

Generations

**SPECIAL
EXPANDED
EDITION**

The Official Publication of the National Ataxia Foundation

Volume 40, Number 4

Winter 2012-13

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

National Ataxia Foundation 56th Annual Membership Meeting “Driving Together Towards a Cure” Detroit, Michigan – March 15-17, 2013

The National Ataxia Foundation (NAF) Board of Directors and the National Ataxia Foundation Northeast Regional Support Groups invite you to attend the 56th Annual Membership Meeting. Please join us at the Detroit Marriott at the Renaissance Center in Detroit to learn, share, network, have fun, and enjoy the sites.

The 2013 Annual Membership Meeting will bring together NAF members and their families

not only to meet and learn from world-leading ataxia researchers and clinicians, but also to build new friendships and reunite with old friends.

Meeting Registration


The meeting registration form and more information is available on NAF’s website, www.ataxia.org, and in this issue of *Generations* on pages 31-33. Please fill out the registration form completely, including your travel information, as we need all the information to finalize plans. You are encouraged to register before February 15, 2013 to receive the early registration rate. There will be an additional charge for registrations received after February 15. Registrations after March 1 will only be accepted on-site at the conference. If you are bringing an attendant, please register together on the same registration form. Each person who is planning on attending daily sessions, the reception, or banquet needs to register. Event entry will be allowed only with properly registered name badges. The meeting registration fee includes attendance at all the

Inside This Issue

- Find great insights on **managing ataxia-related symptoms** on page 17
- An **International Ataxia Awareness Day** event recap begins on page 8
- What is the **Combined Federal Campaign (CFC)**? Find out on page 25
- Annual Membership Meeting **registration information** begins on page 30
- **Chapter and Support Group** news and contact information starts on page 44

Continued on page 3

Please direct correspondence to:

 National Ataxia Foundation
2600 Fernbrook Lane, Suite 119
Minneapolis, MN 55447-4752

Phone: (763) 553-0020

FAX: (763) 553-0167

Internet: www.ataxia.org

E-mail: naf@ataxia.org

Generations Staff:

Julie Braun *Financial Director*

Sue Hagen *Patient Services Director*

Mike Parent *Executive Director*

Lori Shogren..... *Special Projects Coordinator*

Design, Production and Printing *Leader Printing*

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

Copyright 2012 by the National Ataxia Foundation, Inc. All rights reserved.

We ask that other publications contact us for permission to reprint any article from *Generations*.

Disclaimer

The National Ataxia Foundation does not endorse products, therapies, services, or manufacturers. Those that are mentioned in **Generations** are included only for your information. The NAF assumes no liability whatsoever for the use or contents of any product or service mentioned in the newsletter.

Table of Contents

Annual Membership Meeting (AMM)

AMM Information	1
Travel Grant Application Information	3
Exhibitor Space Available	7
AMM Meeting Agenda	27-29
Silent Auction Has New Time	29
AMM Volunteer Opportunities	29
AMM Registration Instructions	30
I Am The Strength Behind Ataxia Award	21
2013 AMM Registration Form	31-33
AMM Overview	34
Ataxia Researchers Welcome at AMM	35
AMM Recordings Order Form	36
NAF's AMM – Making an Impact Throughout the Year and Beyond	37
NAF's Travel Grant Program Needs Your Support	38

Research

Research Opportunity for the SCA's	41-42
Recruitment Notice for Research on Movement Disorders – UMass Amherst	43
Patients with Ataxia Needed for Immunologic Studies	43

Articles

Recognitions of IAAD	8
Managing Ataxia-Related Symptoms	17
USA Network Announces 2012 'Characters Unite' Award Winner	24
What Is the Combined Federal Campaign?	25
From the Desk of the Executive Director	39
Give Yourself a Pat on the Back	40
Tissue Donation	42
Raise Awareness in India	43
Neurological and Specialty Clinics	43
Remembering NAF in Your Will	54

Membership Topics

NAF Merchandise	22-23
Chapter and Support Group News	44
NAF Directory of Chapters, Support Groups and Ambassadors	48
Calendar of Events	53
Memorials and In Your Honor	55

Personal Stories & Poems

Living with Ataxia	41
--------------------------	----

The deadline for the Spring issue of Generations (mailed in late April) is March 8, 2013

2013 Annual Membership Meeting Continued from page 1

sessions, light appetizers at the Welcome Reception and a delicious plated meal at the Banquet.

Member Registration Discount

Being a member of the National Ataxia Foundation has its benefits – one benefit is paying a lower registration fee for the Annual Membership Meeting. If you are not currently a member of the Foundation or if your membership renewal is coming soon or if you are uncertain of your membership status, please consider this a great opportunity to call the office at (763) 553-0020 or go online at www.ataxia.org to become a member or renew your membership. This will prevent unnecessary extra fees or errors in your membership status when you register for the 2013 Annual Membership Meeting. Thank you for taking the time to renew or become a member of the National Ataxia Foundation.

Travel Grant Program

Because of the generosity of several donors, the National Ataxia Foundation is able to offer Travel Grants to help with a portion of the travel costs associated with attending the meeting. Adults or children with ataxia are eligible to apply for a travel grant. Individuals interested in the program are required to submit a Travel Grant application. Adults or children with ataxia are eligible to apply for a travel grant. Applications will be accepted until January 26, 2013. Travel Grant applicants will be notified of the status of their application after the application deadline and after all applications have been reviewed. Visit the NAF website, www.ataxia.org, to download the application. If you would like an application sent to you in the mail, contact Lori Shogren at (763) 553-0020 to request one.

About Detroit

Detroit is the largest city in the state of Michigan, and the seat of Wayne County. Known as the world's traditional automotive

center, "Detroit" is a metonym for the American automobile industry and an important source of popular music legacies celebrated by the city's two familiar nicknames, the Motor City and Motown.

Downtown Detroit has seen an increased role as an entertainment hub in the 21st century with the opening of three casino resort hotels, new stadiums, and a revitalized riverfront. The city's Greektown and three downtown casino resort hotels serve as part of an entertainment hub. Many of the area's prominent museums are located in the historic cultural center neighborhood around Wayne State University and the College for Creative Studies. These museums include the Detroit Institute of Arts, the Detroit Historical Museum, Charles H. Wright Museum of African American History, the Detroit Science Center, as well as the main branch of the Detroit Public Library. Other cultural highlights include Motown Historical Museum, the Pewabic Pottery studio and school, the Tuskegee Airmen Museum, Fort Wayne, the Dossin Great Lakes Museum, the Museum of Contemporary Art Detroit (MOCAD), the Contemporary Art Institute of Detroit (CAID), and the Belle Isle Conservatory. Important history of America and the Detroit area are exhibited at The Henry Ford, the United States' largest indoor-outdoor museum complex. The best and fastest way to discover downtown Detroit is to travel on The People Mover. The People Mover schedule and route can be found on their website, www.thepeoplemover.com/WE-LL-TAKE-YOU-THERE!.id.2.htm.

Weather in Detroit

Typically the weather in March in Detroit is characterized by the transition from winter to spring. There are fewer days in the month that see freezing temperatures of 32 degrees or lower. In fact, the average temperature range is 28.5 to 45.2 degrees. That's not to say there are no

*2013 Annual Membership Meeting
Continued from page 3*

exceptions. In fact, Detroit has seen both highs of 81 degrees and lows of -4 in the month.

Detroit Metro Convention & Visitors Bureau Website

For more information about Detroit, visit www.visitdetroit.com.

About the Detroit Marriott & GM Renaissance Center

The Detroit Marriot Hotel is the official conference hotel of the 2013 NAF Annual Membership Meeting. The Detroit Marriott is located 21 miles from the Detroit-Wayne County Airport (DTW) on the Detroit Riverwalk at the Renaissance Center, 400 Renaissance Drive, Detroit, MI 48243. The Marriott boasts stunning views of the Detroit River and Canada.



The Detroit Marriott Hotel is the official conference hotel of the 2013 Annual Membership Meeting.

Internet at the Detroit Marriott

NAF AMM attendees staying at the Detroit Marriott will enjoy a 50% discount off their guest room internet charges. The current regular price for internet per day is \$12.95. When connecting to the internet the full price will be listed on the website. Your discounted price will be reflected on your guestroom billing statement.

Parking at the Detroit Marriott

Self-parking and valet parking are available. The Detroit Marriott has extended a 40% discount in the Miller & Beaubien parking garages to NAF conference attendees for hourly and overnight parking. NAF does not have a group rate for valet parking. There is a height restriction into the parking ramps of 6' 11" at the Miller Garage, 8' at the Beaubien Garage, and 7' 11" at the Port Atwater Garage. A map of the parking garage options is posted on NAF's website.

Service Dog Information

The service dog relief area in the Detroit Marriott is located on the Lobby Level, outside on the terrace between the lobby and the Volt lounge. Please visit the Detroit Marriott website for more information: www.marriott.com/hotels/travel/dtwdt-detroit-marriott-at-the-renaissance-center.

Accessibility at the Detroit Marriott

The Marriott is located in the GM Renaissance Center. The Renaissance Center is a large facility. Please take some time to familiarize yourself with the facility and the accessible routes to the meeting room levels, food court, and second level. In order to successfully navigate these routes, it is important to understand the location of the elevators that provide transportation between levels. Due to its size, GM Renaissance Center is a complex building to navigate, especially for visitors to the building. The base of the building has three public levels (2, 1, and A in descending order). A series of overhead way-finding signs are located throughout the common area of the building to assist individuals in finding their destination. Each sign contains general way-finding information and specific barrier free information. On certain signs, the information applies to both general and barrier free requirements. On other signs, specific barrier free information is listed separately either in orange text or with a barrier free ►►

symbol. Some of the key barrier free routes are as follows:

Barrier Free Access to Level 2

Level 2 contains several destinations including access to the Office Towers 100-400, Riverfront 4 Theatres, Renaissance Conference Center, People Mover, Millender Center, and Courtyard by Marriott Detroit Downtown. In order to access locations in the south half of the building on Level 2 (the Detroit River half), the P9 elevator is the access point from Levels 1 and A. The P9 elevator is located in the GM Wintergarden in the far southeast corner at each level. Signs are in place to assist in identifying this elevator.

In order to access locations in the north half of the building on Level 2 (the Jefferson Avenue half), there are two different sets of elevators to note. From Level 1 coming up to Level 2, the Tower 200 Shuttle Elevators – noted as elevators #14 and #15 are the correct elevators to use and are marked with signs.

From Level A coming up to Level 2 in the north half, it is necessary to take two sets of elevators. From Level A to Level 1, the Tower 200 #4 elevator is required. Once on Level 1, it is necessary to transfer to the Tower 200 Shuttle Elevators to travel to Level 2 (described in the paragraph above).

Barrier Free Access to Level 1

Level 1 contains several destinations including access to River East Center (Towers 500-600), Jefferson Avenue, Beaubien Place (covered walkway to parking structure), most of the Ren Cen shops, and the Detroit Marriott at the Renaissance Center. In order to travel to or from Level 1, the same elevators are available as described above in “Barrier Free Access to Level 2.”

Barrier free access to the Detroit Marriott at the Renaissance Center is available directly from the common area into the back entrance of the hotel motor lobby. A push button operator is located at this access point.

Barrier Free Access to Level A

Level A contains several destinations including access to Atwater Street, GM Wintergarden, Food Court, and several other retail locations. In order to travel to or from Level A, the same elevators are available as described above in “Barrier Free Access to Level 2.”

There is a free one-hour tour available of the Renaissance Center offered Monday through Friday at noon and 2 p.m. For information on touring, shops, and dining in the Renaissance Center visit www.gmrencen.com/home.axis.

Hotel Reservations

Guest room reservations are available for a special group rate of \$139 per night plus tax. Please be sure to make your reservations early in order to secure the special group rate. To book your stay online go to https://resweb.passkey.com/Resweb.do?mode=welcome_ei_new&eventID=9525602 or call 1-877-901-6632 or (313) 568-8300 and request the National Ataxia Foundation group rate.

ADA Hotel Rooms and Equipment

ADA rooms are available on a first-come, first-serve basis. To inquire about the availability of an ADA room at the Detroit Marriott Hotel please contact the National Ataxia Foundation at (763) 553-0020 or naf@ataxia.org. ADA rooms cannot be reserved through the hotel.

If you need ADA equipment you must bring it with you or make arrangements to rent equipment locally. NAF is unable to provide ADA equipment however the hotel may have some extra equipment available. The width of the bathroom door in the standard guestrooms is 26 inches. Please reserve an ADA room if you require a wider bathroom door or accessible equipment.

Transportation and Getting There

Please use the following information as you plan your transportation needs to Detroit and to

2013 Annual Membership Meeting
Continued from page 5

the hotel.

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

Also visit the website of the Detroit-Wayne County International Airport at www.metroairport.com. Because larger scooters and electric wheelchairs will not meet you at your gateway upon arrival at the Detroit-Wayne County International Airport, passengers traveling with larger scooters and electric wheelchairs should indicate to their airline that they will need wheelchair assistance at the gate upon your arrival. Wheelchair assistance will then meet you at your gate and transport you to oversized luggage in the baggage claim area to claim your scooter or electric wheelchair.

Passengers arriving on Delta may have a long walk to baggage claim. Please request wheelchair assistance if you are arriving on Delta and have trouble walking a long distance. Passengers requiring any in-flight assistance should contact their airline before traveling. Airlines will generally work with passengers to try to meet their particular in-flight needs. We look forward to having you attend the 2013 Annual Membership Meeting and wish you Happy Flying!

Detroit-Wayne County Airport Ground Transportation

The Detroit Marriott does not provide transportation to and from the airport. All ground transportation services including on- and off-airport parking lot shuttles, taxis, luxury sedans, hotel and rental car shuttles, in addition to trans-

portation between terminals are located in the Ground Transportation Centers at the McNamara Terminal and North Terminal. Metro Cars is the only ground transportation company with on-site staff to provide ground transportation from the Detroit-Wayne County Airport. However, all transportation companies are permitted to drop passengers off at the Detroit-Wayne County Airport.

Metro Cars Sedan Service – To arrange for a wheelchair accessible vehicle, please call 1-800-456-1701 or visit www.metrocars.com. Round trip reservations are recommended. Estimated car service fare to the Detroit Marriott is \$56.

Metro Cars Taxicab Service – To arrange for a wheelchair accessible vehicle, please call 1-800-456-1701. Round trip reservations are recommended. Estimated fare to the Detroit Marriott is \$50.

Transportation between terminals – The terminal-to-terminal shuttle stops at the:

- North Terminal Ground Transportation Center
- LC Smith Building Lower Level (Outer Curb)
- McNamara Terminal Westin Hotel (Departures level)
- McNamara Terminal Ground Transportation Center

For a wheelchair accessible terminal shuttle, please call 1-800-377-1032.

Public Transportation – The SMART bus stop is located closer to the terminals, eliminating the need for a terminal shuttle for riders. SMART buses now stop on the outer roadway (lower level) near the Ground Transportation offices at the North Terminal. Most schedules run during heavy commuter times. For a SMART bus schedule call 1-866-962-5515 or visit www.smartbus.org.

Detroit Area Services and Resources

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

Wheelchair Van Rental

American Access Mobility Rental, LLC

1-855-260-4384, (810) 503-4450 or www.wheelersvanrentals.com/Detroit-Michigan

Mobility Works

1-877-275-4915 or www.mobilityworks.com/Detroit.php

Accessible Equipment, Wheelchair, and Scooter Rentals

Binsons Home Health Care Service and Repair Center

1-888-246-7667, (586) 755-2300 or <https://binsons.com/in-store-services.html>

Medical Town LLC

1-877-701-6765, (480) 659-6765 or <https://medicalltowne.com/rentals/>

Volusia Medical Supply

1-866-956-2025, (386) 756-2025 or www.volusiamedicalsupply.com

Scootaround

1-888-441-7575 or www.scootaround.com

Border Crossing

www.crossingmadeeasy.com

Personal Care Attendants (PCA)

If you need a personal care attendant, please make arrangements prior to attending the meeting to have someone accompany you or have a PCA hired before you arrive in Detroit. The following may be used as a helpful guide.

HomeCare Network of Michigan

(248) 254-3711 or www.hcnmi.com

Please note that NAF is unable to provide attendant care services. Due to liabilities and health concerns, NAF staff or volunteers and hotel employees are not able to provide PCA services.

Pharmacy

CVS Pharmacy

GM Renaissance Center Level 2 Tower 200
(313) 567-3523 or

<http://gmrencen.com/shop/cvspharmacy.axis> ❖

Exhibitor Space Available

If you are a company or organization that provides products or services that would benefit a person with ataxia, you are encouraged to become an exhibitor at the 2013 Annual Membership Meeting that will take place in Detroit, March 15-17, 2013. Persons with ataxia, family members, friends and caregivers will be at this meeting. We anticipate over 600 people will attend. They are very interested in learning about services and products that can enhance daily living or are valuable to a person with mobility, speech, or swallowing difficulties or gait imbalance.

If you are affected by ataxia and know of a company or organization who has provided you with an excellent product or service, please invite them to consider being an exhibitor at the membership meeting.

If you are an ataxia researcher with an IRB-approved research study, you may qualify to receive complimentary exhibit space. If you are unable to attend the meeting, your recruitment fliers can be available to meeting attendees. Please contact Sue Hagen for more information at susan@ataxia.org.

Exhibitor space is very reasonable with excellent visibility to the meeting attendees. Information is available on the NAF website, www.ataxia.org, by e-mailing naf@ataxia.org, or by calling (763) 553-0020.

iSearchiGive.com

iSearchiGive.com is a search engine powered by Yahoo! Search and iGive.com, the internet's first online shopping mall where a portion of each purchase is donated to a charity of your choice. Sign up today and indicate that the National Ataxia Foundation is your favorite cause. It is free with no hidden fees and provides support for the important work of the Foundation.

