” Machado-Joseph Disease is another name for SCA3. In this study, they created neural stem cells that were implanted directly into the cerebellum of mice carrying the SCA3 mutation. They did see some rescue in the motor problems exhibited by these SCA3 mice but one of the interesting findings that the study presented was that it was unlikely that these cells were replacing cells that die in Ataxia. It appeared more likely that transplanted cells were helping cells that were sick and dying to get a little bit healthier, further supporting what Dr. Paulson discussed earlier. This was compelling research but it is still very early and I am very interested to see where this leads in the future.



Lauren Moore

Other talks that included stem cells focused on the ability to use stem cells as a model of Ataxia so that we can learn more about this disease. That’s what I am going to talk about here. There have been rapid advances in stem cell technology that have revolutionized the way we study Ataxia.

Traditional models of Ataxia

To really understand how stem cells have advanced research in the Ataxias, let’s look back to how Ataxias have been studied in the past and largely still are today. One of the most common ways scientists study Ataxias are through the use of transgenic mouse models. These are mice that have disease-causing mutant genes inserted into their DNA, leading to mice with Ataxia-like symptoms. These mice continue to give us new insights into the processes of disease but they do have some limitations.

Mice are not humans. They only live for one to two years, and as we all know, some of the Ataxias take several decades to develop. Mice also have a much smaller brain so we really can’t capture all the complexity of the human brain in the mice models. In addition, many of these mice are inbred species, which means they have very little genetic variation. That is like trying to understand all the Ataxias by only studying a single family.

One of the results of these limitations is that potential therapies that appear promising in mice, have largely shown little to no success in human clinical trials. This failure of translating successes in mice to human disease exemplifies why we as scientists need to find better models that will enable us to not only cure ataxic mice, but also Ataxia in humans.

Another way that researchers study Ataxia is through the use of non-pluripotent cells, most commonly a type of cell called fibroblasts. ►►

These are human cells that are generally derived from skin biopsies, and can be taken directly from patients. When taken from Ataxia patients, these cells do express the disease-causing mutation, but they are more like skin cells than brain cells and we know that Ataxia mostly affects the brain cells. So it's kind of like trying to figure out what's wrong with the car's engine by checking the tires.

Stem cells enable scientists to study Ataxia in the types of human cells affected by disease. We can take human iPSCs or human embryonic stem cells that carry a disease-causing mutation and differentiate them into the type of cells that are most affected in Ataxia, primarily neurons.

To provide some examples of how stem cells have provided new insights into disease pathology, I'm going to present some of my recent findings that I have had while working with Dr. Hank Paulson at the University of Michigan.

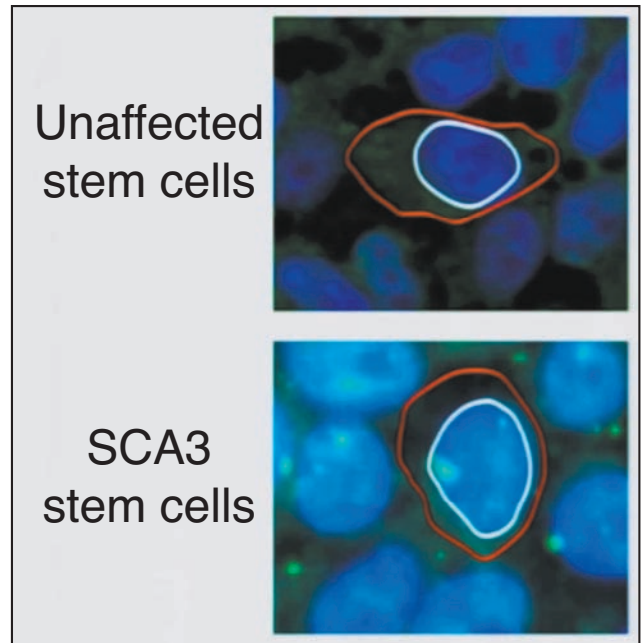
My research focus

My research focus in the lab is to find causes of cell death and dysfunction in SCA3. To do this I have been using what arguably may be the best available cellular model systems to study this genetic disease – the first SCA3 human embryonic stem cell line. This is the first and only such line in the world, and it was NIH approved in September 2014. So it has been my prerogative to see what we can learn about Ataxias from studying this stem cell line.

Can stem cells really replicate human disease?

In the accompanying picture, you can see two photographs I have taken with a microscope. The image on top is of an unaffected embryonic stem cells and below, SCA3-affected stem cells. In both images I have outlined a single cell in red and that cell's nucleus in white. The nucleus is like the control center of the cell.

As you can see there are some apparent differences in these two cells. We have used a green florescent marker to mark all of the ataxin-3,



which is the disease-causing protein in SCA3, and we have marked the nucleus, or control center in blue. As you can see in the affected line, nearly all of the ataxin-3 located to the nucleus; whereas in the unaffected cell it is dispersed throughout the cell. We believe this difference in subcellular localization of the disease protein is an important step in the process of SCA3; when we look at SCA3 transgenic mouse models or post mortem brain tissue from human SCA3 patients, it is one of the pathological hallmarks of the disease.

In addition, we also see the formation of really dense clusters of ataxin-3. These are kind of like protein “trash dumps” within the cell, or protein aggregates. Both of these characteristics, the nuclear localization and the formation of the protein aggregates are known to be important in SCA3 and we think we can learn a lot about this disease by studying the line further.

Deriving SCA3 neurons

The real power of stems cells is that we can study the types of cells that are affected in human disease. Using various differentiation factors we

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can take these undifferentiated stem cells, the totipotent stem cells, and convert them into human neurons that form the very complex structures similar to the human brain. This is why neural stem cells are sometimes referred to as “disease in a dish” or “brain in a dish.”

Why do we care?

Looking at these neurons we can start to ask questions like:

- What are the important steps in disease?
- What is causing these cells to die?
- What are some of the early steps that lead to cellular dysfunction?

By comparing neurons derived from the SCA3-affected stem cells to those derived from unaffected stem cells, we can start to identify some of the toxic changes that might be driving neuron death in SCA3.

Moving closer to a cure

In addition to advancing our understanding of SCA3 and Ataxia toxicity, we can also use SCA3 neurons to test novel therapies for Ataxia. As one example, we have been investigating and testing in the lab antisense oligonucleotides (ASOs) – a new therapeutic strategy that can stop genetic diseases at their source by preventing production of the disease-causing toxic protein (“gene silencing”). Promising findings in other disorders offer hope for possible ASO therapy in neurological disorders like the Ataxias. We have obtained ASOs developed by Ionis Pharmaceuticals and are testing them in our transgenic mouse model of SCA3. After we treat these mice with the ASOs we look inside their brains to see if the levels of the toxic protein are reduced. Preliminary results are encouraging.

Our ultimate objective is to try to bring this possible therapeutic strategy to human clinical trials. But as we mentioned, most new drugs that show success in mouse models fail in human

clinical trials. So the major obstacle in moving a new drug to clinical trials is to convince funding agencies that the drug has a decent chance of succeeding in human trials. We hope that by treating our SCA3 affected human neurons and showing that we can rescue disease-specific abnormalities, we will be able to speed up the “bench-to-bedside” process. If we can demonstrate success in both human neurons derived from stem cells and SCA3 transgenic mice, we can provide even more support and confidence that ASOs will be successful in patients.

Using induced pluripotent stem cells to test novel therapies

Finally, I wanted to outline a couple other ways stem cells are being used to test novel therapies. I’ve talked about how we can test candidate drugs, like ASOs, on stem cells. But stem cells can also be used in high-through-put screens to try to identify novel drugs out of large libraries of existing drugs. There are libraries of compounds and molecules that scientists have developed, many including FDA-approved drugs and drugs that we think could have benefit for many different biological disorders. High through-put screens involving stem cells are enabling scientists to test tens of thousands, even up to more than 200,000 molecules, within a very short period of time. This way we could see if any of these drugs, including some already used by people for various other conditions, could be used to treat Ataxia. Also, through the use of disease-specific iPSCs (remember, these are cells taken from a patient and reprogrammed into stem cells), in the future we may be able to develop patient-specific therapies.

From my perspective as a graduate student, this is an exciting period in the field of Ataxia and I feel that we are getting closer to finding cures for these diseases.

Insights from an Ataxia researcher

I’d like to finish by giving some insights that I have had both as an Ataxia researcher and proud daughter of an Ataxia patient. One of the first ►►

things I realized when I joined the Ataxia field is that there is no disease that is too rare. Before entering Ataxia research, I wondered pessimistically, how many people could really be researching my family's disease, a disease that only affects one in 50,000 people? The answer was hundreds. For some rare disorders, it seems as if there may be more researchers studying the disorder than people actually affected by them. So, no matter how rare the disorder, there IS someone out there working on it and the NIH is continuing to pay for the research with grant support.

The Ataxia community is huge. This week there were over 160 researchers and each of them are just representatives from some of the many Ataxia labs. There were many different countries that were represented, including Portugal, Australia, Germany, UK, and the list goes on; there are people all over the world working on this disease.

You do have advocates in the scientific community. We as scientists truly are focused on finding a cure. It may seem sometimes that scientists are only interested in the science behind the disease, but the end result of all these studies

is the same: we all want a cure.

New discoveries are happening every day. Like Dr. Paulson said, the industry has been revolutionized in the past 20 years. Even in the last two years, since I joined the research community, I've seen rapid advancements in many of the tools and techniques being used. With the speed that science is advancing right now, I truly believe that cures not only are possible, but inevitable.

And finally, to stick with the theme of this conference here in Orlando, there is a thin line between science and magic. I am bewildered every day when I get to walk into the lab and see these cells up-close and personal. With that, I want to thank you all for listening. Thank you.

Disclosures

Henry Paulson has a research grant from Ionis Pharmaceuticals and research grants from the NIH, ALS Association and, in past years, from the National Ataxia Foundation.

Lauren Moore has no specific grant relationships or business relationships, but she does have a grant from the Michigan Brain Initiative. ❖

Macy's 'Shop for a Cause'

Purchase a Macy's "Shop for a Cause" shopping pass today for \$5 and help the National Ataxia Foundation. Your special Macy's "Shop for a Cause" shopping pass gives you access to a special three-day sales event at Macy's stores nationwide Friday, August 26 through Sunday, August 28.

Pass holders receive a 25% discount on regular, sale, and clearance items, including home. You will even save on most brands that are usually excluded! Pass holders will also save 10% on electronics, watches, furniture, and rugs/floor coverings. Exclusions apply. Pass holders are also eligible to register to win a \$500 Macy's gift card. NAF will sell the shopping passes until August 19th.

To purchase your shopping pass today, you can order online through the NAF's online store or by mailing a check made payable to the National Ataxia Foundation to 2600 Fernbrook Lane, Suite 119 Minneapolis, MN 55447. Write "Macy's Shopping Pass" in the memo line. You may also call the NAF office to place an order or to contact for more information at (763) 553-0020.



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Joel Sutherland Named the National Development Director of the NAF

The National Ataxia Foundation has announced the hiring of Joel Sutherland as the foundation's National Development Director effective March 21. Joel comes to the NAF after spending the last four years as the Executive Director for the Minnesota/Dakota Chapter of the Cystic Fibrosis (CF) Foundation in Minneapolis.

In his four years with the Cystic Fibrosis Foundation, Joel saw first-hand the impact financial resources can have on a community dealing with an orphan disease. "As I witnessed the success of the Cystic Fibrosis Foundation, it became quite clear that money buys research and research finds answers," Joel said. That mantra is one that he hopes to instill in our community here at the NAF to empower all of us to do more. "With financial resources in place we can have a chance to improve quality of living and develop treatments for our families. Without it, we're no place," he added.

