Generations

The Official Publication of the National Ataxia Foundation
Volume 41, Number 2
Summer 2013

International Ataxia Awareness Day (IAAD)

Chances are that if you had stopped 100 people on the street anywhere in the world 20 years ago and asked the question "What is ataxia?" not one would have had an answer. From that question, a new initiative was born … International Ataxia Awareness Day (IAAD).

IAAD is an international effort from ataxia organizations around the world to dedicate September 25 as International Ataxia Awareness Day. The first IAAD occurred on September 25, 2000 and was the first time that ataxia organizations throughout the world declared and recognized September 25 as IAAD.

Inside This Issue

- Uplifting **personal stories** abound and are listed in the Table of Contents on page 2
- For the schedule of **Walk n' Roll for Ataxia** events, turn to page 6
- Find out about the **new ataxia patient registry** on page 7
- A **new FDA website** that gives patients a bigger voice is detailed on page 14
- Reservation information for the **2014 AMM** in Las Vegas appears on page 23

Creating Ataxia Awareness

The goal of IAAD is for everyone who is impacted by ataxia to participate in some activity, creating awareness about ataxia. Make an impact by sharing your story with someone who has never heard of ataxia, educating others by speaking at a school or civic group, getting in touch with your local media, or wearing ataxia awareness apparel. Many have contacted city, county, or state government officials to receive a proclamation recognizing September 25 as IAAD. Others start or participate in an IAAD event, get

Continued on page 3

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

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Table of Contents

Annual Membership Meeting (AMM)

Planning Your Trip to Las Vegas? 4
2014 AMM Announcement 23
2013 AMM Photos 24-25

Research

NEW Ataxia Patient Registry Now Open for Enrollment 7
Patients Needed for Studies 18, 22
Tissue Donation Program for the SCAs and Sporadic Ataxia 30
Friedreich Ataxia Tissue Donation Program 30

Articles

International Ataxia Awareness Day 5
Walk n' Roll for Ataxia 6
2013 Chuck and Duck Dodgeball Tourney 9
What MRI Can Do for Ataxias and Why More MRI Research is Needed 10
From the Desk of the Executive Director 13
New Website Helps Patients Have a Bigger Voice at FDA 14
Planning Around Government Assistance Programs 17
Move YOUR Way for Rare Disease Day 21

Articles (cont.)

Macy's "Shop for a Cause" 22

Membership Topics

IAAD Apparel 4
Share Your IAAD Story 5
NAF Merchandise 28-29
2013 NAF Membership Drive 34
Chapter and Support Group News 35
NAF Directory of Chapters, Support Groups and Ambassadors 38
Calendar of Events 43
Memorials and In Your Honor 47

Personal Stories & Poems

Improvement with Ataxia Physical Therapy 15
After the Diagnosis 16
Ataxia Does Not Define Me 16
Humor 20
Our Honeymoon Trip to South America 26
Toe Wedge Helps with Balance 30
True Strength 31
Everyone Has a Story, and Here's Mine 32
My Dad, My Hero 33

The deadline for the Fall issue of Generations is August 9.

International Ataxia Awareness Day
Continued from page 1

involved or organize a Walk n' Roll for Ataxia, or participate in the Virtual Walk n' Roll.

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

International Reach

IAAD helps creates ataxia awareness, but IAAD also creates a way to raise much-needed funds. Funds raised through NAF Walk n' Rolls and other National Ataxia Foundation IAAD events have helped support vital ataxia research studies not only here in the United States, but also has helped fund promising ataxia research in other countries. International Ataxia Awareness Day's impact is truly international.

Walk n' Roll for Ataxia

In recognition of IAAD, NAF Walk n' Rolls for Ataxia began seven years ago to help create ataxia awareness and to raise funds to help support the important work of NAF. The first Walk n' Roll was hosted by the San Diego Ataxia Support Group, led by Earl McLaughlin, their Support Group Leader.

Over the past seven years, NAF Walk n' Rolls for Ataxia have been conducted throughout the United States and have raised more than $700,000 to support research and programs. Participating, organizing, or donating to a local Walk n' Roll is now easier through a new web-based fundraising module called Friends Asking Friends (FAF). On the Foundation's website, *www.ataxia.org*, select your local support group who is conducting a Walk n' Roll and click to their site. You are able to participate, donate, create a team, register, or let others know about the event.