Recognitions of International Ataxia Awareness Day

– September 25, 2012 –

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

There is a great deal to be proud of with the growth of this initiative. In addition to “spreading the word” about ataxia and showcasing ataxia awareness apparel, these events create awareness through print and electronic media, radio and television interviews, and further support from government officials. IAAD events have brought the meaning of the word “ataxia” across the country and beyond. Tens of thousands are now better informed about ataxia. 2012 IAAD activities raised more than \$220,000 to help support the important work of the National Ataxia Foundation.

Thank you to all who have organized and participated in an IAAD activity. Through International Ataxia Awareness Day, we honor those who are affected by ataxia, those who we have lost, and their family, friends and caregivers. IAAD news articles can be found on NAF’s website under “News.” More pictures and video from the Walk n’ Roll events can be found on the NAF website on the Walk n’ Roll page under the “Events” section.

Events

Virtual Walk n’ Roll

Individuals and groups participated in the 3rd Annual Virtual Walk n’ Roll for ataxia to raise awareness and support in their local areas. This event allows anyone to share their stories, create teams, and stay active. This year’s Virtual Walk n’

Roll raised over \$5,000 thanks to teams and individuals such as the Seattle Ataxia Support Group, Unstoppable Grandma, and Team Rita.

New Hampshire Support Group

In September we promoted IAAD in 2011 and again in 2012, spreading the word by posting flyers, distributing bookmarks and sponsoring minute messages in various churches.



The Denver Run, Walk n’ Roll raised over \$40,000.

Denver Run, Walk n’ Roll

Submitted by Charlotte DePew

Three-hundred people participated in Denver’s Ataxia Support Group’s 2nd Annual Run, Walk n’ Roll (RWnR) on September 9. It was a typical Colorado day; a sunny and crisp blue morning, perfect for a stroll or run through the beautiful Denver City Park. Our initial fundraising goal was \$25,000. That was the amount we raised in 2011. Then in early August, 2012 we increased our goal to \$32,000. To date, donations are nearly \$41,000! We had not imagined such success. It was accomplished through ambitious ASG members, families and generous businesses often associated or somehow ►►

connected with an ataxian or their family and friends.

We had an enthusiastic and experienced DJ/MC with a sound system who volunteered his equipment and time. His music from set-up to clean-up provided a festive ambiance. After a five-minute warm-up session before running or walking, participants selected their desired distance up to about 5K. Refreshments of bananas, bagels, water and donated Jenny Craig snacks were available after the event as well as booths to visit which included two service-dog organizations, a NAF information table, a gym for the disabled, MedVed's MV1 vehicle (adapted for people who use motorized chairs), and more. The most popular attraction for kids and young-at-heart was a face painter who had her son help with face painting due to the high demand. We also had a drawing of about 20 donated items from area merchants and two baskets assembled by committee members.

The guest speaker was Dr. Abigail Collins, Assistant Professor of Pediatrics and Neurology at the School of Medicine, University of Colorado, and The Children's Hospital, Aurora, CO. This past July, her efforts to open an adult ataxia clinic at the "U" came to fruition, and we hope it will develop into an ataxia center.

We also increased ataxia awareness activities with these events. Nate Redman (SCA7) and his father had a live interview with a Channel 9 morning news show. An interview with Shawna Hysong (oculomotor apraxia type-2) was printed in the Laramie, WY daily newspaper. International Ataxia Awareness Day was proclaimed by the Denver and Longmont, CO mayors.

We thank our membership and community for their support and enthusiasm. Above all, we owe our tremendous RWnR's success to the dedicated and resourceful RWnR committee members. The anticipated date for our 2013 event is September 8, 2013 at 8 a.m. We plan to increase promoting the employer-matching donations concept.



The Auburn Walk n' Roll raised over \$4,500.

Auburn Walk n' Roll

Submitted by Dana & John Mauro

The 5th Annual Auburn Walk n' Roll, hosted by the Ride for John, was held on Sunday, September 16. The goals this year were fundraising and awareness. To date, funds raised total \$4,500. Additional corporate donations are still outstanding.

Other successes in raising awareness this year include: 1) John Mauro and Denise Kapulka partnered with Senator Michael Moore and Representative Paul Frost to pass a resolution recognizing September 25 as International Ataxia Awareness Day in the state of Massachusetts. 2) Local radio station Kiss108 made a Twitter post about ataxia that reached 74,000 people. 3) John Mauro and Lori Shogren appeared on the local Jordan Levy radio show to speak about ataxia. 4) John Mauro, Denise Kapulka and Senator Michael Moore appeared on Hank Stoltz's local TV show to promote the Walk n' Roll and raise ataxia awareness. 5) The company John Mauro works for, which employs 2,800 people, sent out a mass e-mail asking folks to take five minutes to read about ataxia. 6) John and Denise Kapulka appeared on local channel 3 to promote the Walk n' Roll and raise ataxia awareness.

Plans are already underway to raise even greater awareness next year.

*International Ataxia Awareness Day
Continued from page 9*



The Atlanta Walk n' Roll raised \$10,000.

Atlanta Walk n' Roll

Submitted by Greg Rooks

In celebration of International Ataxia Awareness Day, the Greater Atlanta Ataxia Support Group held its second annual Atlanta Walk n' Roll for Ataxia fundraiser. The Walk n' Roll took place on September 22 at Shorty Howell Park in Duluth, GA (suburb of Atlanta). Shorty Howell Park has a beautiful paved trail of 1.25 miles through the park. The smiles on everyone's faces were as bright as the sun in the sky on that day.

Our fundraising goal was set at \$7,000. We are proud to announce that we exceeded our expectations. More than 90 people showed up to participate and raised over \$10,000. Each participant received a commemorative event

T-shirt. Several large teams participated this year including Team Mooney, Team Olivia, Team Sharon, Team Jon, and Team California Izzy. Team Olivia was the top fundraising team at over \$3,200. We say "Thank You!" to everyone who participated. Individuals and teams did their own fundraising by asking friends, family, neighbors, and co-workers for donations. All did a fantastic job and made this event a huge success.

Refreshments of water, bananas, chips, crackers, and other snacks were provided for everyone's enjoyment. We thank Marcie Anthonie for obtaining the donation of water from the Coca-Cola Company. Thanks to Will Morris for obtaining our sound system from Atlanta Soundworks. Other sponsors included the law firms of Monge & Associates and Galloway & Lyndall, LLP. To further awareness an information table contained brochures and pamphlets about the ataxias, NAF, and our Atlanta support group.

Fun for all ages, but especially the kids, was the face painting and arts and crafts station provided by Camp Dream, a local nonprofit organization providing recreational opportunities for children with serious illness or disability. Camp Dream also provided us with several volunteers in other areas. We really appreciate their involvement with this event.

See how much fun we had by checking out the video of the Walk n' Roll on NAF's YouTube Channel (search for "Atlanta" and "ataxia"). ►►

GoodSearch

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

GoodSearch.com donates 50 percent of its revenue to the charities designated by its users. Simply go to the site and follow the easy steps to make NAF your charity of choice. Then use GoodSearch as you would any other search engine. You'll make a difference in the lives of those with ataxia!



The Detroit Walk n' Roll event was the scene of beautiful fall weather.



The Central New York Ataxia Support Group celebrated IAAD by eating this delicious cake.

Central New York Luncheon

Submitted by Mary Jane Damiano

The Central New York Ataxia Support Group met on Saturday, September 22, to celebrate Ataxia Awareness Day. We had our annual luncheon with everybody bringing a dish or two to share. We ended our meeting with an IAAD cake. This meeting concluded the 2012 meeting schedule. Our next meeting will be in April, 2013 with the date to be announced.



Minnesota's Walk, Stroll n' Roll raised nearly \$60,000.

Minnesota Walk, Stroll n' Roll

Submitted by William Sweeney

Unlike the chilly, blustery, damp weather which greeted participants at the first two Minnesota walk events, clear skies and a temperature in the low 70's welcomed more than 400 participants to Wolfe Park for the 3rd Annual Minnesota Walk, Stroll n' Roll on September 15. Participants from the Twin Cities, Duluth,

St. Cloud, and Rochester were joined by families from Iowa and Wisconsin in a 1.2-mile walk around Wolfe Park in the Minneapolis suburb of St. Louis Park. But it was not the walk which was the focus of the morning, but the camaraderie among those directly affected by ataxia with their friends, neighbors and co-workers during the social hours before the walk and after the day's program.

Dr. Larry Schut, NAF board member and former NAF medical director, spoke to the crowd in the park amphitheater after the walk. He discussed the founding of NAF by his father and uncle in 1957, and of the important work the Foundation does today.

Mark Allison, chair of the Bob Allison Ataxia Research Center at the University of Minnesota, relayed his family's story of ataxia, and how his father Bob, the 1959 American League Rookie of the Year, first noticed balance and coordination issues while playing in a Minnesota Twin old-timers game in the mid 1980's.

The program concluded with a drawing for several donated gift baskets, gift certificates, and the grand prize of a 40" flat screen television.

We cannot fully express our thanks to the sponsoring businesses and individuals who contributed refreshments, prizes for the drawing, and such generous financial support to NAF. Special thanks to those on the planning committee and the volunteers who contributed their valuable time to make this the most successful Minnesota Walk event to date. We far exceeded the original \$45,000 goal – raising more than \$58,000 for NAF – and have already begun to raise our sights even higher for 2013.

Seek A Miracle Ataxia Group (SAMAG) Ataxia Seminar

Submitted by Chandu George

Seek a Miracle Ataxia Group (SAMAG) celebrated International Ataxia Awareness Day on September 25. It was observed by organizing an

International Ataxia Awareness Day
Continued from page 11

ataxia seminar which was co-hosted in association with Osmania General Hospital (Hyderabad, Andhra Pradesh, India).



Chandu George speaks at the Seek A Miracle Ataxia Group seminar in India.

The event began with a welcome note by Satish, who gave an explanation of IAAD, its significance and why it is observed, and on SAMAG's activities. Chandu gave his presentation titled "Ataxia Centers," during which gave a brief background on the situation and plight of ataxians in India, such as the difficulties in coping with ataxia as well as what shall be done. To help ataxians in any possible way, he presented a proposal to establish an "Ataxia Center" to cater to the needs of the ataxia population in India. Later, Chandu made a request for the medical and pharmacy community present to come forward and help the ataxia cause by taking up ataxia research activities or programs and seminars which directly benefit the ataxia population in India.

A presentation on ataxia – its symptoms, causes, types, diagnosis, research work as well as incidence of ataxia around Europe, the U.S., Asia and the world was given by Dr. Shwetha, Neurologist, Osmania General Hospital. Dr. Radha Krishna, Professor and Head of the Neurology Department and Chief Neurologist, Osmania General Hospital, spoke about new studies being undertaken for treating ataxia. He discussed ataxia in India and highlighted the patterns of

ataxia, such as SCA as a common form of inherited ataxia in India and particularly in north India, whereas most cases of diagnosed ataxias reported in south India are found to be Friedreich's ataxia. Dr. Krishna's presentation was followed by a question-and-answer session that included questions related to ataxia, available treatments, available medicines, and drugs that are in the clinical trial phase.

The event concluded with a "Vote of Thanks" by George Sr., who thanked by felicitating SAMAG mementos and appreciation letters to Dr. Krishna; Dr. Lakshmi; Dr. Shwetha; Dr. Vinod; Dr. A.K. Meena, Chief Neurologist-Professor of Neurology, NIIMS Hospitals, Hyderabad; and the entire faculty of the Neurology Department at Osmania General Hospital as well as Dr. Akshaya Srikanth, all of whom were instrumental in organizing this seminar at Osmania General Hospital. We also thanked our other supporting partners, including the National Ataxia Foundation, BabelFamily, Catholic Hyderabad Arch Diocese, Rare Diseases India, Bin Adam Foundation for FA in Pakistan as well as all our volunteers who worked tirelessly to make this event a success. This was followed by refreshments which concluded the event.



The Orange County and Los Angeles Walk n' Roll raised over \$45,000.

Orange County/Los Angeles Walk n' Roll

Submitted by Daniel Navar

The 4th Annual Orange County and Los Angeles Walk n' Roll was a success. Teams and participants raised over \$10,500 on the online ►►

fundraising page, before the walk. Team DeMint, Team Serge, Sophie's Team, Team Ching, and Team Chad were some of the teams, sponsors and generous donors coming together for a great cause. The total amount raised by the event was over \$45,000. The estimated number of participants on September 22 was over 300 walkers and rollers. Our goal is to continue growing next year. Please join us!



The Delaware/Pennsylvania Walk, Roll n' Run event raised over \$20,000.

Delaware/Pennsylvania Walk, Roll n' Run *Submitted by Chris Rakshys and Joe DeCrescenzo*

Our event was held at Glasgow Park in Newark, DE on Saturday, September 29. Our original goal was \$5,000. That amount was easily reached in the summer months, however, so the planning committee increased the goal to \$20,000. This new amount was ultimately reached and surpassed: thanks to the combined contributions of late registrations, donations and raffle ticket sales.

The morning of the event was very nice for September, with some sun and little winds. It was a perfect T-shirt day (long-sleeve or short-sleeve – your call)! Approximately 150 participants attended and had the choice of completing a half-mile path or a 2.7-mile course. We started out with some stretching exercises, led by a trainer from one of our sponsor companies. Afterwards, we had exhibitors and a raffle for donated items from local restaurants and companies.

Mt. Airy Bikes of Mt. Airy, MD, brought along a few tester bikes for the participants to try out. The most popular style was the recumbent cycle, which tied in very nicely with the talk given by our featured speaker. Kyle Bryant, the inspirational recumbent cyclist who has Friedreich's ataxia (FA), shared with us some of his personal experiences as an ataxian with FA. Additionally, he was very impressed with the event. He cheered us on to no end! A woman representing Canine Partners for Life, a dog service program located in Cochranville, PA, was also available to answer questions of the participants.

Many, many thanks to our planning committee for the hard work, efforts and contributions: T-shirt graphics, food, tables, signs, exhibitor and registrant information, event photos, decorations, etc. And many thanks to all who supported our fundraising effort.

Northern California Walk n' Roll and Exercise & Mobility Matters Faire

Submitted by Joanne Loveland

Our celebration of International Ataxia Awareness Day was attended by 75 supporters, family and friends. Activities began with three "Olympic Games" – a bean bag toss for points, a coin toss for points, and a balloon relay race. Raffle tickets were given to winning teams. Team spirit and comradery were shared by all. The games were followed by our Annual Walk n' Roll. Everyone gathered for our traditional "stretching exercises." With a cheer we all took off on our half-mile "marathon." At the finale we gathered for the annual group picture. Pulled pork sandwiches and a full lunch were then ready for the hungry crowd.

The afternoon was an experience, with three movement professionals present. Dr. Tom Clouse met with a group where he showed individuals how we can move more if we trust our feet and position our bodies as we move, bend, sit, walk, and stand. He has SCA14, and

Continued on page 14

International Ataxia Awareness Day
Continued from page 13

is living proof that you can re-learn to walk with lots of exercise and re-training your body. Robert Schick DC, is one of only three chiropractors in the San Francisco Bay Area trained to do Quantum Neurology. He showed a group how he can stimulate the CNS by stimulating



The Northern California Ataxia Support Group poses for a group photo after their Walk n' Roll event.

the vestibular system, our senses and our cranial nerves. His patients include those with Parkinson's, ataxia, strokes and patients who have brain injuries from an accident. Several members of NCASG see him regularly and see improvement with mobility. Carol Fisher showed her groups how to relax with yoga stretches in the wheel-



Michael Carter hoists himself up during the Bowling Green Pull-Up Competition.

chair or scooter. Carol teaches yoga classes weekly to Parkinson clients. Stiffness and rigidity are something we all deal with. Her classes relate directly to learning to cope with stiffness, stress and the other symptoms of a movement disorder.

We had a table of NAF items, a silent auction table and raffle items. Our closing 30 minutes was announcing the winners. We also had our drawing for the person who won the \$500 Apple gift card. Dr. Tom Clouse picked the lucky winner.

Bowling Green Pull-Up Competition

Submitted by
Michael Carter

My name is Michael Carter. I am a fitness instructor and have worked in a gym called Bowling Green Parks and Recreation

for 12 years. I was the event host for the 2012 Bowling Green Parks and Recreation IAAD Pull-Up Competition. We were able to raise over \$500 during our event. We had lots of fun while we spread ataxia awareness. Yes, there were lots of pull-ups done, there was a competition, and there was a winner, but like I said during the event, "We're here to kick ataxia in the butt!" So the focus was on fun, not just competition, while promoting fitness.

I have ataxia and I have incorporated fitness in my life for over 15 years. Through my years of practical and professional experience, I see fitness as the only viable treatment for ataxia. Feel free to contact me regarding fitness. I would like to share my knowledge with you!

Special thanks to Bowling Green Parks and Recreation, MGM Specialties, Complete Nutrition, and McWhorter Chiropractic.

P.S. – During the event I think we formed a small, unofficial support group in Bowling Green, KY. If you are interested in a local ►►

support group, let me know! Michael Carter, cartermw@yahoo.com (I'm also on Facebook).



Bingo for Ataxia raised money and awareness in Maryland.

Bingo for Ataxia

Submitted by Dana Simpson

The Friends of the National Ataxia Foundation in Berlin, MD, held their 2nd Annual Ataxia Awareness Bingo on Saturday, September 29, at the Berlin Fire Hall. We had a great response with approximately 125 people playing bingo. Many volunteers helped with the bingo games and also in the kitchen cooking and serving food.

The local community businesses donated multiple items to be used for our Chinese Auction. The winners of our 20 games walked away with Vera Bradley handbags and filled Longaberger baskets. The event was a huge success and everyone was very supportive of our efforts to raise money for ataxia research.