In 2015 the NAF generated almost \$1.6 million in revenue on a national basis. Joel and his staff generated almost \$3 million for CF's Minnesota/Dakota Chapter in 2015. "We, as the Ataxia community, have a lot of work to do. It's in our hands to go make things happen and give our research community the resources they need. I am extremely excited to lead the way for the National Ataxia Foundation," Joel said.

Before joining the non-profit world in 2012, Joel spent 27 years in sports marketing. Serving in sales and marketing roles with the Los Angeles Dodgers in Vero Beach, Florida, the

Minnesota Twins and the Minnesota North Stars, Joel also has a corporate sports marketing background with ConAgra Snack Foods Division. He founded several baseball teams in the Northwoods League, a summer collegiate baseball league operating much like minor league baseball.

Joel finds similarities in working with the NAF and his sports marketing background. "In sports we need season ticket holders, here we need donors. Both industries need corporate support

to make things happen and both industries have small, dedicated staffs that are able to do many things well. In sports we generate revenue during games, here we hold events. The big difference is in sports you win or lose every game. Here at the NAF, we're going to win, it's just a matter of time and money," Joel concluded.

For those who attended this year's Annual Ataxia Conference in Orlando, you were able to hear Joel speak at the Saturday evening banquet. There he thanked the NAF Board of Directors for entrusting him with this responsibility and the many families for their warm welcome to the NAF. His message that night remains the same today. "Money buys research, research finds answers." You can be assured that message will not change until the treatments and cure our families need are finally found.

You can watch Joel Sutherland, the NAF's National Director of Development, speak at the 2016 Annual Ataxia Conference here: <http://tinyurl.com/JoelSutherland>. ❖



Joel Sutherland

What is Clinical Trial Readiness?

“Clinical Trial Readiness” is a phrase used by researchers and pharmaceutical companies to describe a disease-specific community’s preparedness for clinical trials of medications or treatments to be tested in human participants. To be “clinical trial ready,” it is essential to have an understanding of the disease mechanism. In other words, what is causing the disease.

The National Ataxia Foundation (NAF) has funded basic scientific research for years and by leveraging those research dollars with NIH funding, Ataxia researchers have discovered genes, created mouse models and we now have a better understanding of what causes Ataxia. While there is a need to continue to fund basic scientific research, there is now enough known about Ataxia to move forward with developing symptomatic therapies and disease modifying therapies. That is when being clinically trial ready is essential.

Components of trial readiness include:

- **Validated rating scales.** Ataxia researchers developed the Scale for the Assessment and Rating of Ataxia (SARA), which provides an assessment of cerebellar Ataxia on an impairment level.

- **Natural History Studies** (Longitudinal Studies). These studies provide understanding of the presentation and course of the disease by examining patients regularly and using SARA to measure progression of the Ataxia.

- **Patient Registry.** A well-populated patient registry provides an efficient way for researchers or pharmaceutical companies to recruit research participants.

- **Biomarkers.** A biomarker is a measurable substance or other change (e.g. MRI measures) in the human body whose presence indicates disease activity and might change with treatment.

NAF has been committed to clinical trial readiness since the early 1990’s by supporting the efforts of the Cooperative Ataxia Group (CAG). This was a consortium of investigators who

conducted Ataxia research at their institutions. The mission of the CAG was to perform clinical research leading to improved treatments for the Ataxias. While the CAG is no longer a formal entity, many of the original investigators and many new investigators continue to be actively involved in clinical Ataxia research. In 2009, the Clinical Research Consortium for the Spinocerebellar Ataxias (CRC-SCA) was funded by the National Institutes of Health for two years, and in 2013 it was re-funded by the National Ataxia Foundation to continue moving clinical Ataxia research to that all important goal of Clinical Trial Readiness.

Each individual in the Ataxia community has an important role to play in clinical trial readiness. At the very minimum all those who are affected with any form of Ataxia and those who are at risk to develop Ataxia should enroll in the CoRDS/Ataxia Patient Registry. The weblink to the registry enrollment site is on the left side of the NAF’s homepage, www.ataxia.org. For those who have completed the registry, it is important to log back on periodically to update your record. Some examples of updates include a change of e-mail address or phone number, a change in mobility rating, a diagnosis that was given after enrollment in the registry or an additional family member who may have been recently diagnosed who was not at the time of your enrollment.

The Ataxia community, which includes patients, family members, researchers, clinicians and NAF, is anxious to have treatments and a cure for Ataxia.. Clinical trial readiness is an important part of making that happen. ❖

Deadline

The deadline for submitting materials for the Fall issue of *Generations* is August 5.

CoRDS-The National Ataxia Patient Registry

Submitted by Austin Letcher, Sr. Research Associate, Sanford Research

The National Ataxia Foundation (NAF) and Coordination of Rare Diseases at Sanford (CoRDS) have now been official partners for over three years. One of the numerous benefits of partnering with CoRDS is that CoRDS will send representatives to attend annual conferences for their contracted patient advocacy groups. In case you missed it, there were three members of CoRDS present at this year’s annual conference in Orlando.

Table 1: Top 10 represented Ataxia diagnoses and the number of participants which represent each diagnosis.

| Diagnosis | Number of Participants with Diagnosis |
|--|--|
| Ataxia – Other..... | 448 |
| Friedreich Ataxia | 123 |
| Spinocerebellar Ataxia type 3 | 110 |
| Spinocerebellar Ataxia type 6 | 77 |
| Spinocerebellar Ataxia type 2..... | 54 |
| Spinocerebellar Ataxia type 1..... | 50 |
| Spinocerebellar Ataxia type 8..... | 42 |
| Spinocerebellar Ataxia – Unknown | 29 |
| Spinocerebellar Ataxia type 7..... | 22 |
| Acquired Ataxia | 14 |



(Left to right) Jeremy Morgan, Director; Catie Olson, Previous Director; and Angela Van Veldhuizen, Project Manager

Director Jeremy Morgan met with the NAF leadership prior to the conference and was able to present data about those with Ataxia in the registry. He also presented the CoRDS poster at the Ataxia Investigator Meeting (AIM). While at the conference the CoRDS team was able to help participants enroll in CoRDS or update their information along with answering any questions that participants may have had.

Since CoRDS attended the NAF conference in April, there have been 46 participants with Ataxia who have enrolled into CoRDS, seven participants who have updated their information and 21 who have completed the screening form but not finished their questionnaires. This makes a grand total of 94 participants who have either enrolled or updated their information in the registry since the conference.

As exciting as it is to increase the numbers of participants who enroll in the CoRDS registry, it is equally as important for currently enrolled participants to go into the registry at least yearly to update their information. The ability of CoRDS to provide accurate and up to date data is an important service to offer researchers, in order for them to form a hypothesis which they can use to secure funding for research.

Please remember that, currently, the patient enrollment system (PES) is only compatible with the following browsers (program used to access the internet): Internet Explorer, Google Chrome and Mozilla Firefox. If you are a Mac user, you must download one of these browsers to enroll with a user-friendly experience. The default Mac browser (Safari) has not been approved for use with our PES yet. For best results, please use your home computer or laptop with one of the previously listed browsers (i.e. not your smart phone or tablet). CoRDS would like to remind all of our participants to contact us at 1-877-658-9192 or cords@sanfordhealth.org if you ever have questions about the registry or require assistance enrolling. ▶▶

NAF Update: Ataxia Patient Registry Achieves a Milestone

An important milestone was met in June this year when the first request from an Ataxia researcher to access the registry for recruitment of research participants was approved. It is exciting to have a registry that has become a viable tool for Ataxia researchers to recruit participants. It is anticipated that requests from researchers and pharmaceutical companies will increase in the coming months. This makes it extremely important for those who would like to be part of a research study or clinical trial enroll in the CoRDS/Ataxia Patient Registry.

Researchers who are conducting IRB-approved investigations concerning Ataxia will submit an application to CoRDS for access to the registry. The research project is reviewed by the Sanford scientific board with a representative from NAF's Medical Research Advisory Board to determine if the research project will serve

the Ataxia community. Once approved, the researcher can view de-identified data and request that Sanford staff contact participants on the researcher's behalf to inform them that they may be eligible to participate in the research study.

If you are interested in participating in research studies or clinical trials, enrolling in the CoRDS/Ataxia Patient Registry is an important first step. Encourage family members who are affected with Ataxia and those who are at risk to develop Ataxia to also enroll. If you have started the enrollment process, log-in to the registry and complete the process. And if you are fully enrolled, log-in and update your information. To enroll, click on this link: <http://tinyurl.com/enroll-in-CoRDS>.

Thank you for your attention to this important research initiative. ❖

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:

Dr. Margit Burmeister, PhD or Dr. Erin Sandford
Molecular & Behavioral Neuroscience Institute, University of Michigan
5063 BSRB, 109 Zina Pitcher Place, Ann Arbor MI 48109-2200
Telephone: (734) 6472186; (734) 615-3359
E-mail: margit@umich.edu or esandfor@umich.edu

Alliance to Fight SCA3

The 2016 Ataxia Investigators Meeting (AIM) in Orlando again provided a forum for exchange of results and ideas during the scheduled scientific sessions as well as valuable opportunities for scientists to meet informally and to network.

As a result of this meeting five scientists from Germany, Portugal and the U.S. agreed to form an “Alliance to Fight SCA3.”



“Alliance to Fight SCA3” members (back row, left to right) Dr. Olaf Riess, Dr. Thorsten Schmidt, Dr. Henry Paulson, (front row) Dr. Patricia Maciel and Dr. Luis Pereira de Almeida

“For a rare disease like Spinocerebellar Ataxia type 3 (SCA3) also known as Machado-Joseph disease (MJD), we see the need for international

collaborations, especially between Europe and the United States,” said Olaf Riess, head of the Institute of Medical Genetics and Applied Genomics at the University of Tuebingen (Germany).

Patrícia Maciel, Professor at the Life and Health Sciences Research Institute (ICVS) of the University of Minho, Braga (Portugal) added “Even two decades after the identification of the genetic mutation causing MJD/SCA3, we still cannot offer a causative treatment to patients. However, recent progress of all of us five brings us closer to first clinical trials.”

The five scientists agreed to unite their forces in this process and to meet and exchange on a regular basis.

“We all collaborated before on certain research questions but the alliance will give us the opportunity to intensify our exchange,” explained Thorsten Schmidt, group leader of the SCA3 research group at the University of Tuebingen (Germany).

Henry L. Paulson, Lucile Groff Professor of Neurology in the Department of Neurology at the University of Michigan, Ann Arbor said “We all will profit from each other. The Europeans, for example, already several years ago established networking structures, like the EUROSCA consortium, which we are also currently in the process of setting up in the U.S.”

Finally, Luís Pereira de Almeida, vice-president of the Center for Neuroscience and Cell Biology (CNC) at the University of Coimbra (Portugal) stressed “The Alliance is not intended to be a closed club. Other researchers working on MJD/SCA3 are very welcome to join us.”

The researchers of “Alliance to Fight SCA3” plan to exchange their ideas and concepts as well as samples and reagents in order to speed up reaching their ultimate goal to develop a treatment for Spinocerebellar Ataxia Type 3 (SCA3) /Machado-Joseph disease (MJD). ❖

CFC Number

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

The National Ataxia Foundation’s CFC number is 10752. This program provides a convenient way to donate to NAF, and provides great benefit to those with Ataxia. Please give as generously as you can and please ask your co-workers to also give.

National Ataxia Foundation 59th Annual Ataxia Conference

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

The 2016 Annual Ataxia Conference (AAC) was hosted by the National Ataxia Foundation’s Southeast Region. NAF would like to congratulate the Southeast Region on hosting such a successful meeting! More than 500 attendees came for the three-day event. Attendees came from 38 U.S. states, Washington D.C., and from six international countries, including Canada, Denmark, India, Pakistan, Peru and the United Kingdom.