Virtual Walk n' Roll for Ataxia

If there is not a local NAF Walk n' Roll for Ataxia in your area, we have some very exciting news for you … NAF's Virtual Walk n' Roll. You can create your own team, have a friendly competition with a friend, family member or co-worker, and begin creating ataxia awareness and raising funds to support the mission of NAF. On NAF's web site, *www.ataxia.org*, click "Virtual Walk n' Roll" and you will be able to enter the world of "Virtual Walk n' Roll."

After you register through the event website you are automatically signed-up as a Virtual Walk n' Roll participant. A personal fundraising page is created just for you, where you can upload pictures, write personal text, and set your own goal. Then you can forward your fundraising page link to your family and friends, and ask them to "sponsor" you to help you meet your fundraising goals. If you wish to contribute without becoming a participant, please click "General Donation" to support the Virtual Walk n' Roll.

IAAD Events

Other exciting IAAD events could include "Jeans Day" where employees are allowed to wear jeans at work on that day with a donation to NAF. (Ask your employer if they would be interested in participating.) Various restaurants are donating a percentage of sales to NAF during IAAD. Group and family picnics, BINGO events, and many other events are being planned, bringing the word "ataxia" to local communities throughout the country.

Many of the IAAD Events and fundraisers are

Continued on page 4

International Ataxia Awareness Day

Continued from page 3

printed in the Calendar of Events listing located in the back of this issue of *Generations* (starting on page 45).

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

To purchase ataxia awareness apparel or items visit the NAF Merchandise listing on pages 28-29 of this newsletter or NAF's online store at *http://tinyurl.com/nafstore*.

Get Involved

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

Thank You

Thank you to all who are creating ataxia awareness on IAAD and throughout the year. ❖

IAAD Apparel

Create ataxia awareness by wearing an "I am the Strength behind ataxia" T-shirt or other ataxia awareness apparel. You can order ataxia awareness apparel online at NAF's web site *www.ataxia.org* and click "Store."

International Ataxia Awareness Day (IAAD) on September 25 is just around the corner, so order your ataxia awareness apparel today!

Front

Back

iSearchiGive

iSearchiGive.com is a new search engine powered by Yahoo! Search and *iGive.com* is 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 National Ataxia Foundation is your favorite cause. It is free with no hidden fees and provides support for the important work of NAF.

Fall Deadline

The deadline to submit materials for the Fall issue of *Generations* is August 9. Please see page 2 for contact information.

Planning Your Trip to Las Vegas?

Are you planning on attending the 2014 NAF Annual Memberhip Meeting (AMM)? If so, you should request a Las Vegas guide book from the Las Vegas Convention and Visitors Authority to help you plan your journey!

The complimentary guide book is filled with information about the city. This free guide book can be requested by calling 1-877-847-4858, or you may also request or download a copy at *www.lasvegas.com/planning-tools/free-visitors-guide/*.

To find out more about the 2014 NAF Annual Membership Meeting, see the AMM announcement on page 23 or visit NAF's website, *www.ataxia.org*.

International Ataxia Awareness Day (IAAD)

Wednesday, September 25, 2013

"International Ataxia Awareness Day" (IAAD) is an international effort from Ataxia Organizations around the world to dedicate September 25 as International Ataxia Awareness Day. Each participating country, state, or individual may have a specific plan for this event.

For more information on organizing an event in recognition of IAAD please visit *www.ataxia.org/events/international-ataxia-awareness-day.aspx*.

How Did You Participate in IAAD?

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

Your stories on how that day was recognized could live on in a future issue of *Generations*. Please send us your articles, photos, and proclamations so the entire NAF community can relive this historic day.

Thank you.

Walk n' Roll for Ataxia

The ultimate finish line … a cure for ataxia

What is Walk n' Roll for Ataxia?

The Walk n' Roll for Ataxia program is the National Ataxia Foundation's largest national grassroots fundraising event.

Walk n' Roll for Ataxia currently takes place in cities across the United States. Since its inception in 2007, Walk n' Roll for Ataxia has raised more than $700,000 thanks to the support and tireless commitment from walkers, rollers, runners, volunteers, donors, and sponsors.

Why Walk or Roll?

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

How Can I Participate?