Zumba in the Park

Submitted by Jalean Retzlaff

In Park City, KS, the first “Zumba in the Park” was held. There were 30 people who attended the event. \$123 dollars was raised from donations collected at the event. All the T-shirts were sold, which raised another \$180. “Body by Vi” was there. Dave donated his trailer for the Zumba instructor to stand on. Bottled water was donated by the local grocery store Leekers. My church helped with making the cookies and the use of the tables and chairs. I am starting the planning again to have another fundraiser for the NAF.



Georgia Governor Nathan Deal and members of the Greater Atlanta Ataxia Support Group

Proclamations and Resolutions

A Proclamation declaring September 25th as International Ataxia Awareness Day was signed in Georgia by Governor Nathan Deal. This is an annual initiative of the Greater Atlanta Ataxia Support Group. Several support group members attended a signing ceremony on September 19 with Governor Nathan Deal at the state capitol.

IAAD proclamations were also received from the Village of North Syracuse, County of Onondaga, and the City of Syracuse, NY. These proclamations were obtained by the Central New York Ataxia Support Group.



Village of North Syracuse Trustee Fred Ferguson presents an IAAD proclamation to Mary Jane Damiano.

IAAD was also proclaimed by the Denver and Longmont, Colorado mayors. These proclamations were displayed at the Denver Run, Walk n’ Roll event and shown twice on the local Longmont TV news channel.

A resolution was passed declaring September 25 International Ataxia Awareness Day in Massachusetts. This resolution was passed thanks

International Ataxia Awareness Day
Continued from page 15



Longmont, CO mayor Dennis Coombs, Debbie Crystal, and Don and Shirley Stanosheck with the city's IAAD proclamation

to the collaborative efforts of John Mauro, State Senator Michael Moore, and State Representative Paul Frost.

The Delaware/Pennsylvania Support Group again this year requested renewal of the Pennsylvania House Resolution No. 824: "Resolved, that the House of Representatives designate September 25, 2012 as 'Ataxia Awareness Day' in Pennsylvania and urge all citizens to honor and support those individuals with ataxia and their caregivers, in the hope that a cure will soon be found." In 2006, William Lee prompted the initial passing of this resolution.

Media Coverage

The following press releases and articles highlighting IAAD can be found at www.ataxia.org/news/ataxia-news.aspx.

- The Florida Times-Union (*Jacksonville.com*) on October 9: "One of Us: Man remembers day he awoke and his whole world had changed"
- Laramie Boomerange on October 6: "A Diagnosis rarely heard"

- North Jefferson News on September 26: "Mt. Olive woman is local face of ataxia"
- Auburn Daily Voice on September 25: "Auburn Man Helps Pass Ataxia Day In Mass."
- Charter TV 3's Hank Stolz Show on September 25: "John Mauro on what is Ataxia"
- Falmouth Enterprise on September 25: "Grateful for Those Who Help:"
- Midland Daily News on September 21: "Midlander helps spread awareness about ataxia at Detroit Walk and Roll"
- Sun Sailor on September 17: "Walk, Stroll n' Roll for Ataxia September 15 in St. Louis Park"
- Charter TV 3 News on September 14: "Auburn Walk n' Roll"
- Auburn Daily Voice on September 13: "Walk n' Roll Steps Off For Charity Sunday In Auburn"
- WTAG AM 980's Jordan Levy Show on September 8: "What is Ataxia today with Jordan Levy"
- *9News.com* on September 4: "Nate Redman wants people to know why he's in a wheelchair"

Wearing Ataxia Gear to Raise Ataxia Awareness

Submitted by Amanda Wood

I wore an ataxia awareness shirt at my job in a doctor's office to raise awareness for my dad!

The day was great. Many patients asked me what exactly ataxia was and who could be affected by it. I was also asked if it was a difficult diagnosis to be determined.

All in all, I was very impressed with all the feedback that my patients and coworkers gave me and the information I was able to provide to them.



Amanda Wood

Continued on page 21

Managing Ataxia-Related Symptoms

By Michael Wilensky, MD

Dr. Wilensky is a graduate of Tulane Medical School in New Orleans. He completed a Neuromuscular Fellowship at the University of Utah. Dr. Wilensky is currently in private practice in the Greater New Orleans area. He has special interest in the hereditary ataxias and multiple sclerosis. He serves as the Medical Director for the Louisiana Chapter of the National Ataxia Foundation and has been working with ataxia patients for many years. He is also a member of the NAF Medical and Research Advisory Board.

The following was presented at a NAF Annual Membership Meeting and edited for publication in Generations.

This talk is about the treatment of ataxia-related symptoms. Ataxia is a syndrome which causes problems with balance but along with that we frequently have other associated symptoms that cause problems. Sometimes these problems are worse than the actual ataxia.

What are the symptoms that we are concerned about with ataxia? Some of these include fatigue; unsteady gait; spasticity, which is stiffness in the muscles, or muscle cramps; tremors; coordination, problems with holding a glass or getting a fork to your mouth; dizziness; swollen feet; coughing and choking; shortness of breath; and cognitive issues.

What is a symptom versus therapy treatment?

Therapy treatments are the drugs that alter the gene expression or the protein function; they alter the disease progression. We are really interested in developing these drugs because these are, “cures for ataxia.”

Symptom treatments are the treatments that treat individual symptoms in ataxia like fatigue. They do not alter the course of the disease. Symptom treatment is what this article is about.

Fatigue is associated with any neurologic problem such as Parkinson’s, stroke or multiple sclerosis. Ataxia worsens with fatigue. The symptoms are commonly late in the day. Rest is the best treatment however, there are medications that help the fatigue. They are amantadine or Symmetrel and modafinil or Provigil. A lot of the

anti-depressants work on the serotonin systems and the systems that help reduce some of the fatigue and increase your energy. More important than any of this is **exercise**. Exercise helps fatigue and builds stamina. It can be as simple as walking whether it is with a walker or with a cane. Exercise can be taking a couple of cans of beans and raising them above your shoulders and head with your shoulders stretching. Exercise can be stretching your legs out and moving your feet back and forth. It is very important that you mobilize these joints. I am always surprised at the number of patients who I see who come in with frozen shoulders and there is no reason for that. They don’t have any weakness, they don’t have any problems with the arms but they just don’t use their arms and stretch.

Unsteady gait is familiar to those of you who are walking with canes or walkers. Take small little steps and look at your feet when you walk. Why is that? Because a lot of patients with ataxia have associated spinal cord or peripheral nerve involvement so they can’t feel where their feet are. This creates problems when you get up in the middle of the night and it’s dark and you can’t see where you are going; you tend to trip or fall and bump into things more. Why? Because you can’t tell where your feet are. So look at your feet, but also look where you are going.

Stabilize your walking with a cane or walker. I am surprised at the number of patients who are

Continued on page 18

Managing Ataxia-Related Symptoms *Continued from page 17*

off balance to the point that they are holding onto the walls or their spouses, but they would benefit from a walker or cane. **Pride is not worth a fractured hip.** Wear flat-heeled, wide shoes. I am baffled by some women who are off-balance and are walking in high heels. It is not worth a sprained ankle.

Plan your trips on smooth ground. Avoid rough ground for the sake of taking a short cut. You may fall, which is not going to get you there any quicker. Stay on the sidewalks, walk where it is easy. The smooth ground is much easier to walk on when you are off balance. Don't try to walk over rocks or uneven grass. At home hold onto walls or furniture. Design rooms with walking in mind. There are rehab counselors who can come in and help you set up your house. If you haven't seen a rehab counselor or you don't have a home health service, ask your doctor to get you a referral because those are very important factors that can make your life a lot easier. Try to prevent fatigue. When you're tired you are going to have more difficulty walking.

Muscle Cramps. Exercise the muscles, do range of motion stretching, stretch your arms and move your legs and feet around and stretch them. You don't want to develop deep vein thrombosis or clots in your legs from sitting in one position and not moving around. Avoid sustained positions. Although computers are wonderful; they keep your mind focused, sitting at them for extended periods of time is not good. You need to move around. There are muscle relaxers and anti-spasticity drugs that you can speak to your doctor about. Foods with potassium are important because potassium helps with muscles cramps.

Tremor is ataxia of the upper extremity that makes it difficult to go from point A to point B. When you are trying to get the peas on the fork or spoon to your mouth from the plate, stabilize your elbow or your shoulder by keeping your

elbow on the table. If your elbow is fixed on the table you have less distance to travel and you are much more likely to be able to get from point A to point B and be more stable. Make small movements. There are special gadgets for eating utensils that can help you. With tremors, fatigue medicines help when you are tired. If you are tired and it is late in the day, your tremors and your ataxia are definitely going to be worse.

Cognitive function includes memory problems, concentration and focus. Many cognitive problems worsen with depression. If you are depressed, talk to your doctor. There are medications, such as anti-depressants and anti-fatigue medicines available. Don't be ashamed. If it helps you function, it's a good idea but we will talk about some of the side effects. Treatments that are important in organizational ways include little palm pilots, little computers, little notebooks. Don't be embarrassed if you have to write things down. If you are tired at the end of the day, it's hard to concentrate, to remember and to think. Alzheimer's medications sometimes can help cognitive problems. Even if you don't have Alzheimer's but you're having some cognitive problems, speak with your neurologist. We need to address the issue of side effects with medications. If you are having only minor depression or minor fatigue or minor muscle cramps and you can live with it, then you may not want the side effects of the medications. That is an important consideration to discuss with your physician.

Bladder control, which includes urgency or incontinence, can be common symptoms for those with ataxia. Establish a routine pattern and plan ahead so you know where the bathroom is.

Fluid intake is important. A big problem we see, particularly with some of the late-stage ataxia patients, is they end up in the hospital because of dehydration. Why dehydration? Because people are afraid to drink fluids because then they are going to have to go to the bathroom. But, you need a happy medium; it is important not to become dehydrated just to prevent trips to the bathroom. If you are really having trouble ►►

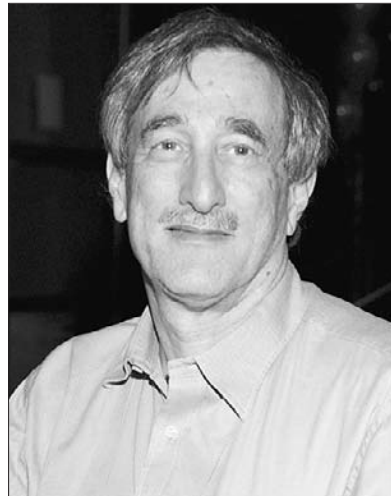
with frequency, it's important to talk to a urologist and take bladder medications. If you are a male with ataxia and you are having bladder frequency, that doesn't mean that it is necessarily due to the ataxia syndrome. All males can get prostate problems which can cause bladder problems. Females, also, can get bladder problems that are not related to ataxia. Make sure you talk to your doctor about your symptoms and have appropriate tests. Sanitation habits are important to avoid infections.

Swollen feet caused by fluid retention can happen in all people. Avoid restrictive clothing and tight socks and tight shoes because they are going to cause fluid problems. Elevate your feet as often as possible. If you have had an injury such as a twisted ankle, you can get fluid accumulation just as easily as anybody else. Just propping your feet up will make the fluid go away. It's a simple thing, you don't need medications. Special stockings are often very helpful. Avoid certain medications that increase fluid. Talk to your doctors and ask, "I am on these medicines. Can any of them be causing my swollen feet?" If all else fails, you may need diuretics or fluid pills to get rid of the excess fluid. Also very important, particularly with Friedreich's patients who are known to have heart enlargement and heart problems, **get a cardiac evaluation**, because swollen feet can be a result of heart problems.

Sensory loss is very important particularly in those who have associated peripheral neuropathy or for Friedreich's patients who often have a loss of feeling. Prevent pressure sores, avoid tight shoes and clothing. Don't wear boots half way up your ankle, wear something comfortable and soft. Avoid pressure on the arm rests or foot rests. Make sure your skin is clean and use creams to keep the skin moist. Don't assume that just

because you don't feel it, it is not a problem because sometimes it is. Look at your feet. You may have stepped on something. On the television drama, "Gray's Anatomy" they had an episode with a diabetic who lost his foot. He could not believe he lost his foot because of an ulcer on his foot that he ignored. Don't do that.

Dizziness can be a problem in patients who don't have ataxia but it is even more of a problem in patients who do have ataxia. Be aware that just because you have ataxia syndromes, that is not necessarily the reason why you are dizzy. Pay attention to the details. Make sure that you don't have neck problems or sinus problems and tell your doctor what the trouble is. Tell him or her when the dizziness started and what kind of trouble you are having. **One of the most common causes of dizziness is medications.** I would venture to say that a large number of patients take medications, not just for ataxia but for blood pressure, for headaches or for all kinds of other things. So be aware that they may cause dizziness. For dizziness avoid sudden movements. If all else fails, talk to your doctor about medications



Dr. Michael Wilensky

that can sometimes help suppress the dizziness.

Shortness of breath is a very serious problem at times. Sometimes it is just fatigue however it can also be an indicator for heart or cardiac disease. How can you help the shortness of breath? By using proper sitting posture and breathing exercises. It is a very simple thing. If you are short of breath all of the time, use this simple exercise that I recommend for all my muscle disease and ataxia patients: just take a deep breath and start counting. See how high you can count. You would be surprised at how **you can improve your breathing function** with just a simple little exercise. Shortness of breath can be caused

Managing Ataxia-Related Symptoms
Continued from page 19

by enlarged heart and irregular heartbeats, Friedreich's patients are all aware of that. If you continue with shortness of breath, don't assume that it is the ataxia and if you are up in age, don't assume it could be ataxia; it could be related to your heart. It could be heart disease, it could be clogged vessels, coronary artery disease. So don't let everybody blame your symptoms on ataxia because there is a possibility it could be related to something else.

Back and neck pain are the most common problems I see in my ataxia patients. Back and head support is important on your wheel chair or any chair when you are sitting. Recliner chairs are great if they give you head and back support. Don't slouch on the sofa with your head all kinked up and wake up two hours later and wonder the next morning why you have this horrible neck pain and the doctor says, "Oh, well, you have ataxia." Avoid awkward positions, maintain foot support, sit with your knees bent and your knees above your waist when you are sitting for long periods of time. For those of you in wheel chairs who can prop up the foot rests, keep your knees up higher. That is important to **take the strain off your back**. Avoid straining the neck by sustained up-gaze. Make sure your computer is at eye level and that your keyboard is comfortable so that you are not holding your arms up. If you don't think it makes a difference, hold your arms up and try that for a minute or so. I guarantee that your trapezius and your neck muscles will start hurting. Then if you are having trouble and it is a persistent problem or if you know that you did something stupid, and we all do, talk to your doctor and sometimes they will prescribe some muscle relaxers and

anti-inflammatories.

Sensitivity to Medication. Medications can cause problems. Ataxia patients are going to be much more sensitive to medications like other patients with central nervous system disease. These patients frequently require lower doses of medications. There is this fallacy in physicians and patients who think that because a medicine is over-the-counter (OTC) that it is safe and it doesn't cause problems. With OTC medicines, sometimes it important to start with half of the recommended dose. Remember, the way that a lot of these medicines got to OTC is by cutting the dose down from the prescription dose and

then it could be OTC. **Drug combinations can be really dangerous**, particularly if you are taking over-the-counter medicines with prescription medications. If you are not sure about the interaction talk to your doctor or pharmacist. Tranquilizers, sleeping pills, cold pills, anti-depressants can all cause confusion, drowsiness, and cognitive problems. So just because you are having trouble focusing, concentrating and remembering things, don't necessarily blame it

on the ataxia. You need to look at the medications that you are taking.

The Good, the Bad and the Ugly. We stole that idea.

The Ugly is severe allergic reactions that can occur to the simplest medications that you take over-the-counter. It can happen to anybody, we don't know who, why, when or where but it happens. So don't take medications with the idea that there are not consequences. **You can have toxic reactions.** You can get very confused and psychotic from the medication that you took over-the-counter. You can get severe gastrointestinal bleeding. When I ask, "Do you take any medicine?" I am amazed at the number of ►

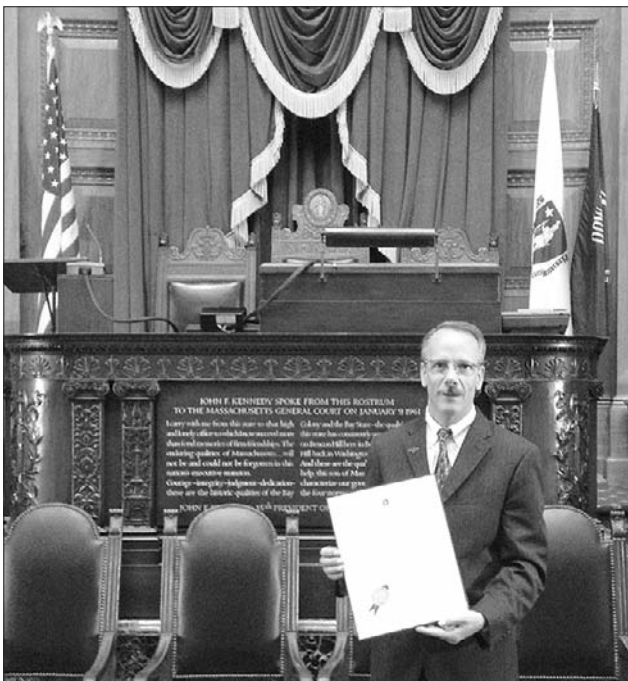
“
**Medications
can cause
problems. Ataxia
patients are going
to be much
more sensitive to
medications...**
”

people who say, “Oh no, all I take is Motrin or Advil.” “How many do you take?” “Oh, eight to 10 a day.” You may get GI bleeding and end up in the hospital with serious complications. Bladders can shut down. A lot of cold pills and anti-histamines can cause problems. If you are sensitive, particularly men with prostate trouble, you can take a cold pill over-the-counter and end up not being able to urinate.