The National Ataxia Foundation would like to extend a special thank you to all the attendees, speakers, facilitators, exhibitors and the outstanding volunteers of the NAF 2016 “The Magic of a Cure” Annual Ataxia Conference held in Orlando, FL. The NAF recognizes the resources, sacrifices, and challenges that many attendees face to attend an AAC. Your attendance is abundantly appreciated. This conference would not have been possible without the time, contributions, and efforts given by so many. Thank you much for the wealth of information

and knowledge that was brought to the conference by all the speakers, facilitators and exhibitors. The information and skills taken away from this conference by the attendees is invaluable and worth more than any words can say. It was so wonderful working with the Southeast Region Leadership. Their commitment and dedication toward the successful execution of this conference was truly exceptional. Thank you to Lora Morn for volunteering as our on-site nurse at the conference. We would also like to thank David Garcia for taking such memorable pictures of this year’s event.

This year’s AAC program was very exciting and was well received! The format of the program was structured so that the General Sessions were scheduled in the mornings and Birds of a Feather Sessions were divided and offered either Friday or Saturday afternoon. This provided many attendees with an afternoon free to visit the exhibitor booths, check out the Activity Room, visit local attractions, visit with other attendees or attend the small group sessions offered in the Activity Room. All General Session presentations slides are available to on NAF’s website, www.ataxia.org. A portion of the 2016 AAC Presentations will be transcribed in future issues of *Generations* and released on NAF’s YouTube Channel throughout the year. Currently, you can find some presentations from the 2015 and 2016 conference general sessions on NAF’s YouTube Channel, <https://www.youtube.com/user/NatlAtaxiaFound>.



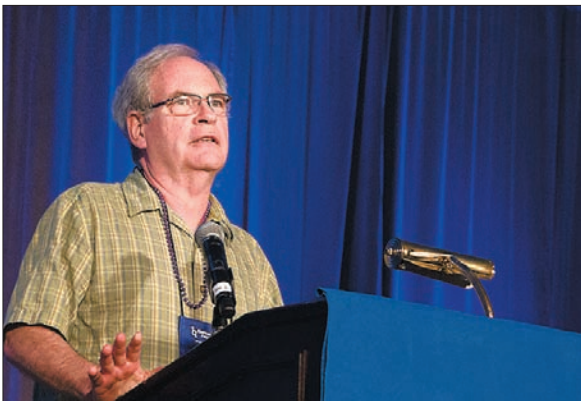
Brad Blas and Doug Greener attend the AAC at the Caribe Royale in Orlando, FL

2016 AAC Recap
Continued from page 27

At this year's AAC the Foundation recognized the numerous fundraising events that were conducted in 2015. "I am the Strength Behind Ataxia" awards were presented to Mike Cammer, Charlotte DePew, and Jane Jaffe. Dr. Harry Orr, PhD, received an Exceptional Service Award for his significant research accomplishments.

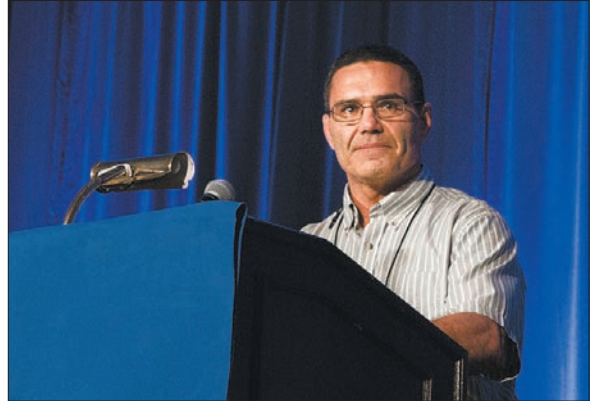
Conference attendees had an opportunity to meet Ataxia researchers on Thursday afternoon to view scientific posters and ask questions about their research efforts. With the Sixth Ataxia Investigators Meeting (AIM) dovetailing with the AAC, this special Poster Session was planned to allow those affected with Ataxia and family members to interact and engage with Ataxia researchers. Many of the researchers are "bench scientists," meaning their research takes place in a lab setting and so they have never met a person who has Ataxia. On surveys completed by the AIM attendees many indicated that the patient/family poster session was one the highlights of the meeting.

Exceptional Service Award Winner



Harry Orr, PhD
<http://tinyurl.com/HarryOrr>

'I am the Strength Behind Ataxia' Award Winners



Mike Cammer
<http://tinyurl.com/MikeCammer>



Jane Jaffe
<http://tinyurl.com/JaneJaffe>



Charlotte DePew
<http://tinyurl.com/CharlotteDePew>



Dr. Brent Fogel and attendees at the AIM poster session

According to Dr. David Lynch, lead organizer of the AIM, “Poster sessions such as this will facilitate the understanding of the advances in research by the patient community.”

The next Ataxia Investigators Meeting will take place in 2018 prior to the Annual Ataxia Conference and the AIM steering committee is already planning to expand and improve the poster session for conference attendees.

The “Rose Lee Show” featured this year’s conference in a segment of their show that aired in April. The segment included interviews with Michael Parent, NAF Executive Director, along with Cindy and Jerry DeMint, NAF Orange County Support Group Members. The segment can be viewed at <https://youtu.be/v2M7ub-9NHQ>.

Considerable appreciation and gratitude goes out to this year’s sponsors: Athena Diagnostics, Biohaven Pharmaceuticals, HB Cares, MetLife Center for Special Needs Planning, and OraLabs. Thank you to the Orlando Convention and Visitors Bureau for the local information provided for this year’s conference. Thank you to the Caribe Royale for their service and hospitality throughout this event.



NAF Receives Perfect 4-Star Rating from Charity Navigator

The National Ataxia Foundation’s (NAF) sound fiscal management practices and commitment to accountability and transparency have earned it a 4-star rating for the fourth consecutive year from Charity Navigator, America’s largest independent charity evaluator.

In 2011, Charity Navigator added 17 metrics, focused on governance and ethical practices as well as measures of openness, to its methodology. These “Accountability & Transparency” metrics, which account for 50 percent of a charity’s overall rating, reveal which charities have “best practices” that minimize the chance of unethical activities and whether they freely share basic information about their organization with their donors and other stakeholders.

“The National Ataxia Foundation’s coveted 4-star rating puts it in a very select group of high-performing charities,” according to Michael Thatcher, President and CEO of Charity Navigator. “Out of the thousands of nonprofits Charity Navigator evaluates, only one out of four earns 4 stars – a rating that demands rigor, responsibility and commitment to openness. National Ataxia Foundation’s supporters should feel much more confident that their hard-earned dollars are being used efficiently and responsibly when it acquires such a high rating.”

“It’s important our donors trust that we’re using our funding wisely to accomplish the National Ataxia Foundation’s mission,” said Michael Parent, Executive Director of the National Ataxia Foundation. “Our 4-star Charity Navigator rating demonstrates to our supporters that we take our fiduciary and governance responsibilities very seriously.”

More-detailed information about the NAF’s rating is available on Charity Navigator’s site at www.charitynavigator.org.

Sixth Ataxia Investigators Meeting (AIM) 2016: “From Basic Science to Clinical Therapeutics”

By David Lynch, MD, PhD, and Gülin Öz, PhD

Under the theme of advancing therapeutics in Ataxias, more than 160 researchers from universities and companies around the world met March 29–April 1 at Caribe Royale in Orlando, Florida. There was representation from 12 countries on four continents at the meeting.

This meeting was generously supported by a grant from the National Institutes of Health as well as industry and foundation sponsors. The National Ataxia Foundation is grateful to the following sponsors for their generous support: Horizon Pharma, Takeda, BioBlast Pharma Ltd., Ataxion Therapeutics, Biohaven Pharmaceuticals, BioMarin, Ionis Pharmaceuticals, The Gordon and Marilyn Macklin Foundation, A-T Children’s Project, Ataxia Ireland, Ataxia UK, Bob Allison Ataxia Research Center (BAARC), Friedreich’s Ataxia Research Alliance (FARA), and Friedreich Ataxia Research Association.

AIM participants heard new presentations from more than 80 investigators. These included work on cerebellar function, new genetic mechanisms,

and potential avenues for therapeutic intervention. Importantly, 17 out of 30 invited talks were about therapy concepts showing that we are at an exciting time for Ataxia treatments. As with previous AIMs, the conference put great emphasis on establishing and nurturing future leaders in Ataxia research as 18 of the 30 lecturers were junior investigators.

Also incorporated into this year’s meeting were specific sessions integrating patient and family perspectives on Ataxia. All of the researchers were particularly moved by these presentations and felt it provided more motivation for their work on Ataxia disorders. The meeting fostered communication between individuals in all aspects of Ataxia research, which helps move new therapies forward at a faster rate. As in previous years, the researchers all felt the meeting was a success and are looking forward to reviewing further progress at the next scientific conference in Philadelphia in 2018. ❖



Investigators from around the world gathered for the Sixth Annual Ataxia Investigators Meeting

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

National Ataxia Foundation 60th Annual Ataxia Conference March 10-11, 2017



The Grand Hyatt San Antonio is pleased to provide the facilities for the 2017 Annual Ataxia Conference (AAC)

Join us in San Antonio, TX for the Annual Ataxia Conference!

Room Reservations-Begins November 2

Room reservations for all room types at the Grand Hyatt will be made available starting November 2. Please note all ADA rooms must be reserved through the NAF office starting on **November 2 at noon CST** by contacting (763) 553-0020 or lori@ataxia.org. Calls or e-mails prior to noon CST on November 2 to reserve an ADA room cannot be honored.

Reservations at group rate will be available until February 13, 2017.

The NAF group rate starts at only \$169 +tax for Standard Rooms.

Meeting Registration-Begins November 2

Registration for the 2017 NAF AAC will open on November 2. You are encouraged to register before January 30, 2017 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. Please note: The conference will conclude with the banquet on Saturday evening.

2017 NAF Annual Ataxia Conference "Support Our Conference" Campaign

<http://ataxia.donorpages.com/2017AACLetterWritingCampaign/>

For more information on San Antonio visit <http://visitsanantonio.com/>.



In Memory

Arnie Gruetzmacher 1938-2016

We are saddened to report that Mr. Arnie Gruetzmacher passed away on Sunday, April 17. Arnie was on the National Ataxia Foundation's Board of Directors from 1971-2016. From 1972-1977, he served as the President of the Board of Directors and had been on the NAF Executive Committee since its formation in the mid-70's until 2014.

Many of you knew Arnie through the Annual Ataxia Conferences. He always had a joke to tell and a new friend to meet. Ataxia impacted Arnie's life when he was very young. He saw firsthand the devastation it can bring to a family through his aunts, uncles, and cousins who were affected by Ataxia. Arnie brought this experience with him in serving on the Board, charting his focus on the NAF's efforts to provide meaningful and compassionate programs.

Arnie's passion to help the Ataxia community

never wavered, particularly when it came to the NAF Annual Ataxia Conference. Arnie chaired the Annual Ataxia Conference Committee from 1980-2016. He would spend countless hours,

every year, helping to create a venue to bring Ataxia families together to share, learn, and network. In honoring the memory of Arnie, the Arnie Gruetzmacher Annual Ataxia Conference Travel Grant Fund has been established. This fund will help provide travel grants to those with Ataxia who would otherwise not be able to afford to attend the conference.

We salute you, Arnie, and thank you for your tireless commitment in helping the Ataxia community. We miss you.

To support the Arnie Gruetzmacher Annual Ataxia Conference Travel Grant Fund, please visit the Foundation's web site at www.ataxia.org. Thank you for furthering Arnie's vision and fulfilling his legacy. ❖



Arnie Gruetzmacher

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.

This link takes you to a page that has a video on why and how to enroll in the CoRDS Registry: www.sanfordresearch.org/cords/aboutcords.