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

Current 2013 Walk n' Roll Events and Locations

- **Now through September 25 – Virtual Walk n' Roll. *www.ataxia.org/walk/virtual***
- September 8 – Denver Walk, Run n' Roll, Denver, CO. *www.ataxia.org/walk/denver*
- September 14 – Minnesota Walk, Stroll n' Roll, St. Louis Park, MN. *www.ataxia.org/walk/minnesota*
- September 21 – Atlanta Walk n' Roll, Duluth, GA. *www.ataxia.org/walk/atlanta*
- September 21 – Jacksonville Walk n' Roll, Jacksonville, FL. *www.ataxia.org/walk/jacksonville*
- September 21 – Detroit Walk n' Roll, Detroit, MI. *www.ataxia.org/walk/detroit*
- September 28 – Central Massachusetts Walk n' Roll, Auburn, MA. *www.ataxia.org/walk/auburn*
- September 28 – Northern CA Walk n' Roll and Fitness Faire, Lafayette, CA. *www.ataxia.org/walk/lafayette*
- September 28 – LA/OC Walk n' Roll, Long Beach, CA Long Beach, CA. *www.ataxia.org/walk/longbeach*
- September 28 – San Diego Walk n' Roll, San Diego, CA. *www.ataxia.org/walk/sandiego*

For more information please visit *www.ataxia.org/events/walk_n_roll.aspx*

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NEW Ataxia Patient Registry Now Open for Enrollment

More than 1,400 people affected by ataxia or at risk for ataxia have initiated or completed enrollment in the National Ataxia Registry (NAR), a web-based patient registry funded by the National Ataxia Foundation and hosted at the University of Florida since its initial launch in March 2010.

There has been great value in this registry. Through aggregate data in the registry, an abstract was submitted and accepted for presentation at the 2012 American Academy of Neurology annual meeting. The Registry was an important component for the Clinical Research Consortium for the Spinocerebellar Ataxias when this group successfully applied for grant funding from NIH. The experience of designing a registry for the ataxia patient population was an essential precursor to developing a long-term, self-sustaining registry. The positive response to the Registry, demonstrated the spirit and determination by those affected by ataxia to move research forward by enrolling in the National Ataxia Registry.

> **“We are confident that the ataxia patient registry… will be of great value in accelerating the entire field of ataxia clinical research…”**

In April 2012 an extensive study began to search for ways to streamline the ataxia patient registry enrollment process for participants and make the registry available to international participants. Members of the National Ataxia Foundation staff, Medical Research Advisory Board, Board of Directors with NAF’s legal expert explored the Coordination of Rare Diseases at Sanford (CoRDS) patient registry. CoRDS is an international rare disease registry designed to accelerate research into rare conditions to include all types of ataxia. Currently the forms are only in the English language, so those who enroll must speak and understand English. The program collects and stores basic contact and clinical information on individuals of any age who have been diagnosed with a rare disease or are at-risk of having a rare disease. CoRDS has partnered with nearly 60 rare disease organizations to accelerate participation in the global registry and increase awareness of rare disease research.

In May 2013, the National Ataxia Foundation reached an agreement with the Coordination of Rare Diseases (CoRDS) at Sanford Research to host its ataxia patient registry to help advance research of all forms of the disease. Within the CoRDS patient registry, the NAF questionnaire, created specifically for ataxia, has the technology support of a world-class, software development company with secure, compliant ways of managing clinical research.

“As the CoRDS database grows, so does the capacity for researchers to make advances in the area of rare disease research,” said Liz Donohue, director of CoRDS. “We are delighted to partner with the National Ataxia Foundation, which will surely serve as a great partner in the growth of our registry.”

“The diligence and study that went into this important decision was a process that was

Continued on page 8

NEW Ataxia Patient Registry…
Continued from page 7

time-intensive and involved the various expertise of many people with one focus … the ataxia patient," said Dr. Susan Perlman, NAF's Medical Director. "We are confident that the ataxia patient registry, being administered through CoRDS, will be of great value in accelerating the entire field of ataxia clinical research now and well into the future."

Using the CoRDS registry, will enhance and expand the experience for enrollees. One of the enhancements is the capability of the enrollee to provide informed consent on-line. This will mean that telephone consent is no longer required. After reading and agreeing to the "Informed Consent Form," participants may click a button on-line which will then expedite the ability to complete the entire enrollment into the ataxia registry. Most participants will be able to complete their enrollment in one sitting, usually taking less than 20 minutes. An option to enroll by postal mail will also be available.

The enrollment process begins with the CoRDS Registry Screening Form shown above.

The expansion of the registry includes more ataxia diagnoses, reminders sent annually so that information is kept current, along with informative correspondence about the Registry for those who have a rare disease, such as ataxia. The CoRDS registry will also allow for national and international researchers who have appropriate approval to utilize the Registry.

"One of the NAF's core goals is to advance promising research, and this partnership is a vehicle to continue moving forward in that area," said Michael Parent, NAF's executive director. "The NAF is pleased to be part of a comprehensive registry that aims to understand and develop treatments for rare diseases."