The Bad is that symptom medications do not alter the disease. They have side effects and can interact negatively with other medications. There are all types of interactions and the one that fascinates me is the grapefruit interaction. There are enzymes in the grapefruit that block some of the absorption of the medications. **Blood tests are frequently required** to monitor the medicines that you are taking. Some medicines are toxic to the kidney, the liver or the blood. So be aware that sometimes they help but there may be a downside.

The Good is that there are medications which we have talked about available to treat some symptoms. Medications are specific to the different symptoms so you take a medicine for a particular problem. Medications frequently work rapidly to give relief. Sometimes you can take it for short periods of time. Those medications are taken “as needed” so sometimes you don’t need to take the medicine every day, sometimes you only need to take it once a day, sometimes twice a day, sometimes you can take these medicines twice or three times a day on one day and on a day that you feel great, you don’t need to take it all. That’s the advantage of symptom treatment as opposed to therapies. When you are set up to take a therapy, you need to take that medicine every day. Always discuss any new symptoms you experience with your doctor who can help you find the appropriate symptom treatment. Thank you. ❖

*International Ataxia Awareness Day
Continued from page 16*



John Mauro accepting the Massachusetts Ataxia Awareness Day Resolution ❖

I Am The Strength Behind Ataxia Award

Thank you to all who submitted an application for I Am The Strength Behind Ataxia Award. There were 29 outstanding entries submitted. Congratulations to all who were nominated for this recognition of excellence award.

The award announcement for this year’s I Am The Strength Behind Ataxia Award will be given on March 16, 2013, during the NAF Annual Membership Meeting’s Saturday night banquet. The profile of each awardee will be in the Spring 2013 issue of *Generations* and will also be available on NAF’s web site, www.ataxia.org, following the annual membership meeting.

Congratulations to the awardees and to all the nominees.

BOOKS

— ATAXIA RESOURCES —

Evaluation and Management of Ataxic Disorders for Physicians

by Susan Perlman, M.D.

This resource is intended to inform and guide physicians who may be caring for patients with ataxic symptoms or who have been diagnosed with ataxia. It will provide health care practitioners with a vocabulary to aid in the understanding of what is and is not ataxia, diagnostic protocols for use in defining the types and causes of ataxia and resources for use in counseling and managing the ataxic patient. Consider buying one for your neurologist and other health care providers. Published in 2007. \$5

Healing Wounded Doctor-Patient Relationships

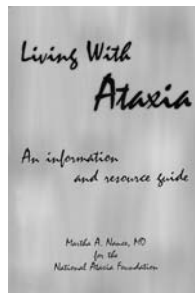
by Linda Hanner with contributions by John J. Witek, M.D. and doctors and patients around the nation

This book is packed with information that anyone who ever goes to a doctor for any reason deserves to know and that every professional who wants to maximize his or her healing power must understand. \$10

Living with Ataxia: An Information and Resource Guide

by Martha Nance, M.D.

This illustrated book provides a compassionate, easy to understand explanation of ataxia with ideas on how to live well with ataxia. It is an excellent tool for building awareness for those who do not know what ataxia is or how it affects a person who has ataxia. This second edition was published in 2003. \$14



Managing Speech and Swallowing Problems: A Guidebook for People with Ataxia

by G.N. Rangamani, Ph.D. with contributions from Douglas E. Fox, M.S.

This 60-page booklet is an excellent resource for those who struggle with speech and/or swallowing problems. It is an easy to understand booklet with straight-forward and realistic suggestions for speech and swallowing management. This second edition was updated in 2006. \$7.50

— FICTION & PERSONAL STORIES —

Ten Years to Live

by Henry J. Schut

The story of the Schut's family struggle with hereditary ataxia and the impact it had on this extended family. It is dedicated to the author's brother, Dr. John W. Schut, who was committed to the cause of finding a cure for ataxia, which claimed his life. \$8.75

There's Nothing Wrong with Asking for a Little Help ... and Other Myths

by Dave Lewis

The story about one man's experiences in living with Friedreich's ataxia. Dave spent the last three years of his life writing his memoir to provide information and inspiration to countless others. Proceeds from the book purchased through NAF will be used to support promising Friedreich's ataxia research. \$15.95

— COOKBOOKS —

Recipes and Recollections by Kathryn Hoefler Smith

Dedicated to the memory of her daughters who had Friedreich's ataxia, Kathryn Hoefler Smith has taken the handwritten cookbook her mother-in-law made for her sons and their families and duplicated it in 2003. It is full of delicious recipes and recollections. Perfect for FRDA research fundraisers. \$10

Cooking for a Cause

by Julie Karjalahti for FRDA research

This 177-page cookbook has kid's recipes, fun craft recipes, along with the usual desserts, breads, beverages and other recipes you would expect from a good cookbook. \$12

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

Merchandise

SHIRTS/MISCELLANEOUS

International Ataxia Awareness Day T-Shirt

Available in youth L, and adult small to XXX-large. \$10

2011 Annual Membership Meeting T-Shirt

Gray, short-sleeved with the "Bringing the Ataxia World Together" logo. Sizes medium to XX-large. **SALE - 3 for \$10 while supplies last!**

SALE!

NAF Shoulder Bag

Blue with white NAF logo. 11x15x2 inches. \$10

NAF Polo Shirts

Mens - Royal blue w/white embroidered NAF logo in medium to XXX-large. Womens - Light blue w/ navy embroidered NAF logo in small to XX-large. \$25

NAF Denim Shirt

Denim with white embroidered NAF logo. \$27.50

"Ataxia is Not a Foreign Cab" T-Shirt

White. New design. Sizes small to XXX-large. \$10

"Ataxia is Not a Foreign Cab" Long-Sleeved T-Shirt

Blue. Sizes small to XXX-large. \$15



"Ataxia is Not a Foreign Cab" Sweatshirt

White. Sizes small to XXX-large.

SALE - \$10 for a limited time only!

SALE!

"Ataxia is Not a Foreign Cab" Refrigerator Magnet

Business card size magnet. \$1

Window Cling or Bumper Sticker

\$1 ea. or 6 for \$5

NAF Ataxia Awareness Band Blue

One size. \$2

NAF Ataxia Awareness Ribbon Magnet

Blue with white lettering/logo. \$4

Reusable Grocery Bag with NAF and Cab Logos

\$5

NAF Lapel Pin

Pin

\$5

VIDEO/CD

Ballads of a Family Man CD

10 songs in memory of Billa Ballard. \$5 of purchase price goes to support the work of the NAF. \$13

"Together There is Understanding" VHS or DVD

Discussion of ataxia. 50 minutes. VHS \$20; DVD \$25

ORDER FORM

Description	Qty.	Size	Each	Total

SUBTOTAL: _____

Shipping within U.S.: Add \$5.00

Shipping outside U.S.: Add \$15.00

ORDER TOTAL: _____

PLEASE ALLOW 4-6 WEEKS FOR DELIVERY

NAME: _____

ADDRESS: _____

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

PHONE: _____

E-MAIL: _____

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

PLEASE CIRCLE ONE: Visa Mastercard Discover

NAME ON CARD: _____

CARD #: _____

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

SIGNATURE: _____

America's Voice for the Bullied

USA Network Announces 2012 'Characters Unite' Award Winners

By *BWW News Desk*

Continuing its highly successful multiplatform public service campaign to address social injustices and bridge cultural divides, USA Network, along with its distribution partners, announced the 2012 recipients of the Characters Unite Awards. Ten winners were selected from hundreds of nominees for their extraordinary efforts in combating prejudice and discrimination while increasing tolerance and acceptance in their communities.

"Congratulations to this year's Characters Unite Award winners, who deserve to be recognized for their tireless work in fighting hate and discrimination and promoting acceptance in their communities," said Bridget Baker, President, NBC Universal TV Networks Distribution.

One of the 2012 recipients was Gabrielle Ford, Founder of Friends of Gabe & Izzy. As a child, Gabrielle loved dance and dreamed of becoming a prima ballerina. That dream was shattered by a rare genetic neuromuscular disease, Friedreich's

ataxia, that would eventually place her in a wheelchair. Gabe not only struggled with the devastation of the illness, but also endured constant and cruel bullying from classmates. The constant torment took her on a path of depression and isolation. That all changed when Izzy,



Gabrielle Ford

a long-eared coonhound pup, entered Gabe's life. Izzy became Gabe's best friend and constant companion. When this special friend mysteriously developed a condition mirroring Gabe's, Gabe re-entered the world to get Izzy the best treatment available. Speaking out for the voiceless Izzy gave her the courage to speak out for another voiceless group: the thousands of children bullied in American schools every day. Through countless

personal trials, Gabe found her way back to the stage as an outspoken advocate against school bullying and has been encouraging and inspiring children all across the country by sharing her story during the last 11 years. ❖

ShopNAF.org

Looking for that perfect gift or items for your everyday needs? Shop online through MarketAmerica's NAF shopping website, www.ShopNAF.org. Each purchase you make through this website will help support the National Ataxia Foundation.

Matching Gifts

Many employers will match your gift to the National Ataxia Foundation through a Matching Gifts Program. Please ask your employer if they have a program. If they do, your gift and the gifts of your co-workers will double in value.

What Is the Combined Federal Campaign (CFC)?

Each issue of Generations includes a small box with the National Ataxia Foundation's Combined Federal Campaign (CFC) number, which appears on the next page in this issue. What is that number for and what is the CFC? Thank you to Milly Lewendon for helping answer that question.

What is the Combined Federal Campaign (CFC)? CFC is the only authorized solicitation of Federal employees in their workplaces on behalf of approved charitable organizations. The CFC began in the early 1960s to coordinate the fundraising efforts of various charitable organizations so that a Federal donor would only be solicited once in the workplace and have the opportunity to make charitable contributions through payroll deduction. Federal employees continue to make the CFC the largest and most successful workplace philanthropic fundraiser in the world. Continuing a long-standing tradition of selfless giving, in 2011, Federal employees raised over \$272.7 million dollars for charitable causes around the world.

What is the structure of the CFC? The CFC is made up of 187 local campaigns that organize the annual fund raising effort in Federal workplaces in the United States and abroad.

How is the National Ataxia Foundation involved with CFCs? The NAF is one of the approved charitable organizations to which Federal employees can designate their charitable contributions.

NAF is Represented at Two CFC Events

On occasion, an NAF member or support group leader will represent NAF at a CFC event. The following are recaps of two such events.

CFC Campaign Seattle, WA – October 4

Submitted by Tony and Milly Lewendon

The Seattle Ataxia Support Group was pleased to be able to support NAF by hosting a table at

the King County Combined Federal Campaign event on October 4. What was truly rewarding in participating in this event for the second year was the fact that we spoke with people who had heard about ataxia. We had one person who remembered Tony and me from last year. Our hope is that this would become more frequent and that those individuals would take back the message to their workplace.



Milly and Tony Lewendon at the King County Combined Federal Campaign event in Seattle

The effects of our economy were certainly present at this event, with fewer charities and attendees participating. Our goal, as always to help educate individuals about what we live with, be it the person with ataxia or a family member or friend of the person with ataxia and to raise

Continued on page 26

*What Is the CFC?**Continued from page 25*

funds to further support NAF and the efforts of the foundation.

Dahlgren Naval Support Center Dahlgren, VA – September 5

Submitted by Glenn and Carolyn Davis

Dahlgren, VA is located on the Potomac River just south of the Harry W. Nice Memorial bridge between Virginia and Maryland, about 90 miles from our home. Our visit was to the Dahlgren Naval Support Center. There are about 10,000 employees, some Navy and some civilian, located there.

Our purpose was to introduce the National



Glenn and Carolyn Davis at the Dahlgren Naval Support Center CFC event in Virginia

Ataxia Foundation to the people on the base as part of the Combined Federal Campaign. We planned to introduce them to ataxia and to encourage them to specify their donation be directed to NAF.

The gathering was on a parade ground in the center of the base. It was a nice facility with a large patio for staging an event. They had two large open tents with tables for presenter displays. The tent we were under had three rows of five tables in each row. Each table accommodated two presenters. We were fortunate to be on the end of one of these rows. We shared our table with a young lady representing a charitable medical facility. Set up required spreading a table cloth over our half of the table and displaying information sheets, bookmarks, and two easels.

We spent the first half hour pasting NAF's CFC number on the bookmarks and the leaflets. By 11 a.m., the official starting time, we were ready. The weather was delightful. Temperature was in the mid-eighties with a gentle breeze. The tent provided us much-appreciated shade. There was a steady stream of people for the next two hours. None had ever heard of ataxia. Almost everyone who came past our table went away with a bookmark and a short explanation of ataxia. We gave out 170 bookmarks and educated attendees as to who we were and why they would want to support NAF ❖

CFC Number

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

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

Please give as generously as you can and please ask your co-workers to also give to the National Ataxia Foundation.

Share Your Story

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

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

2013 NAF Annual Membership Meeting Agenda

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

THURSDAY, March 14

Event	Location	Time
NAF Registration	West Renaissance Foyer	9:00 a.m. - 8:00 p.m.
Leadership Meeting	Cadillac	1:00 p.m. - 3:00 p.m.
Fundraising Meeting	Cadillac	4:00 p.m. - 5:00 p.m.

FRIDAY, March 15

Event	Location	Time
NAF Registration	Renaissance Foyer	8:00 a.m. - 5:30 p.m.
Exhibitors	Renaissance Foyer	8:00 a.m. - 5:30 p.m.
General Sessions	Renaissance Ballroom	8:30 a.m. - 12:15 p.m.
Activity Room	Monet	10:00 a.m. - 2:00 p.m.
Lunch	On Your Own	12:15 p.m.
"Birds of a Feather" Small Groups	Various Meeting Rooms	2:00 p.m. - 5:00 p.m.
Welcome Reception	Renaissance Ballroom	7:00 p.m.

Friday General Sessions: The Michigan Experience

Time	Topic	Speaker
8:30 a.m.	Welcome and Announcements	Camille Daglio, Co-Chair, and NE Region Support Groups
9:00 a.m.	The Michican Experience	Henry Paulson, MD, PhD, University of Michigan
9:20 a.m.	How Genetics Is "Changing the Game"	Margit Burmeister, PhD, University of Michigan
	in Ataxia	
9:50 a.m.	How Neurons Go Haywire in Ataxia and	Vikram Shakkottai, MD, PhD, University of Michigan
	How New Insights Might Lead to Therapy	
10:20 a.m.	Overview of Mechanism of Disease	Peter Todd, MD, PhD, University of Michigan
	in Ataxia	
10:50 a.m.	What Controls Balance and Why	Kevin Kerber, MD, University of Michigan
	It Is a Problem in Ataxia	
11:20 a.m.	New Findings on SCA3 and Ataxin3	Sokol Todi, PhD, Wayne State University
11:50 a.m.	Question and Answer Session	Friday Morning Presenters
12:20 p.m.	Lunch	

Birds of a Feather

These small group sessions are divided into groups based on the type of ataxia the attendee has or the role of the attendee, such as spouse, family member or parent. On the registration form, each attendee will indicate which BOF session they will attend. These facilitated groups will meet in various hotel meeting rooms as indicated in the Annual Membership Meeting Program. Paid PCAs are welcome to attend the session with their client, but are not required unless client requires it. **All sessions meet from 2:00 to 5:00 p.m.** even though some facilitators with circulate in and out to the small groups.

Session	Who Should Attend	Facilitator(s)
SCA 1	Persons diagnosed with SCA 1	Dr. Orr & Dr. Schut
SCA2	Persons diagnosed with SCA 2	Dr. Xia & Dr. Horn
SCA3	Persons diagnosed with SCA 3	Dr. Paulson & Dr. Todi
SCA6	Persons diagnosed with SCA 6	Dr. Schmahmann
SCAs other than 1, 2, 3, or 6	Persons with a diagnosis of any SCA	Dr. Ranum & Dr. Wilmot
	other than SCA 1, 2, 3, or 6	
Episodic & AOA & Unknown	Persons with a hereditary form of ataxia to include EA	Dr. Burmeister & Dr. Todd
with a family history	AOA or an unknown genetic form of ataxia (not SCA)	
Sporadic & MSA & Unknown	Persons with a diagnosis of Sporadic ataxia, Multiple	Dr. Alaedini
without a family history	System Atrophy or an unknown form of ataxia	
	without any family history	

Birds of a Feather (continued)

Session	Who Should Attend	Facilitator(s)
Over age 30 with FA	Persons over 30 years old with a diagnosis of Friedreich's ataxia	Dr. Perlman & Dr. Lynch (2-4 p.m.)
Under age 30 with ataxia	Persons under 30 years old with any form of ataxia	Dr. Ying & Dr. Shakkottai
Parents of children (non-Friedreich's)	Parents whose child(ren) are affected by a form of ataxia other than Friedreich's ataxia	Dr. Kerber and Cathy DeCrescenzo (3:30-5 p.m.)
Parents of children (Friedreich's ataxia)	Parents whose child(ren) are affected by Friedreich's ataxia	David Zilles, Dr. Perlman & Dr. Lynch (4-5 p.m.)
Spouses & partners without ataxia	Spouses and partners who do not have ataxia but their spouse/partner does	Tina Blasberg & Cathy DeCrescenzo (2-3:30 p.m.), Laura Rice-Oeschger (3:30-5 p.m.)
Family members without ataxia	Family members other than parents, spouses, or partners, such as siblings, in-laws, children who do not have ataxia	Laura Rice-Oeschger (2-3:30 p.m.), Camille Daglio & William Sweeney

SATURDAY, March 16

Event	Location	Time
NAF Registration	Renaissance Foyer	8:00 a.m. - 5:00 p.m.
Exhibitors	Renaissance Foyer	8:00 a.m. - 5:00 p.m.
Silent Auction	Cabot	8:00 a.m. - 1:30 p.m.
General Sessions	Renaissance Ballroom	8:30 a.m. - 12:15 p.m.
Activity Room	Monet	10:00 a.m. - 2:00 p.m.
Lunch	On Your Own	12:15 p.m.
NAF Business Meeting	Renaissance Ballroom	1:45 p.m. - 2:00 p.m.
General Sessions	Renaissance Ballroom	2:00 p.m. - 5:00 p.m.
Banquet	Renaissance Ballroom	7:00 p.m.