Research Grant

Development of a Brief Ataxia Rating Scale for Children (BARSc)

By Jeremy D. Schmahmann, MD (jschmahmann@mgh.harvard.edu)
and Franziska Hoche, MD (fhoche@mgh.harvard.edu) Massachusetts
General Hospital, Boston, MA

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

As children grow, they develop the ability to control their body. They begin by developing large muscle coordination like holding up their head, crawling, and walking (gross motor skills). Then they begin to master more precise movements like speaking clearly and writing (fine motor skills). Ataxia is a neurological condition resulting from damage to the cerebellum characterized by difficulty with balance and voluntary coordination of the legs, arms, hands, and eye movements, and impaired speech. Children develop Ataxia as a consequence of a range of cerebellar diseases including tumors, hemorrhage, strokes, infections, and degenerative and inherited disorders.

The ability to measure Ataxia is a key component of the neurological evaluation. It is important for detecting worsening of the condition with time, and for documenting improvements over time either as part of the natural course or in response to treatment. We measure Ataxia using clinical rating scales. The problem we addressed in this study is that Ataxia rating scales currently in use were tested in adults, but the young child's nervous system is still developing. Young

children are not yet fully in control of their motor system, and studies show that typically developing children examined using these adult-derived Ataxia scales look like they have cerebellar Ataxia. This is because age-dependent achievement of fine motor skills, coordination, concentration, and muscle force influences the interpretation of

rating scales in a manner unrelated to the actual disease itself, or the response of the illness to therapy.

In this study we aimed to develop a clinical test of fine and gross motor control that includes reference values for children which would be useful for determining the severity of the cerebellar motor syndrome in children. There is an urgent need for such a scale, and this study was designed to fill that need. We based our evaluation on the Brief Ataxia Rating Scale, a short, validated and reliable assessment method for assessing Ataxia in adults. We asked children below the age of 18 (133 healthy children and 30 children with cerebellar Ataxia) to perform a series of simple activities demonstrating their ability to move in



Dr. Jeremy D. Schmahmann



Dr. Franziska Hoche

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Development of a Brief Ataxia Rating Scale...
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different ways that we know are under the control of the cerebellum. These included motor skills like balancing in different positions, walking in a straight line, and following objects with their fingers. They were also asked to perform fine motor tasks such as making small hand motions, speaking clearly, and following objects with their eyes. We wanted to find out how these cerebellar motor skills differ between typically developing children and children with cerebellar Ataxia at different ages and levels of ability.

The results of our study helped establish a measure of healthy motor function in children that recognizes typical development, and that is sensitive and reliable for distinguishing the neurologically healthy child from one with cerebellar Ataxia. We are now finalizing this new assessment tool – the Brief Ataxia Rating Scale for Children (BARSc), a short battery of tests of walking and sitting, arm and leg control, speech and eye movements. BARSc will be a valuable addition to the examination of the cerebellar motor system in children, and contribute in a meaningful way to the care and cure of children with Ataxia and other cerebellar disorders. ❖

When Tube Feeding Is Necessary

From “Living with Ataxia: An Information and Resource Guide”
by Martha Nance, MD

If eating becomes too tiring or difficult, or if aspiration pneumonias have occurred several times or weight loss occurs despite everyone’s best attempts, it may be appropriate to consider tube feedings. Tube feedings require a tube that goes directly into the stomach or intestines, and a liquid formula that provides all necessary nutrients.

Most often, when tube feedings are planned to continue indefinitely, a tube is inserted through the skin directly into the stomach and then sewn into place. A tube like this is called a gastrostomy tube. For most people, a gastrostomy tube can be placed using sedation and local anesthetic. General anesthesia is usually not necessary. Once in place, gastrostomy tubes do not cause pain or discomfort.

Complications of gastrostomy tubes can include the tube falling out, irritation of the skin around the tube, infection, or leakage of gastric juices around the tube.

Nutrition provided through a gastrostomy tube can include any fluid. Usually, to meet all of

the individual’s nutritional needs, high quality, carefully formulated solutions containing vitamins, minerals, and high protein content are used. These include formulas such as Ensure and Resource, among others. A nutritionist can help the family and physician to select the correct amounts of the correct formula, based on the individual’s weight, body size, and health status.

Although gastrostomy tube feedings can solve the problem of getting enough calories into a person with Ataxia, a gastrostomy tube does not prevent a person from choking on or aspirating saliva. Some physicians think that the risk of heartburn (or “reflux esophagitis”) is higher in people who have a gastrostomy tube. For many people, the decision whether or when to use a gastrostomy tube is not an easy one. Fortunately, it is not usually an emergency, so you have time to talk with your doctor, other professionals, friends, and family about the issues and to make the decision that is best for you. ❖

Ataxia Awareness Program Held in Indore, India

Submitted by Swasti Wagh

Seek a Miracle Ataxia Group (SAMAG) – Indore Chapter organizes seminars and workshops to spread awareness about Ataxia and other rare diseases with success. Due to its efforts, common people now know of Ataxia. Society is becoming more and more aware of the necessity to develop a special care center for such patients. The main aim of such events is to bring more people together so that policies can be framed to help these patients in proper diagnosis and treatment. The transition of the society towards 100 percent friendly environment with special equipment is still a farfetched dream.

In line with the activities of SAMAG in Indore, a seminar was organized on April 29 in collaboration with Choithram College of Nursing. This seminar intended to provide guidance towards special needs of Ataxia patients to students of nursing and physiotherapy/occupational therapy.

The event was initiated and sponsored by Dr. M.R. Rajeshwari, Professor, Department of Biochemistry, AIIMS, New Delhi and co-hosted by Choithram College of Nursing, Indore. The speakers were renowned personalities from their field. The program was inaugurated with lightning of the lamp by all the speakers and honorable guests.

Swasti Wagh gave an introduction of SAMAG and its activities. There was a medical presentation that emphasized the importance of proper diagnosis and DNA testing of Ataxia patients. Also discussed was how to minimize the possibility of passing Ataxia to the next generation. Highlighted was the significance of physiotherapy and speech therapy to an Ataxia patient's well-being. There was an introduction to exercise equipment specially designed for patients who are wheelchair-bound. An enlightening

presentation was made about the role of an occupational therapist in making the patient's life easier, and various aids which can be helpful in doing day-to-day activities easily. A detailed presentation and account of a nurse's role in patient's rehabilitation and necessity to understand the psychology of patient for his/her good care was given. Finally, there was an inspirational speech on how and why to adhere to basic normality of life in adverse situations and the importance of motivational talk, medical aide and physiotherapy in a patient's life.



Participants of the Ataxia Awareness Program held in Indore, India

Though the speakers were from different disciplines, it was not difficult for the audience to connect and understand all the aspects. The feedback on was positive and SAMAG presented mementos to each speaker.

An appeal is made to the public to report cases of Ataxia to SAMAG, so that combined effort is made to overcome hurdles in clinical trials and to seek help from the government to make new policies in support of Ataxia patients.

The National Ataxia Foundation is delighted to have one of its International Support Groups make such a positive impact in India and around the world.



This Is My Story: How I Acquired and Live with Ataxia

Submitted by Sebouh Kandilian

My life turned upside down when I had emergency brain surgery to stop a hemorrhagic brainstem stroke when I was just 22. I had recently graduated from college with a BS in biology and read my acceptance letter to optometry school while I was recovering at Mass General Hospital (MGH). The stroke was related to my pediatric brain tumor (astrocytoma), which was first partially removed in 1984 at the age of seven. It was both the happiest day of my life and the saddest at the same time. I was not sure of my future and if I would be able to attend optometry school, something I had worked hard for.

I could tell things were a little different this time when I woke up from this surgery, unlike the previous five procedures I had at MGH while I was in college. I woke up the next morning in the ICU with my family next to my bed. They were so happy that I was still with them and informed me that the tumor was removed. I could tell they were standing next to me but I was not able to hear them very well. My right ear had a constant ringing, a condition called tinnitus. As the surgeon, doctors, physical, speech, occupational therapists came to work with me the clearer it all became to me. As I stood in front of the mirror, I could tell my right eye was not aligned correctly and I had lost significant weight and muscle. The team of doctors had to remove the tumor in order to stop the bleeding which left me with some permanent damage. Now that I look back I understand why the decision was

made not to remove it completely years ago when I was a child.

I had now acquired Ataxia. My doctors showed me scans of the MRI taken while they removed the tumor from the cerebellum. The MRI scans showed this round empty blank space now in the cerebellum where the tumor was. This caused the Ataxia, which left me with motor impairments. I could barely put my feet together and

take a step without losing my balance. I was determined to not give up hope and had the will and determination to walk again without a wheelchair or walker. Eating was another problem, along with swallowing and drinking. The right side of my face was now paralyzed, which made it hard to eat or drink. I remember in the beginning I was on a puree diet and could only drink liquids with a thickener. As my neurologist came to visit me, I asked him whether the double vision, the ringing in

the ear, Ataxia, and facial paralysis would eventually go away. I did not want to accept it, but the answer was a no. It was all related to the damage and weak facial nerve located near the tumor where all the procedures took place.

I knew the journey to recovery would be a long one, but something worth fighting for. It was my life and I wasn't willing to give up the fight easily no matter what. As I came home I had a physical therapist show me exercises where I could hold on to my kitchen counter and work on my posture and balance. I sway back and forth when I close my eyes and eventually the therapist ►►



Sebouh Kandilian

catches me so I don't hit the floor. I remember the morning walks I went on with my therapist as I practiced walking again. I hated them because walking was so hard and difficult now. I easily got fatigued and did not want to do them but I knew it was something I had to do. I had to get used to my new life now. I could not walk like before, run up the stairs, jump or run and play basketball like I did before. I had to be careful of falling, I'd lose my balance easily. I did a lot of "furniture walking" as time went on. I had to hold on to the chairs and tables. Eventually I learned to compensate for my losses by shifting my weight. When I got fatigued I needed to touch the walls slightly to give me support, something I still do today. It is part of my new way of life. Even like the surface of where I am standing is something I need to pay attention to so I can be safe. Surfaces like uneven grounds, inclines, or walking outside in the winter scares me so much if I see snow and ice on the ground. I pay attention to everything I walk on now.

Today I am 39 and still remember the first days, months, and years of life with Ataxia. I never knew that brain recovery took so long and what brain plasticity was. It has been more than 16 years and I still have to pay attention to how fast I walk so I don't lose my balance and things most people don't pay attention to. I can't use the bicycle or climb a single step without a railing or the assistance of someone next to me. I have to be extra careful at night when it is dark out, it's easy to lose my balance.

I visit graduate schools, such as the Mass General Hospital Institute in Charlestown, Northeastern, Boston University, where I work with the PT students in their labs as they examine hemorrhagic stroke patients with cranial deficits and Ataxia. I have heard the phrase "wide base of support" so much now and the standard PT examination names are so familiar to me and the procedures too. Sometimes I wish I could still be the clinician and not be the patient and survivor. But I am happy that I am helping them with the learning process and they appreciate it so much.

I have decided to eat a healthy, nutritious diet most of the time, and I can't thank my mother enough for all that she does for me. Exercising is also a big priority in my life and I keep doing some physical activity whether it is weights or going for short walks depending on how I am feeling. I always have my camera on me and sometimes I struggle with it because you need good balance if you are not in a chair. It is often common for me to be leaning against a wall or a tree so I can get a sharp clear image.

I also keep in mind to always keep smiling, think positive, be with supportive friends, not be negative, and visualize the things you want to happen because I know there is a connection between emotions and health.