The data currently held in the National Ataxia Registry (NAR) will not be transferred to the new CoRDS Registry. Therefore, those individuals who are fully enrolled or are partially registered in the NAR are encouraged to re-enroll in the new CoRDS Registry. More details regarding this was communicated to these registrants by earlier email from Dr. Subramony, Principal Investigator of the National Ataxia Registry at the University of Florida.

"It has been a pleasure to work with NAF to develop the first web-based ataxia patient registry. I am grateful to the many people who registered on the NAR however, because of requirements by the Institutional Review Board, individual patient data stored in the National Ataxia Registry (NAR) will not be transferred to the CoRDS registry," said Dr. S.H. Subramony. "I encourage current registrants in the NAR to re-register in the new patient registry at CoRDS. Although this may be a bit of an inconvenience, the 20 minutes or so to complete the ataxia questionnaire in the new registry at CoRDS will insure the availability of participants for future clinical research studies."

With your help, support and enrollment in the patient registry, ataxia research will move forward to help end ataxia. By enrolling in CoRDS, participants who qualify will be notified of any opportunities to participate in clinical trials as well as other research opportunities. To enroll in the ataxia registry within the CoRDS patient registry go to *www.sanfordresearch.org/CoRDS/CoRDSRegistryForm/* to submit the CoRDS Registry Screening Form to indicate if you

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would like web-based or mail-based enrollment, your referring Organization (National Ataxia Foundation), and the disease-specific registry in which you would like to enroll (National Ataxia Foundation registry). A screen shot of the Screening Form is shown on the preceeding page.

If you have any questions about the National Ataxia Registry or the ataxia registry within CoRDS patient registry, you may contact Sue Hagen, NAF Patient Services Director at (763) 553-0020 or *susan@ataxia.org*. If you have questions about CoRDS or how to register, you may contact CoRDS personnel at (605) 312-6423 or *CoRDS@sanfordhealth.org*. ❖

2013 Chuck and Duck Dodgeball Tournament

The gym at Charlton Heights was rocking on April 19 as third, fourth and fifth grade students participated in the Fourth Annual "Chuck and Duck" Dodgeball Tournament. Staff members, parent volunteers, and students raised over $3,000 for the National Ataxia Foundation in honor of former student Jacob Van Buren.

Jacob learned of this rare disease when he was a third grade student at Charlton Heights. His family has since moved to Florida where he attends sixth grade. "Jacob is such a great kid," said teacher Alison Donofrio. "We wanted him to know that we have not forgotten him and will be there to support him even though he is 1,200 miles away."

Students showed great sportsmanship while competing in the dodgeball tournament. "Students played hard, fair, and showed their true character during this event," said Steve Jones, a physical education teacher. "We could not be more proud of our students and the community we teach in. We also appreciate all the support from the PTA. It truly shows that a child's education while at Charlton Heights is a team approach!"

Kids were all smiles during the Fourth Annual "Chuck and Duck" Dodgeball Tournament, which raised over $3,000 for NAF.

Plans are already in the works for next year's event. Event planners are thinking of new ways to make the event bigger and better. "We want this dodgeball event to become part of the Charlton Heights culture," said Andrew Haluska, a third-grade teacher. "We want students to look forward to when they can participate in the tournament. We want to create a buzz surrounding the event, but at the same time, remember we are raising money and awareness for a disease that many people do not know exists." ❖

What MRI Can Do for Ataxias and Why More MRI Research is Needed

By Gülin Öz, PhD

Center for Magnetic Resonance Research, Department of Radiology, University of Minnesota, Minneapolis, MN

The brain, or "the three pounds of matter that sits between our ears" as President Obama described it, is unlike any other organ: a complex network of more than 80 billion neurons encased in the skull, surrounded by cerebrospinal fluid and protected by the blood-brain barrier from potentially hazardous chemicals in the circulation. Highly protected and not easily accessible…