Saturday General Sessions

Time	Topic	Speaker
8:30 a.m.	Living Well and Cultivating Well-Being with Ataxia	Laura Rice-Oeschger, LMSW, University of Michigan
9:00 a.m.	Vibrotactile Sensory Substitution Devices for Improving Balance	Kathleen Sienko, PhD, University of Michigan
9:30 p.m.	Strategies to Improve Speech and Swallowing in Ataxia	Karen Kluin, MS, CCC, BC-ANCDS, University of Michigan
10:00 a.m.	Balance in Ataxia and Balance-Based Torso-Weighting	Cynthia Gibson Horn, PT, Motion Therapeutics, Inc.
10:45 a.m.	The Four Components of an Effective Therapy Session	Polly Swingle, PT, Project Recovery, LLC
11:15 a.m.	Cerebellum and Cognition: New Information, New Implications	Jeremy Schmahmann, MD, Harvard Medical School
11:45 a.m.	Question and Answer Session	Saturday Morning Presenters
12:15 p.m.	Lunch	
1:45 p.m.	NAF Business Meeting	Char Danielson, NAF President
2:00 p.m.	Financial Planning	Mary Anne Ehlert, CFP, Protected Tomorrows, Inc.
3:00 p.m.	Wheelchair Yoga	Ralph Miller, Gilbert, AZ
3:30 p.m.	Why is My Ataxia Worse than Yours?	George "Chip" Wilmot, MD, PhD, Emory School of Medicine
4:00 p.m.	Update on Induced Pluripotent Stem Cells as Models for SCAs	Guangbin Xia, MD, PhD, University of Florida
4:30 p.m.	Question and Answer Session	Saturday Afternoon Presenters

SUNDAY, March 17

Event	Location	Time
NAF Registration	Renaissance Foyer	8:00 a.m. - 11:00 a.m.
Exhibitors	Renaissance Foyer	8:00 a.m. - 11:00 a.m.
General Sessions	Renaissance Ballroom	9:00 a.m. - 1:00 p.m.

Sunday General Sessions

Time	Topic	Speaker
9:00 a.m.	Patient Registry/Medications/CoQ10	Susan Perlman, MD, University of California – Los Angeles
9:30 a.m.	Friedreich’s Ataxia – What’s New?	David Lynch, MD, University of Pennsylvania
10:00 a.m.	NAF Research Advancement: Progress to Therapies	Harry Orr, PhD, University of Minnesota
10:30 a.m.	Gluten Ataxia	Armin Alaedini, PhD, Columbia University Medical Center
11:00 a.m.	How Ataxia Genes Affect Neurons: Lessons from SCA5 and SCA8	Laura Ranum, PhD, University of Florida
11:30 a.m.	National Ataxia Foundation Update	Michael Parent, NAF Executive Director
11:45 a.m.	What We Have Learned – Top 10	Sarah Ying, MD, Johns Hopkins University
12:15 p.m.	Question and Answer Session	Sunday Morning Presenters
12:45 p.m.	Closing Remarks	Camille Daglio, NAF AMM Co-Chair

Pre-orders for MP3/MP4 Audio and PowerPoint Presentations can be purchased through Digital Conference Providers at www.dcpvidersonline.com/naf or by using the order form on page 36.

Silent Auction Has New Time

The Silent Auction held during each Annual Membership Meeting is a fun way to support NAF and for you to bid on quality items from various states and countries. Bidding begins on Saturday, March 16 at a new time – 8:00 a.m. – with the final bidding ending also at a new time – 1:30 p.m.

Auction items should range from something that represents your state or country, art work, sports memorabilia, theme baskets, hand-crafted items, hotel stays and weekend getaways. Donated items should be delivered to the Silent Auction room at the hotel by Friday, March 15 at 2 p.m.

If you are not able to attend the meeting, but have a quality item that you would like to donate for the auction, please call (763) 553-0020 or e-mail naf@ataxia.org for details on where to ship your item.

Donate an item and then have fun bidding on the items of your choice! Thank you for supporting this event and sharing items from your local area. Good luck!

AMM Volunteer Opportunities

Volunteers donating their time contribute greatly to the success of each National Ataxia Foundation Annual Membership Meeting. We need volunteers for the 2013 AMM to be held in Detroit, MI, on March 15-17, 2013.

To sign up as a volunteer at the 2013 AMM or to get more information about the volunteer opportunities available, please contact Gloria Sharrar at (804) 323-3305 or gksharrar@gmail.com.

Deadline

The deadline for submitting materials for the Spring issue of *Generations*, which will be mailed in late April, is March 8, 2013.

Please send stories, events and reports by e-mail to naf@ataxia.org or by mail to the address listed on page 2.

“Driving Together Towards a Cure” Meeting Registration Instructions

Dates: March 15-17, 2013

Location: Detroit Marriott at the Renaissance Center
400 Renaissance Drive
Detroit, MI 48243
1-877-901-6632 or (313) 568-8300

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

Individuals eligible for the member rate include current:

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

Early Registration Fee (*includes registrations received or postmarked by February 15, 2013*):

- Members: \$95/person
- Non-Members: \$150/person

Registration fee after February 15, 2013 – *You are strongly encouraged to register before 2/15/13 (includes registrations postmarked after February 15, 2013 and all registrations at the door):*

- Members: \$120/person
- Non-Members: \$175/person

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

Instructions for Registration:

1. **Please fill out the registration form completely** and mail with your payment, to the NAF office. The requested information is necessary to complete preparations for the meeting.
2. **Registration Fees.** Whether you plan to attend the entire conference or just the General Sessions or just the banquet and/or reception, the full per person registration fee will be charged. Children attending the meeting will be charged the following registration fees: children two years and under are free; children three years and over will be charged the full meeting registration fee.
3. Childcare services are not provided by NAF staff, volunteers or local volunteers.
4. Complete and return both pages of the registration form by February 15, 2013. Please fill out the name portion of the registration form as you would like it to appear on your name badge.

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

Early Registration Deadline is February 15, 2013

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

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

2013 NAF Annual Membership Meeting Registration

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

- Please indicate the Birds of a Feather session you plan to attend†:
- SCA1 SCAs other than 1, 2, 3, or 6
 - SCA2 Sporadic/MSA
 - SCA3 Unknown/Episodic/AOA
 - SCA6 Family members
 - Spouses/Partners
 - Parents (non-Friedreich's Ataxia)
 - Parents (Friedreich's Ataxia)
 - Under age 30 with Ataxia
 - Over age 30 with Friedreich's Ataxia

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

- Please indicate the Birds of a Feather session you plan to attend†:
- SCA1 SCAs other than 1, 2, 3, or 6
 - SCA2 Sporadic/MSA
 - SCA3 Unknown/Episodic/AOA
 - SCA6 Family members
 - Spouses/Partners
 - Parents (non-Friedreich's Ataxia)
 - Parents (Friedreich's Ataxia)
 - Under age 30 with Ataxia
 - Over age 30 with Friedreich's Ataxia

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

- Please indicate the Birds of a Feather session you plan to attend†:
- SCA1 SCAs other than 1, 2, 3, or 6
 - SCA2 Sporadic/MSA
 - SCA3 Unknown/Episodic/AOA
 - SCA6 Family members
 - Spouses/Partners
 - Parents (non-Friedreich's Ataxia)
 - Parents (Friedreich's Ataxia)
 - Under age 30 with Ataxia
 - Over age 30 with Friedreich's Ataxia

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

- Please indicate the Birds of a Feather session you plan to attend†:
- SCA1 SCAs other than 1, 2, 3, or 6
 - SCA2 Sporadic/MSA
 - SCA3 Unknown/Episodic/AOA
 - SCA6 Family members
 - Spouses/Partners
 - Parents (non-Friedreich's Ataxia)
 - Parents (Friedreich's Ataxia)
 - Under age 30 with Ataxia
 - Over age 30 with Friedreich's Ataxia

*Indicates required information. PCA = Personal Care Attendant.

†Descriptions can be found on pages 27-28.

2013 NAF Annual Membership Meeting Registration

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

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

TRAVEL INFORMATION

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

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

Air Carrier: _____ Flight Number: _____

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

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

IMAGE CONSENT POLICY

By attending the 2013 NAF Annual Membership Meeting you give your consent, unless you notify us otherwise, to use your image captured during the conference through video, photographs, or digital imagery, to be used by the National Ataxia Foundation in promotional materials, publications, and web site and waive any and all rights to these images.

VIDEOTAPING/FILMING/RECORDING POLICY

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

Early Registration Deadline is February 15, 2013

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

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

2013 NAF Annual Membership Meeting Registration

Not sure if your membership is current? Review the back cover of this issue of *Generations* for your membership status and expiration date, or call (763) 553-0020 to inquire about your membership status.

Take advantage of the MEMBER RATE and JOIN TODAY!	Quantity	Total
<p>Yes, I would like to be a member of NAF! Please add an ADDITIONAL</p> <p> <input type="checkbox"/> \$35 (Annual Individual) <input type="checkbox"/> \$55 (Annual Household) <input type="checkbox"/> \$100+ (Annual Patron) <input type="checkbox"/> \$500 (Lifetime) <input type="checkbox"/> \$55 (Annual Professional) <input type="checkbox"/> \$50 (Individual Outside U.S.) <input type="checkbox"/> \$70 (Household and Professional Outside U.S.) </p> <p>You may register for the meeting as a member if you sign up today!</p> <p><i>*Household, Patron and Lifetime memberships include all individuals who share the same residence.</i></p>		
<p>Yes, I'd like to support the Annual Meeting Fund (provides travel grants, offsets registration fees, helps cover costs associated with the meeting)</p> <p>Here is my sponsorship contribution!</p> <p> <input type="checkbox"/> \$95 (Offset of Registration) <input type="checkbox"/> \$400 (Travel Grant) <input type="checkbox"/> Other: _____ (Any amount is helpful!) </p>		

REGISTRATION FEES (includes all General Sessions, reception, and banquet)	On or Before Feb.15, 2013	After Feb.15, 2013	Quantity	Total
<input type="checkbox"/> NAF Member (applies to NAF members who have an Individual, Household, Patron, or Lifetime membership; <i>member rate is applied to one caregiver per individual member with ataxia</i>)	\$95	\$120		
<input type="checkbox"/> Non-Member	\$150	\$175		

TOTAL CHARGES:

PAYMENT INFORMATION: Visa MasterCard Discover Check enclosed

Name of Card Holder: _____

Address: _____

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

Phone Number: _____ E-mail: _____

Credit Card Number: _____ Expiration Date: _____

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

Early Registration Deadline is February 15, 2013

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

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

AMM Overview

The 2013 NAF Annual Membership Meeting features three days full of activities in “Motown,” Detroit, Michigan. The following is an overview of what to expect.

Thursday, March 14

Pre-Conference Activities

Registration Opens – 9 a.m. – 8 p.m. Come by and get your conference program, name badge, Saturday banquet tickets, and welcome bag. Check in your Silent Auction items and say “Hi” to the NAF staff and volunteers and get acquainted with the hotel layout. Registration will be open Thursday through Sunday morning.

Leadership Meeting – 1 to 3 p.m. This meeting is designed to provide information and support to NAF’s Chapter Presidents, Support Group Leaders and Ambassadors. The meeting is a valuable resource for volunteers who serve in these appreciated positions. If you are interested in becoming a NAF Support Group Leader or Ambassador, contact Lori Shogren at lori@ataxia.org prior to the meeting.

Fundraising Meeting – 4 to 5 p.m. This meeting is for anyone who is interested in learning more about doing a fundraiser to support the important work of the National Ataxia Foundation.

Friday, March 15

General Sessions – 8:30 a.m. to 12:20 p.m.. Friday morning will start the General Sessions in the Renaissance Ballroom. Many of Michigan’s leading ataxia researchers and clinicians will be presenting their latest research and clinical expertise that morning. The General Sessions will incorporate practical aspects in addition to the research and medical topics. A 30-minute Question and Answer session will follow the morning General Sessions with a panel of the morning speakers.

Exhibitors – Exhibitors will be present from Friday through Sunday morning as their schedules permit. If you would like to recommend a

company or service provider to be an exhibitor at the meeting please contact NAF at naf@ataxia.org. If you are interested in information about exhibiting you will find more detailed exhibitor information and an application form on NAF’s website.

Birds of a Feather – 2 to 5 p.m. Attendees will have the opportunity to attend small group sessions. Groups will be divided by different types of ataxia or different roles that attendees are experiencing such as spouse or parent. This is a tremendous opportunity to meet others who share a similar situation or the same ataxia diagnosis. Previous attendees have said these group sessions were the most valuable segment of the annual membership meeting. Medical professionals will facilitate groups and be available for questions.

Silent Auction Items Due – 2 p.m. All items being donated for the Silent Auction are due in the Silent Auction room by Friday, March 15 at 2 p.m. Auction items range from something that represents your state or country, art work, sports memorabilia, theme baskets, hand-crafted items, hotel stays and weekend getaways. Bring an item to donate and then have fun bidding on the items of your choice. Thank you for supporting this event and sharing items from your local area.

“Get To Know Your Neighbor” Welcome Reception – 7 p.m. Please join us in the Renaissance Ballroom for the Welcome Reception. All registered meeting attendees are welcome to attend. Admittance to this event and the snacks that will be served are included with your registration fee. A cash bar will be available.

Saturday, March 16

General Sessions – 8:30 a.m. to 5 p.m. General Sessions continue all day in the Renaissance Ballroom. A 30-minute Question and Answer session will follow the morning and afternoon General Sessions with a panel of the speakers ►

who presented during those sessions.

Silent Auction Bidding – 8 a.m. to 1:30 p.m. The Silent Auction is a fun way to help raise funds for NAF and for you to bid on wonderful items. This long-standing NAF tradition begins on Saturday at a new time – 8 a.m. – with the final bidding also ending at a new time – 1:30 p.m. Good luck! The winning bids will be posted by 4 p.m. Winners must pick up and pay for their items from 4 p.m. until 7 p.m. on Saturday.

Saturday Evening “Motown” Banquet – 7 p.m. in the Renaissance Ballroom. The cost of the banquet is included in your registration fee, however all beverages will be available at a cash bar. The banquet includes a plated dinner entrée that you will select when you register for the meeting. When you arrive at the meeting please reserve your seating and verify your entrée selection prior to the banquet. Volunteers will be at the banquet ticket tables near NAF registration to assist you as you obtain your banquet tickets and select your seating. If you plan to pick up tickets for a group of people please know the

entrée selections for everyone in your party. We look forward to a wonderful dinner together and a fun evening of socializing.

Sunday, March 17

General Sessions – 9 a.m. to 1 p.m. Sunday morning wraps up the 2013 Annual Membership Meeting with the final round of General Sessions in the Renaissance Ballroom followed by a Question and Answer Session with a panel of the speakers who presented during this time. Don't miss this general session which includes a wrap-up of all the presentations, so if you missed any during the weekend, you will hear the highlights of each speaker's presentation.

Meeting Presentations and Recordings

The PowerPoint slides from the general session presentations given will be posted on NAF's website after the meeting. Some general session presentations with audio will be available to view for free after the meeting at www.dcpvidersonline.com/naf, with additional presentations available for purchase. ❖

Ataxia Researchers Welcome at Annual Membership Meeting

Ataxia researchers are welcome to attend the National Ataxia Foundation Annual Membership Meeting in Detroit March 15-17, 2013. This meeting represents the world's largest gathering of people and family members affected by ataxia.

Topics related to ataxia will be presented by leading ataxia investigators and clinicians from the United States and around the world. The latest research in ataxia and the most promising therapies and treatment strategies are reported.

The National Ataxia Foundation provides a specific location in the Exhibitor Area that is designated for researchers to speak with attendees and/or recruit patients for IRB approved studies or clinical trials. In the past, researchers have

actively engaged patients in questionnaire type studies at the meeting.

There is no fee for ataxia researchers to attend. It is hoped that researchers will be at the research recruitment table during portions of the meeting, but researchers may also attend any of the General Sessions.

There are two social events during the meeting that include food, which are the Friday evening welcome reception and the Saturday evening banquet. If a researcher would like to attend either or both of those events, there is a cost of \$95 total.

If you have any questions about this opportunity or would like to register to attend, please contact Sue Hagen at (763) 553-0020 or susan@ataxia.org.

Conference Media Order Form

National Ataxia Foundation
56th Annual Membership Meeting - Recordings

March 15-17, 2013- Detroit Marriott Hotel - Detroit, MI

***SPECIAL* A limited number of free recorded sessions from this year's Conference will be available after the Annual Meeting at:**

www.dcpvidersonline.com/naf/

The free sessions are available for "view only" while purchased sessions are downloadable.

Full Course Package DOWNLOAD - Audio Synchronized with Presentation Material!

Receive **the Full Course Package** download subscription. This consists of all available session audio (MP3 format) and session video (MP4 Format). With each download subscription you will enjoy unlimited access to your purchased files. You may download as many times as desired for one set price. Your account will not expire, so be sure to keep your login information for future access and purchases.

\$89.00 Pre-Meeting!
 \$129.00 Post-Meeting

Full Course Package on DVD-ROM - Audio Synchronized with Presentation Material!