I have good and bad days and I try not to let the losses and setbacks get the best of me. I like to use

my creativity now by taking photographs of everything that captures my interests, whether it is the city, the harbor, memorable events of family like weddings, people or flowers (right). I also like drawing, even though it is a



little more difficult now since the fine motor coordination has been affected. The fatigue and headaches are a part of life and I am still trying and figuring out what works best for me. With hope and an optimistic attitude, I feel I can face life with all its challenges and difficulties and always try to reach my goals to the best of my abilities. I never take anything for granted. I hope many other young adults who are going through this procedure, won't give up and see the light at the end of a very difficult journey.

Today I look at life through the lens of the camera and appreciate what I still have.

If you would like to contact Sebouh, please e-mail him at kan0085@aol.com. ❖



Chapter and Support Group News from Around the Country

Happy Hoosiers Indiana Ataxia Support Group

Submitted by Cheri Bearman

I represented the NAF at the Rare Disease Conference on Monday, February 29, at the Parkview Mirro Center for Research and Innovation. I am not sure how many folks attended or how many rare diseases were represented, but there seemed to be a good number of attendees.

Here is a link to the article that was in the Fort Wayne *Journal Gazette* about the event: <http://tinyurl.com/Indiana-Rare-Disease-Day-2016>.



Cheri Bearman at the Rare Disease Conference

Cleveland Area Ataxia Support Group

Submitted by Carmen Pieragastini

Guest speaker Terry Johnson from A & A Medical Supply brought a U-Step walking stabilizer for us to try. It is specifically designed for individuals with walking/gait issues or that have use of only one hand. It works the opposite of a standard walker in that you use the hand brake to walk and release it to stop. It's designed with a lower center of gravity and wraps around

(like a "U") to provide more stability. You can go to www.ustep.com for more information. Terry also talked about Medicare and how it applies to purchasing needed equipment (walkers, scooters, power chairs, etc.).

Guest speaker Jill Cunnington, occupational therapist for CareTenders, had great information regarding the challenges we all face on a daily basis. She was my in-home-therapist while I was recovering from my broken ankles and has helped make me stronger and safer in my home.

Don Tredent emailed us information regarding a new drug and trials that will begin in the fall from a company called Biohaven. You can read about it on their website: <https://www.prweb.com/releases/2016/03/prweb13246650.htm>.

There is also a *Cerebellum and Ataxia Journal* from Biomed Central which is an open access journal devoted to cerebellar research and disorders, including scientific reports and clinical cases of numerous forms of Ataxia. Find out more at cerebellumandataxias.biomedcentral.com.

HUGE NEWS!!! We will be having our first annual "Walk & Roll to Cure Ataxia" 2K fundraiser on August 21st at Edgewater Park-Upper Shelter West (part of the Cleveland Metroparks system). Sue Kresnye will be the coordinator and will be looking for volunteers to make this event a success! There will be a website set up for participants with pledge sheets. We are also looking for sponsorship. There will be a silent auction as well. The goal is to create awareness for Ataxia and also to raise some money. Important to note that donations go toward supporting the NAF's research efforts. More info to follow but get your walking shoes and wheels ready! ▶▶

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Tampa Bay Ataxia Support Group

Submitted by Linda Farrow

On Saturday, March 19, the Tampa Bay Ataxia Support Group had their annual picnic at Seminole Lake Park in Seminole, Florida. It was raining quite hard in the morning but just about everyone who signed up came and it cleared up in the afternoon. There were some members who grilled our hamburgers and hots and laid out the delicious food that had been brought to be shared. We ate and visited with each other, met some new people and in general had a very good time.



Members of the Tampa Bay Ataxia Support Group at their annual picnic in March

Our meeting dates have been finalized for 2016. We welcome anyone interested in finding out about our group and if you have questions feel free to contact us. We are listed in the NAF Support Group directory.

Many of our support group attended the NAF Annual Ataxia Conference held in Orlando. It was a great meeting, very informative. We met a lot of new and old friends as well as saw our great leader, Nygel Lenz, do one of the presentations. We are looking forward to San Antonio in 2017.

There is a new East Coast of Florida support group starting – the Treasure Coast Ataxia Support Group.

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Treasure Coast Ataxia Support Group

Submitted by Lisa Cole

Our first meeting went well. I am planning on having meetings every other month, excluding



Members of the Treasure Coast Ataxia Support Group at their first-ever meeting

January. Seven people came and it was great! They got to talk and tell their story, plus exchange phone numbers. There were no time limits which was very nice.

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Greater Atlanta Ataxia Support Group

Submitted by Dave, Lealan and Diane

The Greater Atlanta Support Group held their last meeting on April 30. It was a great group meeting with Dr. Chip Wilmot giving everyone and update on the 2016 Annual Investigator Meeting (AIM) and the Annual Ataxia Conference that was recently held in Orlando.

Submitted by Dave, Lealan and Diane

The Greater Atlanta Support Group held their annual picnic on June 11 at Lanier Park on Buford Dam Rd. at Lake Lanier. Hamburgers, hot dogs, utensils and ice were provided. Drinks and side dishes were brought to share. Fun was had by all.



Members of the Atlanta Ataxia Support Group at their annual picnic in June

Chapter and Support Group News
Continued from page 39

Orange County Area Ataxia Support Group

Submitted by Daniel Navar and Cindy De Mint

The April meeting was a success with 28 in attendance. Four were new members. Western University students and Dr. Mary Hudson McKinney showed us some exercises and provided resistance bands to attendees. Highlights from the Annual Ataxia Conference were shared.

At our next meeting, members will be sharing alternative treatments that have worked for them.

Arizona Ataxia Support Group

Submitted by Mary Fuchs

The Arizona Ataxia Support Group held a meeting at the Foundation for Senior Living (FSL) Caregiver House in Phoenix on May 14. We had a great turnout with 17 attending, including three new members. This was our first meeting focusing on our IAAD plans.



Photo by David Garcia

Members of the Arizona Ataxia Support Group at their May meeting

The FSL Caregiver House is a unique and innovative, home-like setting. It offers an abundance of opportunities for learning, sharing and support. They help with individualized group education, information on home designs, home modification, hands-on training for effective use of adaptive equipment and opportunities for self-care and rejuvenation. We all learned a lot!

Alabama Ataxia Support Group

Submitted by Becky Donnelly

The Alabama Ataxia Support Group held its meeting at Covenant Presbyterian Church in Homewood, on May 7, with 18 members present. Karen Dow of E.W. Motion Therapy, Birmingham, presented her vision of neuro-patient therapy, with an emphasis on balance, and demonstrations of vision, vestibular and somatosensory therapy. Members expressed this was the best therapy session we had ever had. There were many questions and answers with demonstrations by Karen, and members felt encouraged by the suggestions Karen gave.



Members of the Alabama Ataxia Support Group at their May meeting

Blair and Stephanie Culbreth and Denise and John Higdon, who attended the NAF Annual Conference in April, gave feed-back on their experiences there and shared with the group what they had learned.

The meeting ended with laughter as Juanita Dorroh, Inspiration Leader, read "This is Us!"

Greater Atlanta Ataxia Support Group

Submitted by Dave, Greg, Diane and Lealan

At the last support group meeting, Dr. Wilnot discussed the possibility of a number of clinical trials in the near future. At the Ataxia Investigators Meeting in Orlando, investigators discussed the importance of being "clinical trial ready" and having a database of possible participants to ensure that trials move forward. Please register with the CoRDS registry if you have not ►►

done so. Here is a link to their website: <https://cordsconnect.sanfordresearch.org/BayaPES/pp/participantLogin>.

Seek A Miracle Ataxia Group (SAMAG)

Submitted by Chandu George

A charitable event was held on May 7 by the Shree Society for donating wheelchairs and general vitamins to Ataxians from the Hyderabad area (India) It was a good get-together for Ataxians from the area. The meeting started with the traditional Lighting of Lamp and later, Dr. John and Dr. Swomya gave a brief presentation on Ataxia and a scenario of Ataxia patients in India. The value and how helpful physical therapy is for Ataxians was highlighted.

Submitted by Chandu George

Chandu George returned home safely from Barcelona, Spain after attending EURORDIS and speaking as an advocate for Ataxia awareness.



Chandu George at EURORDIS in Spain

Later, Mr. Pratap (Shree Society) and Sudhakar Rao (DFO) spoke on how the Shree Society has come forward for this noble cause and instilling the values of “Bringing Humanity Back” for the betterment of society, which is also the Shree Society’s tag line. The local media covered the proceedings of the meeting,

Wheelchairs and general health vitamin supplements were given to the Ataxians that attended and the meeting ended with good dinner for all. We are thankful for Shree Society and the Lions Club of Hyderabad for their support.



Members of the Seek A Miracle Ataxia Group at their May meeting

Western PA (WPA) Ataxia Support Group

Submitted by Ed Schwartz

In late April, on Peters Township (PT) community TV channel 7, Ed Schwartz started doing a three-part video series about Ataxia. The program was conceived as an Ataxia awareness vehicle for support group viewing and focuses on Ed’s journey with Ataxia. The first episode is entitled “What Your Family Needs to Know about Ataxia” and can be seen online at <http://tinyurl.com/WEFSKApt1>.

On June 6, the WPA will partner with Max & Erma’s Restaurant with a coupon where the restaurant will give back 20% of receipt to benefit the NAF.

Peters Township Community Day is June 25, and the WPA will have a booth and talk with those who are interested in learning about Ataxia.

In August, Linda and Ed will be in Cleveland to help Susan with her first Walk n’ Roll.

Once again Macy’s will have their Shop for a Cause coupon and we will be available from August 26-28 to purchase the coupon from the WPA. This year the \$5 pass will allow you to save up to 25% on designated in-store items.

Please visit our fundraiser site at www.ataxia.org/walk/wpa. We will hold our Second Annual 5K Walk, Run & Roll to Cure Ataxia at Corri-gan Drive in Allegheny County’s South Park.

Chapter and Support Group News
Continued from page 41

We are so excited about the upcoming WPA planned activities!

Greater Denver Area Support Group

Submitted by Charlotte DePew

The quarterly meeting of the Greater Denver Area Support Group meeting on April 16 was cancelled due to a blizzard and heavy snow that affected most of Colorado. It was not rescheduled, but the speaker, Dr. Terry Chase, kindly agreed to come for our next meeting in July and will speak on using the pleasure of your senses for better health and wellness.

Please visit our fundraiser site at www.ataxia.org/walk.denver. Our Sixth Run, Walk n' Roll will be held September 11 at Denver's City Park.



Members of the Greater Denver Area Support Group at the AAC in Orlando

Tri-State Ataxia Support Group

Submitted by Kathy Gingerelli

What a huge turnout for our May 12 meeting! We welcomed new members, old members who haven't been there in a while and our faithful constants. We covered many topics.

An Abilities Expo was held April 29 to May 1 at the Convention Center in Edison, NJ. So many people stopped by to ask questions and be educated about Ataxia. What a great feeling it was to spread the awareness and meet new people interested in learning about Ataxia.

I spoke about the Second Annual Disability

Pride Parade & Festival on July 10 in NYC. The parade starts at 10 a.m. in Union Square Park and goes up Broadway to Madison Square Park where there will be a festival and huge celebration until 4 p.m. I registered our entire group under the National Ataxia Foundation. For more information, please visit the website at www.disabilitypridenyc.org.

We heard from new and long-time group members about many things related to having Ataxia, especially the importance of exercise. Ian Bouras spoke about how Ataxia forces you to modify your way of doing things. We were able to show some of Ian's latest YouTube clips, including interviews, musical performances and his stand-up comedy routine. Check him out at www.youtube.com and search "Ataxia/Ian" then sit back and enjoy! Remember, it's not that you can't do it ... you just have to do it differently.

Lastly, I talked about our first-ever Walk 'n' Roll event to celebrate International Ataxia Awareness Day being held on August 27 at Liberty State Park in Jersey City, NJ. We are going to make this an event that grows year after year!