Receive **the Full Course Package** on DVD-ROM. The DVD-ROM plays on your computer and consists of all available session audio (MP3 format) and audio synchronized with the presentation material (MP4 format). DVD-ROM contains the same content as our download subscription mailed to you on a disc.

\$89.00 Pre-Meeting!
 \$129.00 Post-Meeting
 Plus S/H

**Visit Us Online Today! Purchase the Full Access Download before
 The Conference Begins & Receive the Discounted Rate of Only \$89.00!
 Full Set & Individual Options Available at:**





<http://www.dcpvidersonline.com/naf/>

Downloads are Available Online Shortly After the Meeting Concludes

Order Information:

ORGANIZATION :			
FULL NAME :			
ADDRESS :		SUITE :	
CITY :	STATE :	ZIP :	COUNTRY :
EMAIL :			
PHONE :			
USERNAME :		PASSWORD :	
<i>Required for Download Purchasers</i>		<i>Required for Download Purchasers</i>	

Payment:

TOTAL :	<input type="checkbox"/> Full Course Package Download \$89.00	<input type="checkbox"/> Full Course Package Delivered on DVD-ROM \$89.00 + Shipping/Handling (\$5.00 US, \$10.00 INT'L)
CREDIT:	<input type="checkbox"/>  VISA <input type="checkbox"/>  MC <input type="checkbox"/>  AMEX <input type="checkbox"/>  DISC	CARD # : CCV : EXP :
CHECK :		
CASH :		
MONEY ORDER :		

Digital Conference Providers, Inc. 100 S. Cass Ave., Suite 200, Westmont IL, 60559
Phone (630) 963-8311 Fax (630) 963-8312 Customersupport@dcpviders.com

NAF's Annual Membership Meeting – Making An Impact Throughout the Year and Beyond

One of the centerpieces of the National Ataxia Foundation is its annual membership meeting held each year normally in March. The National Ataxia Foundation's bylaws require that an annual membership meeting is held to elect board members and to conduct any other necessary business. However, NAF's Annual Membership Meeting includes much more than the required business meeting. For three days, 25 general sessions are presented on topics related to ataxia by leading ataxia investigators and clinicians from the United States and even around the world. The latest research in ataxia and the most promising therapies and treatment strategies are reported.

The meeting represents the world's largest gathering of people affected by ataxia. Other activities include ataxia-specific small group sessions, leadership and fundraising training, exhibitors who display ataxia-related products or services, and plenty of opportunities – both formal and informal – for socializing with others who are affected with ataxia.

But that is not all!

On Sunday afternoon, the meeting may end with attendees and the National Ataxia Foundation staff, board members and volunteers packing up to return home, but the meeting's more far-reaching value has just begun.

Conference attendees have had the opportunity to network with others who face many of the same challenges. Although the annual membership meeting is only three days in length, the memories of what was learned and the new friendships that have developed often last a lifetime.

Because of the meeting, support group leaders are better equipped to return to their local support groups and provide the latest information to their support group members who were unable to attend. They also return to their hometowns with a wealth of ideas they have learned from other support group leaders across the country.

The General Session presentations have been taped and are available to those who are unable to attend the meeting. In addition, some of the presentations are transcribed and published

in NAF's quarterly newsletter, *Generations*. These topics include genetic testing, medications for ataxia symptoms, sporadic ataxia, and many other pertinent issues. Those articles have been distributed to newly diagnosed people, even years after the presentation was given. The Foundation's website has a separate webpage dedicated to including PDF files of *Generations* articles of the meeting presentations at www.ataxia.org/resources/generations-articles.aspx.

The NAF website also includes the PowerPoint presentations of the General Sessions which are available for download.

Another important aspect of the annual meeting is the opportunity for researchers and clinicians to meet with patients. Many investigators have said that meeting a patient with ataxia reinvigorates them to return to their labs with a renewed focus on their ataxia research activities. Many clinicians tell us that much of what they learn about ataxia they learn from patients. In addition, the meeting is an occasion for clinicians and investigators to have face-to-face meetings

“
The meeting represents the world's largest gathering of people affected by ataxia.
 ”

Making an Impact Throughout the Year...
Continued from page 37

to form collaborative research efforts and share best practices.

The Annual Membership Meeting planning committee members are aware that due to physical or financial constraints many who would like to attend the annual meeting are not able. Directly following the meeting, members are invited to call or e-mail the NAF office

and the most up-to-date information from the meeting will be provided by a staff or volunteer who attended the meeting and heard the presentations.

Anyone who is affected by ataxia is encouraged to attend an annual membership meeting when it is hosted near your hometown, but if you cannot attend, be assured that the meeting provides value for the entire ataxia community long after the meeting is over. ❖

NAF's Travel Grant Program Needs Your Support

The National Ataxia Foundation's Annual Membership Meeting (AMM) is a special event that connects the ataxia community. In addition to valuable presentations about ataxia research and therapy, the meeting has a large social component in which individuals with ataxia, their family members, and caregivers have the opportunity to interact with others who understand the challenges of ataxia. The meeting program is designed to foster learning, understanding, and connection.

For those with ataxia, traveling to an AMM can be financially difficult. Our Travel Grant pro-

gram was created to assist individuals with some of the costs associated with attending the AMM.

A past recipient of one of the travel grants said "Many, many heartfelt thanks to all who donated so I was financially able to attend this meeting, where I fit in. Thank you so much!"

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

We thank you for your support and for making the AMM experience possible for an individual affected by ataxia. ❖

Happy New Year
from everyone at
the National Ataxia
Foundation!



From the Desk of the **Executive Director**

As we enter a new year with great promise and an unwavering resolve to continue to build upon our important research efforts, I am reminded that it took many generous individuals, families, and organizations in order for NAF to support crucial ataxia research studies being conducted in 2013 throughout the world.

A support group leader recently wrote to his support group members the following note: "It may seem as if you are constantly asked for donations but the fight against ataxia is a constant fight..." I appreciate the candor of this note and its reality; ataxia is indeed a constant fight. Your support is giving researchers the tools to fight back and those affected by ataxia a fighting chance.

Our thanks go to our anonymous donor who again so generously supported this year's research studies through a three-year, \$1.5 million dollar research commitment, to The Michael and Patricia Clementz Family Fund for SCA3 Research for their

continued financial commitment, to the Angeldance Fund in Memory of Sue Cowles Shoup of The Dallas Foundation for their most generous gift, and to The Gordon and Marilyn Macklin Foundation for their continued support and generous \$150,000 matching research gift.

A special thank you to the families, individuals, support groups, chapters, and ambassadors who conducted events and Walk n' Rolls to help raise ataxia awareness and funds to support NAF's important mission and to the donors, sponsors, and volunteers of these events.

To each individual who gave so generously in supporting NAF's research drive, thank you. To the individual donor who called NAF and wanted to donate \$10,000 to help NAF reach its matching goal, thank you. To the children around the nation who have conducted fund raisers at their local schools to create better ataxia awareness and to support important research, thank you.

Thank you to those who choose to include NAF in their wills; their legacy lives on in supporting meaningful ataxia research today and establishing the pathways for further research. Thank you to our monthly and quarterly pledgers and to those who have given each year for more than 30 years. We are also truly grateful to those who contributed more than once this year to help NAF reach the Macklin Foundation research matching gift.

It is through this united front that we were able to support more ataxia research than ever before. Promising research that gives all of us

hope in ending ataxia. Through your generosity, the National Ataxia Foundation has awarded more research funding than any other year in its history. Research studies with new approaches, translational research, and funding that supports Young Investigators and Post Docs in their ataxia research.

Meaningful research that is far reaching and brings us closer to finding the answers to end ataxia. This has been made possible through your commitment and support. We are all truly grateful to you as we move forward in our search to find effective treatments and a cure. Thank you.



Michael Parent

Give Yourself a Pat on the Back

An article for caregivers that honors the important work they do

Caregiving for a person with a disability, regardless of the person's age, is an experience you can't fully understand until you have done it. To someone who has never been a caregiver, it is hard to imagine how stressful, confusing, exhausting, frustrating and often depressing it may be, but on the other side of the coin, how rewarding it can be.

If you were a parent, you probably had a pretty good idea about what a parent's role would be in the development of a child. In other cases, the need to be the primary caregiver for an aging parent or loved one is rarely planned for. Our plans are changed, we no longer have the free time we once had, and we find that we may be missing activities with friends and other family members. What we had planned for our vacation is on hold and many of our entertainment plans are cancelled. Tempers get short and misunderstandings often occur. We often feel no matter how much we do, how fast we do it, it never seems to be enough.

How do we, as caregiver's, get past this? First, take a few minutes and give yourself a pat on the back. You deserve it. Be proud of your efforts and the difference you are able to make in another person's life. You've taken the time to make your loved one more comfortable, to make him/her laugh, to sing a song with him/her, to read to them, shop for them, and the list could go on and on. It may be what others consider to be mundane tasks, but to us, these tasks have given us the opportunity to spend quality moments with our loved one. Sometimes while doing the bathing, dressing, shopping, cooking, feeding, it seems time slows down. Enjoy this priceless time. Don't forget to seek the help of others. When someone volunteers to help, let them do so. They may not do things the same way you do, but taking time for yourself gives

you time to breathe and gives your loved one a break as well. Down the road, you will be able to reflect and recognize that in addition to making your loved one feel valued, they also helped you grow as an individual.

As hectic as our daily lives are, it is important to make the most out of the simple things. It may help if you have a quiet moment or a goal for everyday. This will give you, as a caregiver, and your loved one something to look forward to. Try to take a few minutes everyday and plan some leisure activity. It doesn't need to be extravagant or expensive. It may be as simple as watching the birds out the window, reading a story, or going for a stroll in the neighborhood. You will remember these small activities fondly.

The key is to take a few minutes and enjoy yourself and your loved one so that life's difficult moments are more meaningful and rewarding.

Mary Anne Ehlert is the founder and president of Protected Tomorrows, Inc., the leader in enhancing the lives of families with members who have special needs. By guiding families through its comprehensive, proprietary planning process, Protected Tomorrows helps ensure the well-being of a loved one by creating a Future Care Plan™. Through their work with clients and the family's advisors, and alongside of other advocates and legislators, Protected Tomorrows addresses many concerns of families with special needs such as: future care funding, government benefits, legal considerations, residential options, employment opportunities, recreational choices, education options and family communication. For questions, contact info@protectedtomorrows.com or visit www.protectedtomorrows.com.

Thank you to Millie Lewendon for her contributions to the above article. Read more about Milly and her husband, Tony, at right. ►

Living with Ataxia

By Milly Lewendon

Living with Ataxia is a challenge – as life is in itself. We all have challenges to face.

Tony and I have found ways to be active, going places in our 24-foot RV and seeing the sights is one of our favorite things. Tony can get around in the RV and we have all the comforts of home.

Cycling is another thing we really enjoy doing. We have great trails in our area and have traveled to many areas in our state that offer cycling trails. We both have a “Sun” recumbent tricycle. What Tony likes about cycling is that he is a “normal” guy riding his “cool” cycle. I like it because I get a good workout with an easy (seated) ride and we’re both enjoying the outdoors.

We have both been involved in supporting NAF by attending conventions and helping host the 2009 convention that was held here in Seattle. We help get the word out and share about ataxia by representing NAF at various events, holding local Walk n’ Rolls and meetings



Tony Lewendon riding his recumbent tricycle

for people connected to someone with ataxia.

To sum up our involvement, the more involved we have been the more blessed we have been, meeting many great people and finding ways to live with ataxia and most importantly: enjoy life! ❖

PATIENTS WITH

SCA1, SCA2, SCA3, SCA6 and MSA-C
needed for an MRI study

to evaluate the chemistry of the brain in ataxias

at the Center for Magnetic Resonance Research at
University of Minnesota

You will lie in the scanner for ~1.5 hour while listening to music of your choice. Expenses will be covered and you will be reimbursed for your time.

If you are interested or have questions, please call

Diane Hutter @ (612) 625-2350 or email hutte019@umn.edu.



Research Opportunity for the SCA's

Recruitment continues for additional research participants for a Natural History study. Participants must have a confirmed diagnosis of SCA 1, 2, 3, or 6. Please use the information below to inquire about participation or to contact the research coordinator of the institution that is nearest to you.

University of California – Los Angeles (UCLA) Ataxia Center

Susan Perlman, MD

Los Angeles, CA 90095

(310) 206-8153

Research Coordinator: Maria Casado

mcasado@mednet.ucla.edu

Emory University

Movement Disorders Center

George Wilmot, MD, PhD

Atlanta, GA. 30329

(404) 728-4909

Research Coordinator: Rebecca McMurray

rebecca.s.mcmurray@emory.edu

University of Florida Movement Disorders Center

Tetsuo Ashizawa, MD, FAAN

S.H. Subramony, MD

Gainesville, FL 32610-0236

(352) 273-9194

Columbia University

Sheng-Han Kuo, MD

New York, NY 10032

(212) 305-5558

sk3295@mail.cumc.columbia.edu

University of California San Francisco Memory and Aging Center

Michael Geschwind, MD, PhD

Sharon Sha, MD

San Francisco, CA 94158

Research Coordinator: Gigi Satris

(415) 476-2909

gsatris@memory.ucsf.edu

Johns Hopkins Ataxia Center

Sarah Ying, MD

Baltimore, MD 21287

(410) 502-5816

Research Coordinator: Ann Fishman

ataxiaresearch@jhu.edu

University of Minnesota Ataxia Center

Khalaf Bushara, MD

Minneapolis, MN 55455

(612) 625-2350

Research Coordinator: Diane Hutter

hutte019@umn.edu

Harvard University Massachusetts General Hospital Ataxia Unit

Jeremy D. Schmahmann, MD

Boston, MA 02114

(617) 726-3216

Research Coordinator: Jason MacMore

jmacmore@partners.org

Tissue Donation

Donating tissue for medical research is an important and deeply personal decision. Proper planning can help ensure that wishes are honored at the time of your or a loved one's passing.

For more information or to make arrangements for tissue donation please follow-up with Dr. Arnulf Koeppen directly using the following contact information:

Dr. Arnulf Koeppen

Professor of Neurology & Pathology

VA Medical Center

113 Holland Ave., Albany, NY 12208

(518) 626-6377 Fax: (518) 626-6369

E-mail: Arnulf.Koeppen@va.gov or

akoeppen@nycap.rr.com

Thank you for your support of this important research initiative.



Recruitment Notice for Research on Movement Disorders – UMass Amherst

Who: We are looking for individuals with movement disorders due to atrophy of the cerebellum.

Studies: Studies are designed to investigate how the brain controls learning and movement. We look at simple finger and arm movements in response to various cues.

Time: Studies are conducted in 1-2.5 hour sessions. You can participate in as many sessions as you like. You are free to withdraw at any time.

Compensation: You will be paid \$10 an hour for your time.

It is important to realize that this research is not

related to any medical treatment. The research is being conducted to learn more about the cerebellum with the intent of eventually designing therapies based on these results.

If you would like to participate in this research, please call (413) 545-4831 or e-mail *cognac lab@gmail.com* or Professor Rebecca Spencer, the director of the lab, directly at (413) 545-5987 or *rspencer@psych.umass.edu*.

Research conducted by Dr. Rebecca Spencer, UMass – Amherst. Department of Psychology. 419 Tobin Hall, Amherst, MA. Approved by the UMass IRB. ❖

Patients with Ataxia Needed for Immunologic Studies

Patients with ataxia are needed for immunologic studies in ataxia at the Center for Parkinson's Disease and Other Movement Disorders Clinic at Columbia University in New York, NY.

If you are 18 years old or above and have ataxia, or if you are friends and families without ataxia and interested in participating in this study, please contact us.

You will come in for a 45-minute clinical visit for neurological examination and also a blood draw. This will help us to understand ataxias and possibly develop treatments for ataxias.

For more information, please contact Dr. Sirinan Tazen at (212) 305-9718 or e-mail *st2748@columbia.edu*, or Dr. Sheng-Han Kuo at (212) 305-5558 or e-mail *sk3295@columbia.edu*.

Raise Awareness about Rare Diseases in India

If you are a person of Indian ethnicity living in the United States who is affected with ataxia, please contact Sue Hagen, Patient Services Director at *susan@ataxia.org* for more information about a program that is raising awareness about rare diseases (to include ataxia) in India.

Neurological and Specialty Clinics

The National Ataxia Foundation provides lists of neurologists, ataxia clinics, and movement disorder clinics at *www.ataxia.org/links/neurologists-specialty-clinics.aspx*. Please e-mail *naf@ataxia.org* with updates or additions so we can keep the list current.



Chapter and Support Group News *from Around the Country*

.....
Delaware Support Group

Submitted by Joe DeCrescenzo

The Delaware Support Group held its inaugural meeting on Nov. 17 at Christiana Hospital with over 10 attendees. Lisa Coggins, Esq., of Ferry, Joseph & Pearce presented elder care topics and fielded questions from the attendees. The second half of the meeting involved discussions among the attendees about both common and unique challenges faced by ataxins or caregivers, and how they were addressed.

Our next meeting will be in April 2013. We expect a representative from “Yes U Can,” who will demonstrate and lead us through an exercise routine.

.....
Denver Support Group

Submitted by Charlotte DePew

About 30 individuals attended the October 20 meeting. Charlotte thanked all those who participated, donated, and formed teams for the September 9 Run, Walk-n-Roll fundraiser, which exceeded last year’s event. Over 300 attended and over \$41,000 was raised.

Dr. Clouse was here for six weeks during July and August, saw over 12 individuals, and plans to return to Denver next summer. One person traveled from Alabama to take part. Appointments were conducted at Swedish Medical Center meeting rooms at no cost. We are very grateful for their assistance.

Dr Clouse’s coaching helped many of us improve mobility and we learned it requires diligent practice, work, exercise, and patience. The reward is very gratifying: two are no longer using canes; one who used a cane and one who

used a walker are now playing racquetball (chasing the ball more than volleying); another was able to get out of the wheelchair and use her walker again; one member, in a wheelchair for several years, learned to transfer himself out of and back into his wheelchair, plus Dr Clouse got him to draw again! These are just some of the examples.

With a smaller group and shorter program, we were able to spend more time on sharing whatever was on our minds Don and Shirley Stanosheck and Debbie Crystal received an Ataxia Awareness Day Proclamation from the Longmont mayor. We were all pleased to see Tom and Donna Sathre (former leaders for our group) at the meeting. Last meeting, Tom was in the hospital.

We watched the DVD of Jessica Jerke’s two-year ataxia experience as shown on Discovery Channel’s “Diagnosis: Dead or Alive” this past summer. Her father, Bill Jerke, was there to explain how the Discovery people contacted them, the interview and taping, how Jessie continues to give gifts in many ways, and how much she is missed. Any Support Group member who met Jessie remembers her fondly. Dr. Abbie Collins was interviewed and in the show as well as the family. It was a very well-done presentation.

.....
Middle Tennessee Support Group

Submitted by Vicki Tyler

The Middle Tennessee Ataxia Support Group will meet in 2013 in January, April, July, and October; the specific dates will be decided later. If you’re interested, e-mail me (Vicki) at tylerv2@comcast.net, and I’ll add you to our ►►

e-mail list so that you'll hear about the specifics of all meetings.

We always meet at Amerigo's restaurant in Cool Springs (Nashville Cool Springs Mall area at 1656 Westgate Cir., Brentwood, TN 37027) at 2 p.m. on a Saturday. I will try to pick a Saturday which most people can make. Family members or friends are welcome! We usually have 10 to 20 people in attendance, but that varies. At our informal meetings, we talk about things that concern us, get help from others who are there, and definitely get understanding from all. Sometimes we have a speaker. Either way, we eat a late lunch together and then, talk. It's just nice to spend a little time with others who are "in the same boat."



Members of the Maine Support Group at their August picnic (submitted by Kelley Rollins)

I am always reminded that we all have problems and hardships when it comes to daily life that are almost impossible for other people to understand. Depending on what particular kind of cerebellar ataxia you have, symptoms vary a little, but we can all relate to each other. Of course, it's also good to share our improvements and successes, too.

So it's important to get together when we can. We try to offer support to each other, no matter what's going on in our lives. It would be great if you can join us!! We always learn so much from each other, and it's just nice to be around others who can really understand.

.....
New Hampshire Support Group

Submitted by Jill Porter

The New Hampshire Ataxia Support Group has been meeting once a month, on a Saturday morning, for a year now. Our first meeting was held in September, 2011 at a church in Bow, NH. In January 2012 we moved our meetings to the Stop and Shop in Bedford, NH, to be more centrally located to our members. This location is convenient to I-93, I-293 and NH 101, is handicapped accessible and provides us with a suitable meeting room.

In November, 2011, we met jointly with the North Shore Coffee Club, a sub-group of the New England Ataxia Support Group at a mid-point location in Salem, NH. In May and October members attended the spring and fall get-togethers of the NE Ataxia Support Group held at Massachusetts General Hospital.

During this past summer we had a growth spurt with a newcomer at each meeting.

With all of the varieties of ataxia out there, there is no one individual in our group who has the same type of ataxia. One of our members has spastic paraplegia.

Through our group, members with SCA 1, 2, 3 or 6, learned about and are participating in the Natural History Study that is being conducted through the University of Florida at sites across the country. It requires four visits to Massachusetts General Hospital, one every six months. More candidates are still needed for this study.

In August we promoted the Macy's Shop for a Cause Event by contacting family and friends telling them how we are involved with the National Ataxia Foundation, how ataxia affects us and how participating in this event helps

Chapter and Support Group News
Continued from page 45

support research for a cure.

In September we promoted IAAD 2011 and again for 2012, spreading the word with posting flyers, distributing bookmarks and sponsoring minute messages in various churches.

We are open to new ideas for meetings, welcome newcomers and enjoy sharing and helping each other. All of our chapter information is posted on the NAF website. Please contact me if you are interested in more information about our group.

.....
Northeast Florida Support Group

Submitted by Mac Kelso

The Northeast Florida Ataxia Support Group met at Baptist South Hospital on August 11 at 1 p.m. Our meeting had 19 attendees.

John Richwine opened the meeting by introducing himself and welcoming all members. Several topics were addressed in a round table forum, beginning with International Ataxia Awareness Day on the 25th of September. The Support group decided to celebrate IAAD at Aunt Kate's on September 29 at 1 p.m. All members are encouraged to wear an ataxia t-shirt or apparel in support of this very special day. Next, an updated address list was given to all members present and a copy was sent to members who could not make the meeting. All corrections should be given to Mac Kelso for updating. The group then discussed a proposal for bringing in a speech therapist to discuss techniques for decreasing or prevention of coughing episodes at the February 2013 meeting. The group enthusiastically agreed to the proposal.

Other members shared some of their personal experiences with the group. Laura Lightsey discussed pain management using an epidural for severe pain in her back, and Steve Brown discussed the EZ ceiling lift: a battery-operated patient lift that is mounted in tracks that are installed into the ceiling. The lift is used with a

slings or walking harness to transfer the patient along the track to the bathroom, bed, or throughout the house. The members were interested and would like to hear more on the subject. Steve will let the group know if a representative will come and speak to the group.

Another proposal was made to generate a used handicap equipment list donated by members to other members in need. Corey Hannan expanded on this proposal with a proposal of his own. He has developed a business plan for My World Now Corp. His mission statement: "To provide quality new/used mobility devices to individuals with disabilities who otherwise may not be able to afford the equipment they require to enjoy a mobile life-style." The group was very supportive of his business adventure and individuals who would like to donate to this organization or to other members in the group who need handicap equipment, may certainly do so. For more information please contact Corey at (904) 314-2061 or coryhannan@hotmail.com.

The last two topics: bumpers stickers will be made for the group and Linda Snow and Judy (Carole sister) said they would be happy to make any member a bib. Linda Snow's e-mail is snowline@comcast.net and Judy's e-mail is judyragusa@aol.com. The group decided to have short 30-minute breakout groups for ataxians and caregivers and convened to different rooms.

In closing, all members who attended the "Corky Bells" outing in July said they really enjoyed the great lunch and seeing each other. The next proposed meeting will be November 17 in the Azalea and Begonia conference rooms at Baptist South. All members were invited to come to Applebee's after the meeting.

.....
Tri-State Ataxia Support Group

Submitted by Kathleen Gingerelli

Our September 13 meeting started on time at 6:30 p.m., and boy did we have a full house! There were some new faces and a few familiar faces not seen in awhile. ▶▶

Our first topic of the night was from Jordan Taylor, an assistant professor from Princeton University. Jordan spoke about motor coordination and the cerebellum. He showed some studies used in the office and demonstrated the cursor and screen study. Jordan spoke about how the brain needs to learn how to follow new rules given, i.e. rotating the screen and measuring accuracy. Can other areas of the brain be trained to take over cerebellar like activities? Feel free to contact Jordan about studies being performed and to express interest in participating. His e-mail is jordanat@princeton.edu.

Dr. Kuo and Siri spoke of a study they are performing at Columbia University researching any contributing factors between ataxia and gluten sensitivity. They are accepting any volunteers for this study, which includes a short neurological examination and then bloodwork. Friends and family are welcome to be tested and all types of ataxia are being accepted. If you want to make an appointment, contact Siri at st2748@columbia.edu.

A few tidbits that you might find interesting:

- Check out the “Bruised But Not Broken” Facebook page. Share your stories and pictures to spread awareness.
- Denise recommends a product called Biotene for anyone suffering from dry mouth as a side effect from certain medications. Biotene comes in toothpaste, a mouthwash, and an oral spray.
- Denise also passed on the idea for a great read, “A Delicate Balance – Living Successfully with Chronic Illness” by Susan Milstrey Wells, available at Amazon.

.....
West Central Florida Support Group

Submitted by Linda Farrow, Secretary

Cindy Steever-Ziegler, President, along with Jessica Chiarito from AAA, answered questions about our upcoming “Cruising to Create Ataxia Awareness” on November 15. They encouraged everyone to ask others to join us and Jessica told us about an AAA event happening on Sunday, at which she would be speaking about our cruise and encouraging them to join us. We are very excited about this cruise; there are people cruising with us from several states. Families are finding that they are getting a great price and they are planning to vacation while they are visiting



Members of the West Central Florida Support Group at their October meeting (submitted by Cindy Steever-Ziegler)

with their relatives here in Florida. Most of the accessible rooms are booked but if you are interested in joining us, please contact Cindy Steever-Ziegler at csteever@msn.com for information and availability. One of the side trips we will be doing is swimming with the dolphins. This cruise will serve as a way to advance knowledge of ataxia and to encourage ataxians to travel, even if it may take them a bit longer to visit different places of interest. The plan for our 2013 trip is going to be a little longer, probably leaving from Ft Lauderdale. Then in 2014 we plan to visit Alaska. ❖

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

Please submit your 2013 meetings and event listings to lori@ataxia.org.

NAF Directory of Chapters, Support Groups and Ambassadors

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

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

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

Social Networks

NAF BULLETIN BOARD

Moderator – Atilla and Bear

www.ataxia.org/forum/toast.asp

NAF CHAT ROOM

Moderator – Della (ddpokernut@yahoo.com)

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

NAF FACEBOOK GROUP

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

NAF FACEBOOK CAUSES

www.causes.com/causes/368602?m=71bb3202&recruiter_id=52877151

NAF FACEBOOK FANS

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

NAF YOUTUBE CHANNEL

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

Chapters, Support Groups and Ambassadors

– ALABAMA –

ALABAMA SUPPORT GROUP LEADER

Becky Donnelly

Hoover, AL

(205) 987-2883

E-mail: donnelly6132b@aol.com

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

AMBASSADOR

Dianne Blain Williamson

Huntsville, AL

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

E-mail: diannebw@aol.com

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

– ARIZONA –

PHOENIX AREA SUPPORT GROUP LEADERS

Rita Garcia

Chandler, AZ

(480) 726-3579

E-mail: rtg22@cox.net

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

Mary Fuchs

Sun Lakes, AZ

(480) 883-7633

E-mail: mary111115@msn.com

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

AMBASSADOR

Bart Beck

Tucson, AZ

(520) 885-8326

E-mail: bbeck15@cox.net

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

– ARKANSAS –

AMBASSADORS

Judy and David King

Hot Springs Village, AR

E-mail: drkingpd@suddenlink.net

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

– CALIFORNIA –

LOS ANGELES AREA SUPPORT GROUP LEADER

Sherry McLaughlin

Altadena, CA

(626) 791-1558

E-mail: ccherilynmc@yahoo.com Web: <http://laasg-ca.info>

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

N. CALIFORNIA AREA SUPPORT GROUP LEADER

Joanne Loveland

Danville, CA

E-mail: joaneloveland@gmail.com

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

ORANGE COUNTY AREA SUPPORT GROUP LEADER

Daniel Navar

Montebello, CA

(323) 788-7751

E-mail: danieln27@gmail.com

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

AMBASSADORS

Barbara Bynum

Merced, CA

(209) 383-1275

E-mail: bjb@vtlnet.com



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

Earl McLaughlin

El Cajon, CA

(619) 447-3753

E-mail: sdasg@cox.net

(Earl: emclaugh@cox.net)

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

Deborah Omictin

Hayward, CA

(510) 783-3190

E-mail: rsisbig@aol.com

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

— COLORADO —**DENVER AREA SUPPORT GROUP LEADER****Charlotte DePew**

Aurora, CO

(720) 379-6887

E-mail: cldepew77@comcast.net

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

— CONNECTICUT —**TRI-STATE SUPPORT GROUP LEADER****Denise Mitchell**

(212) 844-8711

E-mail: markmeghan@aol.com

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

AMBASSADOR**Terre Di Placito**

Torrington, CT

(860) 489-5092

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

— DELAWARE —**DELAWARE SUPPORT GROUP LEADER****Joseph DeCrescenzo**

Newark, DE

(302) 369-9287

E-mail: jdecr@comcast.net

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

— FLORIDA —**NORTHEAST FLORIDA SUPPORT GROUP LEADERS****Steve & Carole Brown**

Reddick, FL

(352) 591-5095

E-mail: Bike4brown@aol.com

John & Sherri Richwine

Jacksonville, FL

(904) 996-0699

E-mail: ajrichwine@gmail.com

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

WEST CENTRAL FLORIDA SUPPORT GROUP LEADER**Cindy Steever-Ziegler**

Naples, FL

(239) 878-3092

E-mail: csteever@msn.com

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

AMBASSADORS**Jim Henderson**

Orlando, FL

(407) 568-9092

E-mail: jamesone24@aol.com

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

Meghan McBrearty

Tallahassee, FL

(850) 524-9060

E-mail: megra10@hotmail.com

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

— GEORGIA —**GREATER ATLANTA SUPPORT GROUP LEADERS****Lynn Robinette**

Lawrenceville, GA

(770) 982-0275

E-mail: lynn.robinette@comcast.net

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

Greg Rooks

Atlanta, GA

(404) 822-7451

E-mail: rooksgj@yahoo.com

Dave Zilles

Atlanta, GA

(770) 399-6710

E-mail: dzilles@earthlink.net

AMBASSADOR**Kristie Adams**

Savannah, GA

E-mail: opal1011@comcast.net

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

— ILLINOIS —**GREATER CHICAGO AREA SUPPORT GROUP LEADER****Jonas Cepkauskas**

Oak Forest, IL

(708) 535-0928

E-mail: jonas@fightataxia.org

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

METRO AREA CHICAGO SUPPORT GROUP LEADER**Christopher Marsh**

Chicago, IL

(312) 662-1127

E-mail: cmarsh34@ameritech.net

http://health.groups.yahoo.com/group/u_r_notalone/

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

AMBASSADOR**Elaine Darte**

Belleville, IL

(618) 397-3259

E-mail: elainedarte@yahoo.com

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

— IOWA —**IOWA SUPPORT GROUP LEADER****Emily Medina**

West Des Moines, IA

(515) 727-8713

E-mail: emily061578@yahoo.com

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

NAF Directory

Continued from page 49

— KANSAS —

AMBASSADOR**Jalean Retzlaff**

Park City, KS

(316) 303-2351

E-mail: jlrtrolls@yahoo.com

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

— KENTUCKY —

AMBASSADOR**Janice Johnson**

Brownsville, KY

(270) 597-3854

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

— LOUISIANA —

LOUISIANA CHAPTER PRESIDENT**Elizabeth Tanner**

Baton Rouge, LA

(225) 241-3745

E-mail: louisiananaf@yahoo.com

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

— MAINE —

MAINE SUPPORT GROUP LEADER**Kelley Rollins**

Bowdoinham, ME

E-mail: kelley3902@myfairpoint.net

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

— MARYLAND —

CHESAPEAKE CHAPTER PRESIDENT**Carolyn Davis**

Vienna, VA

(703) 759-2008

E-mail: ccnafpres@gmail.com

www.ataxia.org/chapters/Chesapeake/default.aspx**JOHNS HOPKINS ATAXIA SUPPORT GROUP LEADER****Bailey Vernon, Health Educator**

Baltimore, MD

(410) 616-2811

E-mail: bvernon1@jhmi.edu

www.ataxia.org/chapters/JHASG/default.aspx**AMBASSADOR****Karen Rosenberger**

Frederick, MD

(301) 682-5386

E-mail: kdrosenberger@comcast.net

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

— MASSACHUSETTS —

BOSTON AREA SUPPORT GROUP LEADERS**Donna and Richard Gorzela**

Andover, MA

(978) 475-8072

E-mail: donna.gorzela@gmail.com

www.ataxia.org/chapters/Boston/default.aspx**CENTRAL MASSACHUSETTS
SUPPORT GROUP LEADERS**

John and Dana Mauro Jr.