Tarheel Ataxia Support Group

Submitted by Ron Smith

We had a great meeting on Saturday, June 18 with more than 20 people showing up for fellowship, networking and education. This was our fifth annual picnic. The guest speaker was Lynn McConnell from the North Carolina Assistive Technology Program, a division of the Department of Health and Human Services.



Members of the Tarheel Ataxia Support Group at their June meeting



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) \$5

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) \$5

Ten Years to Live
by Henry J. Schut \$9

There's Nothing Wrong with Asking for a Little Help ... and Other Myths
by Dave Lewis \$10

Evaluation and Management of Ataxic Disorders: An Overview for Physicians, 2nd Edition – Updated
by Susan L. Perlman \$5

VIDEO/CD

Together There is Understanding VHS \$5 DVD \$5

SHIRTS/MISCELLANEOUS

NAF Wheelchair/Walker Pouch
9.5"Wx5"Hx1"D \$5

Original NAF IAAD T-Shirt S & XXXL only \$10

NAF Baseball Cap (White or Blue) \$10

SHIRTS/MISCELLANEOUS (cont.)

IAAD T-Shirt Sizes S to XXXL \$10

IAAD Sweatshirt Sizes S to XXXL \$25



NAF Polo Shirts \$20

Mens – Royal blue w/white NAF logo S, M & XXXL
Light blue w/royal blue NAF logo in L to XXXL
Womens – Light blue w/navy NAF logo in S to XXL

NAF Denim Shirt w/white NAF logo \$20

“Ataxia is Not a Foreign Cab” T-Shirt \$10
White sizes S to XXL

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

“Ataxia is Not a Foreign Cab” Sweatshirt
White sizes S to XXXL \$20

NAF 50th Anniversary Coffee Mug \$3

Ataxia Necklace, 20” Chain \$20

“Ataxia is Not a Foreign Cab” Magnet \$1

Window Cling or Bumper Sticker \$1 ea. or 6 for \$5

NAF Ataxia Awareness Band, Reflex Blue
One size \$1 ea. or 3 for \$2

NAF Ataxia Awareness Ribbon Magnet \$4

“Know Ataxia” Backpack 20”x16” \$5

NAF Grip n’ Sip Water Mug \$5 **NAF Lapel Pin** \$5

Magnetic Power Clip \$3 **NAF Shoulder Bag** \$10

To place your order, call (763) 553-0020, fax (763) 553-0167, mail a copy of this form to National Ataxia Foundation, 2600 Fernbrook Lane, Suite 119, Minneapolis, MN 55447 or visit www.ataxia.org

ORDER FORM

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

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

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

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

Social Networks

NAF BULLETIN BOARD

Moderator – Atilla and Bear

www.ataxia.org/forum/toast.asp

NAF CHAT ROOM

Moderator – Della (ddpokernut@yahoo.com)

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

NAF FACEBOOK GROUP

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

NAF FACEBOOK FANS

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

NAF YOUTUBE CHANNEL

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

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

Chapters, Support Groups and Ambassadors

– ALABAMA –

ALABAMA SUPPORT GROUP LEADER

Becky Donnelly – Hover, AL

(205) 987-2883

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

AMBASSADOR

Dianne Blain Williamson – Huntsville, AL

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

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

– ARIZONA –

PHOENIX AREA SUPPORT GROUP LEADERS

Angela Li – Peoria, AZ

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E-mail: angelal1010@gmail.com

Mary Fuchs – Sun Lakes, AZ

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E-mail: mary11115@msn.com Facebook

Group: <https://www.facebook.com/groups/arizonaataxia/www.ataxia.org/chapters/Phoenix/default.aspx>

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Bart Beck – Tucson, AZ

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

– ARKANSAS –

AMBASSADORS

Judy and David King – Hot Springs Village, AR

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

– CALIFORNIA –

LOS ANGELES AREA SUPPORT GROUP LEADERS

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Harvey Kahn – Whittier, CA

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E-mail: jhk@aol.com

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

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Sacramento Area Location Representatives

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Donna Hoag – Lincoln, CA

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Teresa Bredberg – Sacramento, CA

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

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

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Sarah Kahn – Stanford, CA

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– COLORADO –

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Facebook Group:

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

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

– CONNECTICUT –

TRI-STATE SUPPORT GROUP LEADERS

Kathy Gingerelli – Parsippany, NY

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Denise Mitchell – Bronxville, NY

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

– DELAWARE – DELAWARE

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– FLORIDA –

TAMPA BAY SUPPORT GROUP LEADER

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GREATER ATLANTA SUPPORT GROUP LEADERS

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

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

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

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

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NAF Directory

Continued from page 45

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S.G. E-mail: ngataxia@outlook.com

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

CENTRAL MA SUPPORT GROUP LEADER

John and Dana Mauro – Auburn, MA
(508) 736-6084

E-mail: john@ataxia.org

E-mail: danamauro63@msn.com

Facebook Group:

www.facebook.com/ataxiadidyouknow?ref=hl

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

– MICHIGAN –

DETROIT AREA SUPPORT GROUP LEADER

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

E-mail: tinyt48221@gmail.com

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

WESTERN MICHIGAN SUPPORT GROUP LEADER

Lynn K. Ball – Grand Rapids, MI
(616) 735-2303

E-mail: lynnkball@aol.com

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

– MINNESOTA –

CENTRAL MN SUPPORT GROUP LEADER

Marsha Binnebose – St. Cloud, MN
(320) 248-9851

E-mail: mbinnebose@hotmail.com

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

TWIN CITIES SOCIAL GROUP

Lenore Healey Schultz – Minneapolis, MN
(612) 724-3784

E-mail: schultz.lenore@yahoo.com

Maryann Sweeney – Minneapolis, MN

(612) 924-4947

E-mail: maryann.sween@gmail.com

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

AMBASSADORS

Julie Schuur – Luverne, MN
(507) 283-2555

E-mail: jschuur@vastbb.net

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

Lori Goetzman – Rochester, MN

(507) 282-7127

E-mail: logoetz@gmail.com

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

– MISSISSIPPI –

MISSISSIPPI CHAPTER PRESIDENT

Camille Daglio – Hattiesburg, MS

E-mail: daglio1@bellsouth.net

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

– MISSOURI –

KANSAS CITY SUPPORT GROUP LEADERS

Jim Clark – Oak Grove, MO
(816) 898-6872

Lois Goodman – Independence, MO
(816) 257-2428

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

ST. LOUIS AREA SUPPORT GROUP LEADER Sarah

“Janeen” Rheinecker – St. Louis, MO (417)
379-3799

Email: stlataxia@gmail.com

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

AMBASSADOR

Roger Cooley – Columbia, MO
(573) 474-7232 before noon

E-mail: rogercooley@mediacombb.net

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

– NEBRASKA –

AMBASSADOR

Linda Snider – Omaha, NE
(402) 212-3060

E-mail: lindasnider@cox.net

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

– NEW HAMPSHIRE –

NEW HAMPSHIRE SUPPORT GROUP LEADER

Jill Porter – Manchester, NH
(603) 626-0129

E-mail: jilleporter@comcast.net



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

– NEW JERSEY –

NEW JERSEY SUPPORT GROUP LEADER

Priya Mansukhani – Bridgewater, NJ
(908) 685-8805

E-mail: priyamans@gmail.com

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

TRI-STATE SUPPORT GROUP LEADERS Kathy

Gingerelli – Parsippany, NJ
(973) 334-2242

E-mail: kgingerelli@msn.com

Denise Mitchell – Bronxville, NY

E-mail: markmeghan2@gmail.com

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

– NEW YORK –

CENTRAL NEW YORK SUPPORT GROUP LEADER

Mary Jane Damiano – N. Syracuse, NY

Judy Tarrants – Fabius, NY
(315) 683-9486

E-mail: jtarrants@aol.com

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

TRI-STATE SUPPORT GROUP LEADERS Kathy

Gingerelli – Parsippany, NJ
(973) 334-2242

E-mail: kgingerelli@msn.com

Denise Mitchell – Bronxville, NY

E-mail: markmeghan2@gmail.com

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

– NORTH CAROLINA –

TARHEEL SUPPORT GROUP LEADERS

Ron and Donna Smith – Garner, NC
(919) 779-0414

E-mail: rsmith@sacherokee.com

E-mail: dsmith@sa-pr.com

AMBASSADOR

Jodie Kawa – Brevard, NC
(828) 384-8414

E-mail: jodiekawa@citcom.net

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

– OHIO –

GREATER CINCINNATI AREA SUPPORT GROUP LEADERS

Jennifer Mueller – Lexington, KY
(513) 284-2865

E-mail: jenmu@yahoo.com

Julia Soriano – Cincinnati, OH
(513) 899-1195

E-mail: julia@epivision.com

Group Blog: <http://ataxiafoundationcleveland.blogspot.com/>

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

CLEVELAND AREA SUPPORT GROUP LEADER

Carmen Pieragastini – Willowick, OH
(216) 272-5588

E-mail: willowpier@roadrunner.com

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

– OREGON –

WILLAMETTE VALLEY SUPPORT GROUP LEADER

Jason Wolfer – Gervais, OR

(503) 502-2633

E-mail: wolfer.jason@gmail.com

Facebook Group:

<https://www.facebook.com/groups/388993597939205/>

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

– PENNSYLVANIA –

CENTRAL PA SUPPORT GROUP LEADER

Michael Cammer – Downingtown, PA
(610) 873-1852

E-mail: michael.cammer62@hotmail.com

Facebook Group:

<https://www.facebook.com/groups/1475283086068548/>

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

POSITIVE PEOPLE IN PA SUPPORT GROUP LEADER Liz

Nussear – Norristown, PA
(610) 272-1502

E-mail: lizout@aol.com

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

WESTERN PA SUPPORT GROUP LEADER

Ed Schwartz – Venetia, PA
(724) 941-2210

E-mail: eds@ataxia.org

Donna Eiben – South Park, PA

(412) 655-4091

E-mail: dawn.eiben@verizon.net

Facebook Group: <https://www.facebook.com/wpaataxia>

<http://nafwesternpasupportchapter.weebly.com/>

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

– RHODE ISLAND –

RHODE ISLAND SUPPORT GROUP LEADER Anabela

Azevedo – Bristol, RI
(401) 297-8627

E-mail: azevedo70anabela@gmail.com

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

– TENNESSEE –

MIDDLE TN AREA SUPPORT GROUP LEADER

Alex Cohn – Nashville, TN
(256) 504-0240

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

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

– TEXAS –

GREATER HOUSTON AREA SUPPORT GROUP LEADER

Ashley Grayson – Houston, TX
(832) 530-0866

E-mail: ashleygrayson90@gmail.com

Facebook Group:

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

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

NORTH TEXAS AREA SUPPORT GROUP LEADER David

Henry Jr. – Trophy Club, TX

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

E-mail: cheve11e@sbcglobal.net

Facebook Group:

<https://www.facebook.com/Ataxiasupport>

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

NAF Directory

Continued from page 47

AMBASSADORS**Dana LeBlanc** – Orange, TX

(409) 883-5570

E-mail: tilessal@yahoo.comwww.ataxia.org/chapters/GoldenTriangle/default.aspx**Debra Whitcomb** – El Paso, TX

(915) 329-0721

E-mail: debrawhitcomb@hotmail.comwww.ataxia.org/chapters/Whitcomb/default.aspx**– UTAH –****UTAH SUPPORT GROUP LEADERS****Grant Beutler** – Salt Lake City, UT E-mail:grant.beutler@gmail.com**Jenny Durrant** – North Ogden, UTE-mail: jenny@utahataxia.org**Lisa Ord, PhD, LCSW** – Salt Lake City, UT

(801) 587-3020

E-mail: lisa.ord@hsc.utah.edu**Facebook Page:** www.facebook.com/utahataxiaS.G. Website: www.utahataxia.orgwww.ataxia.org/chapters/Utah/default.aspx**– VIRGINIA –****CHESAPEAKE CHAPTER PRESIDENT****Carolyn Davis** – Vienna, VA

(703) 759-2008

E-mail: ccnafpres@gmail.comwww.ataxia.org/chapters/Chesapeake/default.aspx**– WASHINGTON –****OLYMPIC AREA SUPPORT GROUP LEADER** Sherry**McLaughlin**

(360) 344-2445

E-mail: ccherilynmc@yahoo.comwww.ataxia.org/chapters/Olympic/default.aspx**AMBASSADOR****Linda Jacoy** – Spokane, WA

(509) 482-8501

E-mail: linda4727@hotmail.comwww.ataxia.org/chapters/Spokane/default.aspx**– WISCONSIN – WISCONSIN****SUPPORT GROUP LEADER****Kory Macy** – Madison, WI

(608) 237-6090

E-mail: kstab77@yahoo.comwww.ataxia.org/chapters/Wisconsin/default.aspx**International
Support Groups & Ambassadors****– CANADA –****OTTAWA SUPPORT GROUP LEADER****Prentis Clairmont** – Ottawa, Ontario

(613) 864-8545

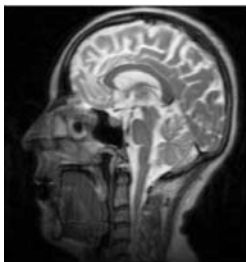
E-mail: prentis.clairmont@gmail.com **Facebook Group:**<https://www.facebook.com/groups/1468963499991380/>www.ataxia.org/chapters/Ottawa/default.aspx**– INDIA –****INDIA SUPPORT GROUP LEADER****"Seek a Miracle Ataxia Group" (SAMAG)****Chandu Prasad George**

Hyderabad, Secunderabad, India

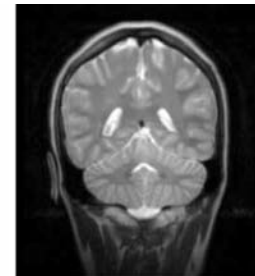
Mobile: 0091-9989899919, 0091-9885199918 E-

mail: sam_ataxiaindia@yahoo.comS.G. E-mail: india.ataxiagroup@gmail.com**Facebook Group:** <https://www.facebook.com/ataxiain>S.G. Website: www.ataxia.inwww.ataxia.org/chapters/Chandu/default.aspx**– PAKISTAN –****AMBASSADOR****Sajjad Haider** – Karachi, Pakistan 0092-

(300) 828-1784

E-mail: sajjadhaiderb@hotmail.com

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



Travel expenses reimbursed.

Contact: Diane Hutter

(612) 625-2350

hutte019@umn.edu

Calendar of Events

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

SUPPORT GROUP MEETINGS

– Wednesday, July 13, 2016 –

Willamette Valley Ataxia

Support Group Meeting – Albany

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

Location: 400 NW Hickory, Albany, OR 97321

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

– Thursday, July 14, 2016 –

St. Louis Area Ataxia Support Group Meeting

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

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

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

Tri-State Ataxia Support Group Meeting

Time: 6:30 – 8:30 p.m.

Location: 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 Kathy Gingerelli at kgingerelli@msn.com or Denise Mitchell at markmeghan2@gmail.com.

– Saturday, July 16, 2016 –

Greater Atlanta Ataxia Support Group Meeting

Time: 1 p.m.

Location: Emory Rehab Hospital, Room 101, 1441 Clifton Rd., Atlanta, GA

Details: For additional information contact the group at (404) 822-7451 or atlantaataxia@gmail.com.

NCASG–Sacramento Area Location Ataxia Support Group Meeting

Time: 1 – 4 p.m.

Location: Sutter Roseville Medical Center, Conference Room B, 1 Medical Plaza Dr., Roseville, CA 95661

Details: For additional information contact Teresa Bredberg at (916) 421-2173 or tredberg@sbcglobal.net.

Ottawa Ataxia Support Group Meeting

Time: 11:30 a.m.

Location: Walter Baker Park, Kanata

Details: For additional information contact Prentis Clairmont at (613) 864-8545 or prentis.clairmont@gmail.com. <https://www.facebook.com/events/544730232386518/>

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](mailto:lenore@yahoo.com).

– Sunday, July 17, 2016 –

Chitown Ataxia Friendship Group Meeting

Time: 1 p.m.

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

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

– Saturday, July 23, 2016 –

Denver Area Ataxia Support Group Meeting

Time: 1 – 4 p.m.

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

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

New Hampshire Ataxia Support Group Meeting

Time: 10 a.m. – noon

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

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

– Tuesday, August 2, 2016 –

Western PA Ataxia Support Group Meeting

Time: 7 p.m.

Location: Bethel Park Community Center, Park Ave., Bethel Park, PA 15102

*Calendar of Events**Continued from page 49*

Details: For additional information contact Ed Schwartz at (724) 941-2210 or eds@ataxia.org.

– **Saturday, August 6, 2016** –

Rhode Island Ataxia Support Group Meeting

Time: 11 a.m. – 2 p.m.

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

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

– **Tuesday, August 9, 2016** –

Utah Ataxia Support Group Meeting

Time: 7 p.m.

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

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

– **Wednesday, August 10, 2016** –

Willamette Valley Ataxia Support Group Meeting – Albany

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

Location: 400 NW Hickory, Albany, OR 97321

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

– **Thursday, August 11, 2016** –

St. Louis Area Ataxia Support Group Meeting

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

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

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

– **Saturday, August 13, 2016** –

Central Minnesota Ataxia Support Group Meeting

Time: 9:45 – 11:45 a.m.

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

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

Kansas City Ataxia Support Group Meeting

Time: 2 – 4 p.m.

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

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

North Texas Ataxia Support Group Meeting

Time: 10 a.m. – 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.

– **Saturday, August 20, 2016** –

NCASG–Sacramento Area Location Ataxia Support Group Meeting

Time: 1 – 4 p.m.

Location: Sutter Roseville Medical Center, Conference Room B, 1 Medical Plaza Dr., Roseville, CA 95661

Details: For additional information contact Teresa Bredberg (916) 421-2173 or tredberg@sbcglobal.net.

Orange County Ataxia Support Group Meeting

Time: 2 – 4 p.m.

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

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

Tampa Bay Ataxia Support Group Meeting

Time: 12:30 – 3 p.m.

Location: The University of South Florida Ataxia Research Center, Morsani Center, 13330 USF Laurel Dr., Ste. 1013, Tampa, FL 33612

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

Twin Cities Ataxia Social Group Meeting

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

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

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

– **Saturday, August 27, 2016** –

New Hampshire Ataxia Support Group Meeting

Time: 10 a.m. – noon



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

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

– **Tuesday, September 6, 2016** –

Western PA Ataxia Support Group Meeting

Time: 7 p.m.

Location: Bethel Park Community Center, Park Ave., Bethel Park, PA 15102

Details: For additional information contact Ed Schwartz at (724) 941-2210 or eds@ataxia.org.

– **Thursday, September 8, 2016** –

St. Louis Area Ataxia Support Group Meeting

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

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

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

Tri-State Ataxia Support Group Meeting

Time: 6:30 – 8:30 p.m.

Location: 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 Kathy Gingerelli at kgingerelli@msn.com or Denise Mitchell at markmeghan2@gmail.com.

– **Saturday, September 10, 2016** –

Central Minnesota Ataxia Support Group Meeting

Time: 9:45 – 11:45 a.m.

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

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

**Mid-Atlantic Ataxia Social Group
3rd Annual Wellness Day**

Time: 10 a.m. – 3 p.m.

Location: BWI Airport Marriott, 1743 W. Nursery Rd., Linthicum Heights, MD 21090

Details: Join us for a fun day full of activities including yoga, dance, group discussions, caregiver massages and lunch. For more information contact Nicola Mennucci at (410) 616-2816 or nmennic1@jhmi.edu.

North Texas Ataxia Support Group Meeting

Time: 10 a.m. – noon

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

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

– **Wednesday, September 14, 2016** –

Willamette Valley Ataxia Support Group Meeting – Albany

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

Location: 400 NW Hickory, Albany, OR 97321

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

– **Saturday, September 17, 2016** –

**NCASG–Sacramento Area Location
Ataxia Support Group Meeting**

Time: 1 – 4 p.m.

Location: Sutter Roseville Medical Center, Conference Room B, 1 Medical Plaza Dr., Roseville, CA 95661

Details: For additional information contact Teresa Bredberg (916) 421-2173 or tredberg@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, September 18, 2016** –

Chitown Ataxia Friendship Group Meeting

Time: 1 p.m.

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

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

– **Tuesday, October 4, 2016** –

Western PA Ataxia Support Group Meeting

Time: 7 p.m.

Location: Bethel Park Community Center, Park Ave., Bethel Park, PA 15102

Details: For additional information contact Ed Schwartz at (724) 941-2210 or eds@ataxia.org.

Calendar of Events

Continued from page 51

– Saturday, October 8, 2016 –

Central Minnesota Ataxia Support Group Meeting**Time:** 9:45 – 11:45 a.m.**Location:** Harvest Bank Branch, 24952 County Road 7, St. Augusta, MN 56301**Details:** For additional information contact Marsha Binnebose at (320) 248-9851 or mbinnebose@hotmail.com.**Kansas City Ataxia Support Group Meeting****Time:** 2 – 4 p.m.**Location:** Northeast Library, 6000 Wilson Rd., Kansas City, MO**Details:** For more information contact Lois Goodman at (816) 257-2428 or Jim Clark at (816) 468-7260.**North Texas Ataxia Support Group Meeting****Time:** 10 a.m. – 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 Sacior's Church, 1035 Carol Ln., Lafayette, CA.**Details:** For more information contact Jen Buehler at (510) 468-6474 or jennbuehler@aol.com.**Rhode Island Ataxia Support Group Meeting****Time:** 11 a.m. – 2 p.m.**Location:** Bristol Pocket and Recreation, 101 Asylum Rd., Bristol, RI 02809**Details:** To RSVP or for more information contact Anabela Azevedo at (401) 297-8627 or azevedo70anabela@gmail.com.

– Wednesday, October 12, 2016 –

Willamette Valley Ataxia Support Group Meeting – Albany**Time:** 11:30 a.m. – 1 p.m. on the second Wednesday of every month**Location:** 400 NW Hickory, Albany, OR 97321**Details:** For more information contact Jason Wolferat (503) 502-2633 or wolfer.jason@gmail.com.

– Thursday, October 13, 2016 –

St. Louis Area Ataxia Support Group Meeting**Time:** 5:30 – 7:30 p.m. Meetings will be held at on the second Thursday of every month.**Location:** Washington University Medical Center, 4444 Forest Park Ave., Room 509, St. Louis, MO 63108**Details:** For additional information contact Janeen Rheinecker at (417) 379-3799 or stlataxia@gmail.com.

– Saturday, October 15, 2016 –

Denver Area Ataxia Support Group Meeting**Time:** 1 – 4 p.m.**Location:** Swedish Medical Center, Second Floor Conference Center (meeting room TBD), 501 E. Hampden Ave., Englewood, CO 80113.**Details:** For more information contact Charlotte DePew at (720) 379-6887 or cldepew77@comcast.net.**INFORMATIONAL, AWARENESS, AND IAAD EVENTS AND FUNDRAISERS**

– TBD –

Concord Walk n' Roll and Swim IAAD Event and Fundraiser**Location:** Newhall Park, Concord, CA**Details:** All proceeds benefit the National Ataxia Foundation (NAF). For more information contact Brian Peterson at smileypetersen@yahoo.com. www.ataxia.org/walk/concord

– Friday, August 5-7, 2016 –

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, 5400 Kirby Dr., Houston TX 77054**Details:** Admission is free.www.abilitiesexpo.com/houston/

– Saturday, August 6, 2016 –

Walk for Dave IAAD Event and Fundraiser**Time:** 9 a.m. – noon**Location:** Onondaga Lake Park, 7199 Onandaga ▶▶

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

Lake Park Tr., Liverpool, NY 13088

Details: All proceeds benefit the National Ataxia Foundation. To volunteer and for more information, contact Marc Alessi (315) 506-3260 or mja244@cornell.edu.

www.ataxia.org/walk/walk4dave

— **Sunday, August 14, 2016** —

**Northeast Ohio Walk n' Roll
IAAD Event and Fundraiser**

Time: Reg. 10 a.m. Walk n' Roll 11 a.m.