Auburn, MA

(508) 736-6084

E-mail: johnmauro62@gmail.com

E-mail: danamauro63@msn.com

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

— MICHIGAN —

DETROIT AREA SUPPORT GROUP LEADER**Tanya Tunstull**

Detroit, MI

(313) 397-7858

E-mail: tinyt48221@yahoo.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 —

TWIN CITIES AREA SUPPORT GROUP LEADER**Lenore Healey Schultz**

Minneapolis, MN

(612) 724-3784

E-mail: schultz.lenore@yahoo.com

www.ataxia.org/chapters/TwinCities/default.aspx**CENTRAL MN SUPPORT GROUP LEADER****Marsha Binnebose**

St. Cloud, MN

(320) 240-9391

E-mail: marshabinnebose@yahoo.com

www.ataxia.org/chapters/StCloud/default.aspx**AMBASSADORS****Lori Goetzman**

Rochester, MN

(507) 282-7127

E-mail: logoetz@gmail.com

www.ataxia.org/chapters/LoriGoetzman/default.aspx**Julie Schuur**

Luverne, MN

(507) 283-2555

E-mail: jschuur@knology.net

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

— MISSISSIPPI —

MISSISSIPPI CHAPTER PRESIDENT**Camille Daglio**

Hattiesburg, MS

E-mail: daglio1@bellsouth.net

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

— MISSOURI —

KANSAS CITY SUPPORT GROUP LEADERS**Jim Clark**

Gladstone, MO

(816) 468-7260

E-mail: clarkstone9348@sbcglobal.net



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

Lois Goodman

Independence, MO

(816) 257-2428

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

AMBASSADORS

Roger Cooley

Columbia, MO

(573) 474-7232 before noon

E-mail: rogercooley@mediacommb.net

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

Susan L. Strode, PhD

Jefferson City, MO

(573) 659-4759

E-mail: drsusie@embarqmail.com

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

— NEVADA —

AMBASSADOR

Bernie Chippoletti

Las Vegas, NV

(702) 362-8774 ext. 0

E-mail: berniec@twdev.com

www.ataxia.org/chapters/LasVegas/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 —

TRI-STATE SUPPORT GROUP LEADER

Denise Mitchell

(212) 844-8711

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 Tarrant

Fabius, NY

Home: (315) 683-9486 Cell: (315) 706-6555

E-mail: jtarrant@aol.com

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

TRI-STATE SUPPORT GROUP LEADER

Denise Mitchell

Bronxville, NY

(212) 844-8711

E-mail: markmeghan2@gmail.com

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

— NORTH CAROLINA —

TARHEEL ATAXIA SUPPORT GROUP LEADERS

Norma Bryant

Cary, NC

(513) 543-9563

E-mail: normbryant1@gmail.com

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

Jerry Hauser

Advance, NC

(336) 998-2942

E-mail: deaconwfu@msn.com

— OHIO —

GREATER CINCINNATI AREA ATAXIA

SUPPORT GROUP LEADERS

Jennifer Mueller

Cincinnati, OH

(513) 834-7002

E-mail: jenmu@yahoo.com

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

Julia Soriano

Cincinnati, OH

(513) 899-1195

E-mail: jpantoga@core.com

AMBASSADOR

Carmen Pieragastini

Willowick, OH

(216) 272-5588

E-mail: willowpier@roadrunner.com

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

— OKLAHOMA —

OKLAHOMA SUPPORT GROUP LEADER

Darrell Owens

Bartlesville, OK

(918) 331-9530

E-mail: droopydog36@hotmail.com

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

AMBASSADOR

Mark Dvorak

Norman, OK

(405) 447-6085

E-mail: czechmarkmhd@yahoo.com

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

— OREGON —

WILLAMETTE VALLEY SUPPORT GROUP LEADER

Ivy Stilwell, CCC-SLP

Albany, OR

(541) 812-4162 Fax: (541) 812-4614

E-mail: istilwell@samhealth.org

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

— PENNSYLVANIA —

SOUTHEAST PENNSYLVANIA SUPPORT GROUP LEADER

Liz Nussear

Norristown, PA

(610) 272-1502

E-mail: lizout@aol.com

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

CENTRAL PA SUPPORT GROUP LEADER

Christina Rakshys

Allentown, PA

(610) 395-6905

*NAF Directory**Continued from page 51*

E-mail: rakshys@ptd.net
www.ataxia.org/chapters/Rakshys/default.aspx

– TENNESSEE –**MIDDLE TN AREA SUPPORT GROUP LEADER**

Vicki Tyler
 Nashville, TN
 (615) 646-3024
 E-mail: tylerv2@comcast.net
www.ataxia.org/chapters/VickiTyler/default.aspx

– TEXAS –**CENTRAL TEXAS SUPPORT GROUP**

Linda Crawley
 Liberty Hill, TX
 (512) 635-9478
 E-mail: lcrawley57@gmail.com
www.ataxia.org/chapters/Linda/default.aspx

NORTH TEXAS SUPPORT GROUP LEADER

David Henry Jr.
 Trophy Club, TX
 (817) 491-4573
 E-mail: cheve11e@sbcglobal.net
www.ataxia.org/chapters/NorthTexas/default.aspx

AMBASSADORS

David Brunnert
 Cypress, TX
 (723) 578-0607
 E-mail: david.brunnert@sbcglobal.net
www.ataxia.org/chapters/Brunnert/default.aspx

Dana LeBlanc
 Orange, TX
 (409) 883-5570
 E-mail: tilessal@yahoo.com
 Web: <http://ladyd1973.tripod.com/index.html>
www.ataxia.org/chapters/GoldenTriangle/default.aspx

Debra Whitcomb
 El Paso, TX
 (915) 329-0721
 E-mail: debrawhitcomb@hotmail.com
www.ataxia.org/chapters/Whitcomb/default.aspx

– UTAH –**UTAH SUPPORT GROUP LEADERS**

Dr. Lisa Ord, PhD, LCSW
 Salt Lake City, UT
 (801) 587-3020
 E-mail: lisa.ord@hsc.utah.edu
www.ataxia.org/chapters/Utah/default.aspx

Grant Beutler
 E-mail: grant.beutler@gmail.com

– VIRGINIA –**CHESAPEAKE CHAPTER PRESIDENT**

Carolyn Davis
 Vienna, VA
 (703) 759-2008
 E-mail: ccnafpres@gmail.com

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

– WASHINGTON –**SEATTLE AREA SUPPORT GROUP LEADER**

Milly Lewendon
 Kirkland, WA
 (425) 823-6239
 E-mail: ataxiaseattle@comcast.net
www.ataxia.org/chapters/Seattle/default.aspx

AMBASSADOR

Linda Jacoy
 Spokane, WA
 (509) 482-8501
 E-mail: linda4727@hotmail.com
www.ataxia.org/chapters/Spokane/default.aspx

International Support Groups and Ambassadors

– AUSTRALIA –**AMBASSADOR**

Renee Moore (Nee McCallum)
 Hocking, W. Australia
 61-8-9404-7052
 E-mail: moorear@bigpond.com
www.ataxia.org/chapters/ReneeMoore/default.aspx

– CANADA –**AMBASSADORS**

Susan M. Duncan
 Ottawa, Ontario
 (613) 820-7990
 E-mail: smduncan1@sympatico.ca
www.ataxia.org/chapters/SusanDuncan/default.aspx

Prentis Clairmont

Ottawa, Ontario
 (613) 864-8545
 E-mail: prentis.clairmont@gmail.com
www.ataxia.org/chapters/PrentisClairmont/default.aspx

Terry Greenwood

Winnipeg, Manitoba
 (204) 488-4155
 E-mail: wpgmagic@gmail.com
www.ataxia.org/chapters/TerryGreenwood/default.aspx

– INDIA –**INDIA ATAXIA SUPPORT GROUP LEADER**

Chandu Prasad George. CH,
 Secunderabad, India
 Phone: 0091-040-27961269
 Mobile: 0091-9949019410 Fax: 091-040-27971043
 E-mail: sam_ataxiaindia@yahoo.com
www.ataxia.org/chapters/Chandu/default.aspxv



Calendar of Events

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

SUPPORT GROUP MEETINGS

– **Saturday, December 29, 2012** –

New Hampshire Ataxia Support Group Meeting

Time: 10 a.m. – noon

Location: Stop & Shop in the Conference Room, 7 Kilton Rd., Bedford, NH 03110. The conference room is located on the second level (mezzanine). It is accessible via an elevator located to the left of the bakery side entrance to the store. Exit the elevator, turn to the right and follow ahead to the conference room. There is an accessible rest room on this level. This location is easily accessible from I-93, I-293 and NH 101.

Details: New folks always welcome. Open to future meeting times. Join us and help us help each other. For more information contact Jill Porter at (603) 626-0129 or jilleporter@comcast.net.

– **Saturday, January 12, 2013** –

West Central Ataxia Support Group Meeting

Time: 12:30 – 3 p.m.

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

Details: Election of officers. For more information contact Cindy Steever-Ziegler at (239) 878-3092 or csteever@msn.com.

– **Saturday, January 19, 2013** –

Denver Area Ataxia Support Group Meeting

Time: 1 – 4 p.m.

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

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

Middle Tennessee Ataxia Support Group Meeting

Time: 2 p.m.

Location: Amerigo, 1656 Westgate Cir., Brentwood, TN 37027

Details: For more information contact Vicki Tyler at (615) 646-3024 or tylerv2@comcast.net.

Tar-Heel Ataxia Support Group Meeting

Time: 1 – 3 p.m.

Location: Hampton Inn at the Advance exit on I-40 (exit #180B)

Details: For more information contact Jerry Hauser at (336) 998-2942 or deaconwfu@msn.com

– **Saturday, January 26, 2013** –

New Hampshire Ataxia Support Group Meeting

Time: 10 a.m. – noon

Location: Stop & Shop in the Conference Room, 7 Kilton Rd., Bedford, NH 03110. The conference room is located on the second level (mezzanine). It is accessible via an elevator located to the left of the bakery side entrance to the store. Exit the elevator, turn to the right and follow ahead to the conference room. There is an accessible rest room on this level. This location is easily accessible from I-93, I-293 and NH 101.

Details: New folks always welcome. Open to future meeting times. Join us and help us help each other. For more information contact Jill Porter at (603) 626-0129 or jilleporter@comcast.net.

– **Saturday, February 16, 2013** –

Northeast Florida Ataxia Support Group Meeting

Time: 2 – 4 p.m.

Location: Baptist South Hospital. From I-95, take exit 335 which is Old St. Augustine Rd. Go East. Follow the signs to the Hospital. We are less than one-half mile off of the interstate. Directions to the conference rooms from main entrance: Come in the main entrance and make a right. Go past the first hallway on left and the Azalea, Begonia and Camellia conference rooms will be next doors.

Details: For more information contact Steve and Carole Brown at (352) 591-5095 or bike4brown@aol.com.

Orange County Ataxia Support Group Meeting

Time: 2 – 4 p.m.

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

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

– **Saturday, March 2, 2013** –

West Central Ataxia Support Group Annual Picnic

Time: Noon – 3 p.m.

Location: Lake Seminole Park, 10015 Park Blvd.

Continued on page 54

*Calendar of Events**Continued from page 53*

(74th Ave. N.), Seminole, Florida 33777

Details: For more information contact Cindy Steever-Ziegler at (239) 878-3092 or csteever@msn.com.**– Saturday, March 23, 2013 –****JHU Ataxia Support Group Support Meeting****Time:** Noon – 2 p.m.**Location:** Johns Hopkins at Green Spring Station Pavilion II, 1st floor conference room behind the café, 10753 Falls Rd., Lutherville, MD 21093**Details:** Guest speaker will be Kate Reed, MPH, ScM, CGC, Johns Hopkins Genetics Counselor. For more information contact Bailey Vernon, Health Educator, at (410) 616-2811 or bvernon1@jhmi.edu. Please RSVP if planning to attend.**– Saturday, April 20, 2013 –****Denver Area Ataxia Support Group Meeting****Time:** 1 – 4 p.m.**Location:** Swedish Medical Center in the Spruce C meeting room, 501 E. Hampden Ave., Englewood, CO 80113**Details:** For more information contact Charlotte DePew at cldepew77@comcast.net or (720) 379-6887.**Orange County Ataxia Support Group Meeting****Time:** 2 – 4 p.m.**Location:** Orange Coast Memorial Medical Center, Breast Center Building, Room 1A, 9900 Talbert Ave., Fountain Valley, CA 92708**Details:** For more information contact Daniel Navar at (323) 788-7751 or danieln27@gmail.com.**– Saturday, May 4, 2013 –****West Central Ataxia Support Group Meeting****Time:** 12:30 – 3 p.m.**Location:** Morsani Center, 13330 USF Laurel Dr. #1013, Tampa, FL 33612**Details:** For more information contact Cindy Steever-Ziegler at (239) 878-3092 or csteever@msn.com.**INFORMATIONAL AND AWARENESS EVENTS****– February 8-10, 2013 –****Abilities Expo****Location:** Georgia World Congress Center, Hall C4, Atlanta, GA**Details:** For more information visit www.abilitiesexpo.com.**– February 28, 2013 –****Rare Disease Day****Details:** For more information visit www.raredisease.org.**– March 15-17, 2013 –****56th Annual NAF Annual Membership Meeting****Location:** Detroit Marriott at the Renaissance Center, 400 Renaissance Dr., Detroit, MI**Details:** For more information visit www.ataxia.org/events/annual-meeting2013.aspx.**– March 22-24, 2013 –****Abilities Expo****Location:** Los Angeles Convention Center, Los Angeles, CA**Details:** For more information visit www.abilitiesexpo.com. ❖

Remembering NAF in Your Will

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

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

Over the years these individuals, who have chosen NAF as a beneficiary, have given any-

where from a few thousand dollars to nearly one million dollars. Their forethought and benevolence has enabled the Foundation to support promising ataxia research and provide meaningful programs and services to ataxia families. We are thankful for their compassionate acts and we will be eternally grateful for the impact they have made in helping ataxia families.

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

Memorials and In Your Honor

The National Ataxia Foundation is grateful to those who have made contributions in memory or in honor of their friends and families whose names are listed below. This list reflects contributions made in August 2012 through October 2012. 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.

Rob & Katie's Wedding	Page Davis Cathy DeCrescenzo	Tommie House Sidney Howell	Rolf Meima Raymond Mellinger	Leticia Schraermeyer
Kyle Acree	Joe DeCrescenzo	Krista Humes	Jasper Miles	Rose Schrick
Remo Agostini	Silvana Deluca	Carol Hunt	Sandy Miller	Derek Semler
Ralph Aiello	Olivia Douglass	Bev Ivie	Ellen Moetsch	Hunter Shankle
Crystal Allsopp	Denise Drake	Bob Ivie	Eileen Monteleone	Henry Skala
Mama Ang	Stephanie Euzebio	Jessica Jerke	Jack Moore	Trevor Smith
Victoria Ash	Shirley Even	Betty Jones	Dolores Morello	Jim Spain
George Bailey	Joseph Falcon	Maureen Jurek	Jospeh Morello	Ester Spillers
Sister Mary Baker	Katherine Falcon	Marvin Kamen	Diana Moxon	Joseph Stamer
Vicki Balogh	Trinity Falk	Troy Kight	Michael Nagle	David Stein
Jeffery Barberi	John Fauver	Richard Korosa	Amy Nakai	Richard Strojny
Brandon Barker	Mike Fink	Jamie Kosieracki	Tribute Name	John Surabian
Cletas Barnes	Kevin Fleming	Marcella Kukelhan	John Norton	Howard Swanson
Jennifer Barnett	Judy Flynn-Coleman	Chester Kulis	Alayne Novalany	Kyle Swier
Mary Barton	Albert Frei	Leonilla Lake	Joe Novalany	Scott Tabor
Alice Battang	Jonathan Fuller	Dina Landphair	Holly Paine	Deborah Taylor
Beth Bax	Katelyn Fuller	Gerald Laukhuf	Donald Peterson	Karen Taylor
Luke Baxley	Gregson Gann	Lorrie Laukhuf	Kinnie Peterson	Grover Taylor Jr.
Cheryl Bearman	Ryan Gibbons	Jen Leader	Domonick Pollino	Ruth Thompson
Cheryl Belsly	Maria Gilbert	William Lee	Ken Porter	Edward Thornton Sr.
Sandee Berst	Tanya Goldman	James Lehr	Denise Price-Dudley	Alan Tindal
Dorothy Biniek	Penny Golminas	Jim Lehr	Scott Quinn	Dr. Aymee Torres-Michels
Joseph Black	Lisa Golomski	Erica Lehrer	Charity Ranger	Margaret Tseng
M/M Josh Bocce	Karen Gorman	Tony Lewendon	Sharon Regalado	Jacob Van Buren
Pasquale Boemio	Diane Greer	Dave Lewis	Jim Richards	Dustin Vande Brake-Haarsma
Ralph Boemio	Lois Griffin's Wedding	Rita Lobascio	Arch Riley	Marie VanHorne
Matthew Bouma	John Gruenfelder	Kate Loftin	Elizabeth Riley	Linda VanValkenburg
Geraldine Brennan	Ricardo Guerrero	Christina Logan	Janet Riley	Shirley Wagner
Donald Britt	Teresita Guerrero	Joanne Loveland	Byron Roberts	Dorothy Walker
Gina Bryzgalski	Aaron Gulick	Michael Lundquist	Bryan Robinson	Deborah Webber
Joseph Cain	John Gulick	John Macy	David Robinson	Michael Webber
Carey Family	Georgie Haddad	Kory Macy	Jaclynn Robinson	June West
Tju-Ko Chuang	Chris Hammack	Anthony Massanova	Nathan Robinson	Betty Westmoreland
Michael Clementz	James Hankins	Bradley Masserant	Don Royer	David Westrick
Patricia Clementz	Jim Hankins	Brent Masserant	Patricia Rust	Sandra Whipple
Coffey Family	Carolyn Harris	Angelo Matrisciano	Patricia Rymut	Michael Williams
Kevin Cook	Gary Hartsock	Margaret McCrory	Donald Santa Croce	Virgie Wince
Lola Cooley	DrBrian Hass	Peggy McCrory	Lucia Schone	Robert Winslow
Catherine Covert	Carol Haukos	Alisa McFarland	Bruno Schraermeyer	Jenifer Wursta
William Covert	David Henry Jr.	Charley McLaughlin		Joanne Yeager
Roberta Crane	Alice Hicks	Earl McLaughlin Jr.		
Jaza Culpepper	Phyllis Hoekstra-Meima	Jose Medeiros		
Roger Cyr		Linda Meier		
Mary Danson				
Kennon Davis				





National Ataxia Foundation

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

Non-Profit
Organization
U.S. Postage
PAID
Madison, SD
Permit No. 32

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

GIFT – HONOR – MEMORIAL

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

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

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

My contribution is:

- In Memory In Honor Gift Membership

Name _____

Occasion _____

Send Acknowledgment Card to:

Name _____

Address _____

City/State/Zip _____

From:

Name _____

Address _____

City/State/Zip _____

MEMBERSHIP

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

- Lifetime membership \$500

Annual memberships:

- Patron membership \$100-\$499
- Professional membership \$55
- Individual \$35
- Household \$55
- Addresses outside the U.S. please add \$15

Name _____

Address _____

City/State/Zip _____

Phone _____

E-Mail _____

- Yes, sign me up for NAF e-mails

PAYMENT INFORMATION

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

- Check. Please make payable to the National Ataxia Foundation.

Total Amount Enclosed \$ _____

Credit Card: Visa MasterCard Discover

Name on Card _____

Card # _____

Exp. Date _____ CVV # _____

Signature _____

Phone Number _____