Location: Cleveland Metroparks West Creek Reservation, Keystone Pavilion, 1885 W. Ridgewood Dr., Parma, OH 44134

Details: All proceeds benefit the National Ataxia Foundation. To volunteer and for more information, contact Susan Kresnye at (440) 343-0985 or susan_kresnye@ataxia.org.

www.ataxia.org/walk/cleveland



— **Friday-Sunday, August 26-28, 2016** —

Macy's "Shop for a Cause"

Details: Your special Macy's shopping pass gives you access to a special three-day sales event at Macy's stores nationwide. Pass holders will receive a 25% discount on regular, sale, and clearance items, including home. Even save on most brands usually excluded. Pass holders will also save 10% on electronics, watches, furniture, and rugs/floor coverings. Exclusions apply. Pass holders are also eligible to register to win a \$500 Macy's gift card. All Macy's shopping pass orders must be received by August 19. For more information please contact NAF at (763) 553-0020. All proceeds benefit the National Ataxia Foundation.

<http://ataxia.donorshops.com/product/89B3F06/macysshopforacausesavingspass.php>

— **Saturday, August 27, 2016** —

**Michigan Walk n' Roll & Symposium
IAAD Event and Fundraiser**

Time: Registration 8:30 a.m.,

Symposium 9:30 a.m., Walk n' Roll 12:30 p.m.

Location: University of Michigan Biomedical Sciences Building (BSRB), 109 Zina Pitcher Pl., 5031 BSRB, Ann Arbor, MI 48109

Details: All proceeds benefit the National Ataxia Foundation. For more information, contact Elizabeth Sullivan (734)232-6247 or elizsull@umich.edu. www.ataxia.org/walk/michigan



Tri-State Walk n' Roll

IAAD Event and Fundraiser

Time: Reg. 9 a.m., Walk n' Roll 10 a.m.

Location: Liberty State Park, Jersey City, NJ



Details: All proceeds benefit the National Ataxia Foundation. For more information, contact Kathy Gingerelli at kgingerelli@msn.com.

www.ataxia.org/walk/tristate

— **Saturday, September 10, 2016** —

**Minnesota Walk, Stroll n' Roll
IAAD Event and Fundraiser**

Time: 9 a.m.

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

Details: All proceeds benefit the National Ataxia Foundation. To volunteer or for more information, contact Terry Sweeney at (612) 760-9320 or mnataxiawalk@yahoo.com.

www.ataxia.org/walk/minnesota

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

Time: 9 a.m.

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

Details: All proceeds benefit the National Ataxia Foundation. For more information, contact Jeannette Viveiros at (508) 837-3565 or jeannette@ataxia.org.

www.ataxia.org/walk/newengland



— **Sunday, September 11, 2016** —

**Denver Run, Walk n' Roll
IAAD Event and Fundraiser**

Time: Registration 8 – 9 a.m.

Event goes until 11 a.m.

Location: Denver City Park, 17th and Colorado Blvd., Denver, CO

Details: All proceeds benefit the National Ataxia Foundation. For more information, or to be added to this group's mailing list, contact Charlotte DePew at (720) 379-6887 or

cldepew77@comcast.net. www.ataxia.org/walk/denver

— **Friday, September 16-18, 2016** —

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, 415 Summer St., Boston, MA 02210

Details: Admission is free.

www.abilitiesexpo.com/boston/

— **Saturday, September 17, 2016** —

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



Calendar of Events
Continued from page 53

Time: 9 a.m.

Location: East Village Community Association Club House and Parking Lot, 5325 Village Center Dr., Yorba Linda, CA 92886

Details: All proceeds benefit the National Ataxia Foundation. To volunteer or for more information, contact Cindy DeMint at (714) 329-4437 or cindyoc_ataxia@gmail.com.

www.ataxia.org/walk/ocla

– **Sunday, September 18, 2016** –

Tour de Shunk – Go On 3! For Ataxia Awareness IAAD Event and Fundraiser

Details: I'm Mike Cammer and I have Ataxia. This year on September 18, I am entering the "Tour de Shunk" for the third 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. For more information contact Mike Cammer at (610) 996-5814 or michael.cammer62@hotmail.com or visit the event website, ataxia.donorpages.com/2016GoOn3TourdeShunk/.

– **Saturday, September 24, 2016** –

Arizona Ataxia Awareness Extravaganza IAAD Event and Fundraiser

Time: 10 a.m. – 2 p.m.

Location: St. Xavier University, 92 W. Vaugh Ave., Gilbert, AZ 85233

Details: Free event. Donations accepted. Ataxia Awareness fair, including vendors, silent auction, raffles, performances, special guests and children activities. All proceeds benefit the National Ataxia Foundation. For more information about attending or exhibiting contact Angela Li (847) 505-4325 or angelali101@gmail.com or Mary Fuchs at (480) 212-6425 or mary11115@msn.com.

ataxia.donorpages.com/2016ArizonaAtaxiaAwarenessExtravaganza/

Atlanta Walk n' Roll IAAD Event and Fundraiser

Time: 9:30 a.m.

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

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

www.ataxia.org/walk/atlanta



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. For more information contact Jane Jaffe at (619) 286-9745 or sicilianmother@cox.net.

Western PA Walk, Run n' Roll IAAD Event and Fundraiser

Time: 9 a.m.

Location: Allegheny County South Park, Corrigan Dr., South Park Township, PA 15129

Details: All proceeds benefit the National Ataxia Foundation. For more information visit the event website or contact Ed Schwartz at (724)

941-2210 or eds@ataxia.org.

www.ataxia.org/walk/wpa

– **Sunday, September 25, 2016** –

International Ataxia Awareness Day (IAAD)

Details: The goal of International Ataxia Awareness Day (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, at www.ataxia.org/events/international-ataxia-awareness-day.aspx.

Tell us how you recognized IAAD and 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 address inside the front cover. Please send us your articles, photos, and proclamations so the entire NAF community can relive this historic day!

– **Saturday, October 1, 2016** –

Utah Walk n' Roll IAAD Event and Fundraiser

Time: 11 a.m.

Location: Layton Commons Park, Layton, UT

Details: All proceeds benefit the National Ataxia Foundation. For more information contact Lisa Ord at (801) 585-6635 or lisa.ord@utah.edu.

www.ataxia.org/walk/utah



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 February 2016 through May 2016. 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.

| | | | | |
|---------------------|--------------------|-------------------|--------------------|---------------------|
| Matthew Agostini | Russell Crystal | Ron Guffen | Sam Naccarato | Lauren Sherlock |
| David Alessi | Joanne Curran | Roy Guffey | Patricia Naccarato | Popi Sideris |
| Crystal Allsopp | Henry Davis | Michael Hephaesto | Steve Noyce | Kathryn Smithers |
| Barbara Almeida | Richard Davis | Craig Hindley | William (Bill) | Jenny Spiller |
| Linda Anderson | Joe DeCrescenzo | Joyce Hoffman | O'Connell Sr. | Robert Stackle |
| Alan Asp | Ernest DiMonte | Krista Humes | Ed O'Connor | The Stafford Family |
| Janet Atkins | Dawn Dizon | Gregory Irwin | Peter Ostrowski | Joseph Stamer |
| Paul Bacigalupo | Randy Dombrowski | Darren Keeble | Carol Pavelich | Harriett Stanley |
| Cheri Bearman | Peter Drakos | Sharon Klas | Norma Payne | David Stein |
| Clair Beck | Dorothy (Sparky) | Jamie Kosieracki | Eric Pederson | John Sturm |
| Betty Beck | Drelick | Jesse Kuenzi | Theresa Penk | Michele Sturm |
| Sheryl Belsly | Daniel Dyson | Marcella (Sally) | Ruth Ann Platts | Kelly Sugrue |
| Giovanni Bertussi | Katherine | Kukelhan | Ray Plaunt | Betty Swale |
| Angela Brown | Dzieszkowski | Sandy LaMaack | David Price | Mike Sweeney |
| Barbara Bynum | Garry Eichholz | Jennifer Leader | Julie Anne | Linda Swinkola |
| Danny Callahan | Mariann H. Ennis | Mary Lee | Quinlivan | Iqbal Tai |
| Sally Callaway | Matthew Farrow | Amy Legault | Charley Quinn | Jerry Tiblier |
| Benjamin Cantor | Christina Fazio | Corby Legault | Matthew Reid | Patricia Tobias |
| Terrance Caster | Sherwin Fink | Johna Leidholt | Lori Rich | Gert Tougas |
| Barbara Caster | Angela Fleischman | Greg Leonard | Laurie Richards | Margaret Tseng |
| Kai Chau | Don Folger | The Lowry Family | Janet Riley | Linda Ueland |
| Chicago Ataxia | Marysue Fredericks | Adrian Lund | Michael Rinella | Pete Vallarino |
| Support Group | Dr. Robin Fross | Frances Mangner | Karen | Brad Van Voorhis |
| Kenneth Church, Jr. | Gregson Gann | Allan Markowitz | Riordan-Coverdale | Amy Van Voorhis |
| Judith Ciofelli | Robert Geffert | Gregory Marshall | Melanie Rose | John Vaughn |
| Lisa Cincotta | William Gill Jr. | Marie Matikowski | Donny Royer | Marlea Waddell |
| Eleanor Clark | Diana Gray | R.L. Maxwell | The Santa Croce | Betty Wahlheim |
| Thomas Cobble | Kitty Greene | Roulene Mead | Family | Leroy Wernsing |
| Deb Cornish | Arnie | Monina Medalle | Linda Schwartz | David Westrick |
| Debra Covington | Gruetzmacher | Reggie Mellon | Ed Schwartz | Martin Willen |
| Robert Craig | Aymee | Suzanne Mondy | Derek Semler | Karen Wills |
| Arlen Crawford | Guerrero-Torres | Kerri Naccarato | Cheryl Serge | Glenn Zoller |



Remembering NAF in Your Will

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

Over the years these individuals have given anywhere from a few thousand dollars to nearly one million dollars. Their forethought and benev-

olence has enabled NAF to support promising Ataxia research and provide meaningful programs and services to Ataxia families. It is because of these quiet heroes that many research studies and programs have been funded.

Please consider remembering NAF in your will, and making a difference in the lives of Ataxia families.



National Ataxia Foundation

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GIFT – HONOR – MEMORIAL

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

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

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

My contribution is:

In Memory In Honor Gift Membership

Name _____

Occasion _____

Send Acknowledgment Card to:

Name _____

Address _____

City/State/Zip _____

From:

Name _____

Address _____

City/State/Zip _____

Is your address correct? Are you receiving more than one issue of *Generations*? If there are any changes that need to be made, please call the 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 – \$65

Individual – \$40 Household – \$60

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

Recurring Gift Membership Program:

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

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

Name _____

Address _____

City/State/Zip _____

Phone _____

E-Mail _____

Yes, sign me up for NAF e-mails

PAYMENT INFORMATION

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

Check. Please make payable to the NAF.

Total Amount Enclosed \$ _____

Card: Visa MasterCard Discover AMEX

Name on Card _____

Card # _____

Exp. Date _____ CVV # _____

Signature _____

Phone Number _____