Ataxias affect the cerebellum (the "little brain") that takes up only 10% of the total brain volume but contains more neurons than the rest of the brain put together. This little brain controls our movements, including our gaze, speech, gait and balance. As in all other neurodegenerative diseases, it is a major challenge to access and monitor the underlying brain pathology in ataxias. Dysfunction and loss of the neurons in the cerebellum cause the balance and coordination problems that can easily be assessed and monitored by a clinical examination, but clinical symptoms do not tell the whole story. Scientists now know that the changes in the brain in neurodegenerative diseases start years before symptoms occur. That is, neurons are struggling long before they die. Using mouse models, researchers demonstrated that neuronal dysfunction is reversible and this 'dysfunction' period would be the time for application of neuroprotective therapies – to delay the onset of symptoms and slow the progression of the disease; to help the struggling neurons. Tools to detect these early changes and to monitor the progression and perhaps even the slowing down / reversal of pathology by novel drugs directly in the brain have been limited. In addition, drugs that improve symptoms such as the balance problems in ataxias, do not always slow the progression of the brain pathology. Therefore tools that can distinguish such symptomatic effects from 'disease-modifying' effects of drugs are highly desirable. That is where non-invasive neuroimaging technologies such as magnetic resonance imaging (MRI) come in.

MRI technology uses radio frequency pulses and strong magnetic fields to allow non-invasive access to brain structure and function. It does not involve radioactivity ("ionizing radiation") and therefore serial scanning does not present a concern. There are many ways to use the MRI scanner to obtain different and complementary information about the brain. MRI techniques most commonly measure the water in the body (the brain is made up of 70-80% water), but other brain chemicals (neurochemicals) can also be detected and quantified by a specialized MRI modality called MR spectroscopy (MRS). Clinical MRI scanners typically have a magnetic field strength of 1.5 tesla (T), but high (3T) and ultra-high (7T) field scanners provide even higher sensitivity, better images and more reliable structural and functional information on the brain – which is why many academic hospitals are now also using 3T scanners.

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MRI is currently used in the clinical care of ataxias as a diagnostic aid, to detect the atrophy (shrinkage) of the cerebellum. But this is only the most basic information that the MRI scanner can provide on brain anatomy. Using different MRI techniques we learn about the connectivity and wiring in the brain (diffusion MRI), brain chemistry (MRS) and blood flow and function (functional MRI) among others. All of these various MRI techniques have been used to study ataxias. For example, using structural MRI, researchers have observed different patterns of brain atrophy in different ataxias and that the brain tissue loss reflects disease severity. Others have shown that disruptions in the brain connectivity in ataxias can be detected using diffusion MRI. Chemical changes that occur with disease progression can be detected by MRS and they reflect the severity of cerebellar pathology.


Dr. Gülin Öz

The potential for all this new information to one day effect clinical decision making is great, but there is much more to do. These new technologies, which can one day help with differential diagnosis in ataxias (e.g. which genetic test to perform first when a family history is not available), with monitoring drug effects in clinical trials and with understanding disease processes so that novel treatments can be devised, need to be tested and validated thoroughly for the many ataxia subtypes before they can be used in the ataxia clinic – which is why continued support for this research by the National Institutes of Health (NIH) and other organizations is critical.

Unfortunately when it comes to NIH funding, we are currently in a pickle. The economic struggles of the last decade are also felt strongly in the research environment. The NIH receives more and more grant applications, most of which cannot be funded as NIH's purchasing power has been reduced by 20% over the last 20 years due to flat budgets.

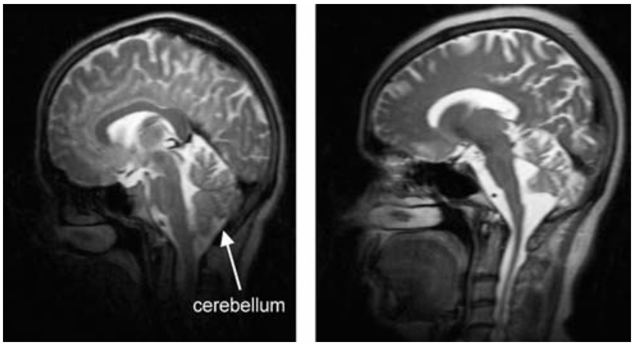
In this tough environment with waning support for biomedical research, the new Brain Initiative (Brain Research through Advancing Innovative Neurotechnologies, *www.whitehouse.gov/infographics/brain-initiative*) is most welcome and expected to provide some support for MRI research. The Initiative is launching with $100 million in funding for research supported by the NIH, the Defense Advanced Research Projects Agency (DARPA), and the National Science Foundation (NSF), pending congressional approval of the President's Fiscal Year 2014 budget. Additional commitments from several foundations and private research institutions have also been secured.

However, the future of this initiative and support for biomedical research in general, including MRI research, is far from guaranteed. Quoting the President of the Society for Neuroscience, Dr. Larry W. Swanson, "scientists will be challenged to make progress on even these initial (BRAIN) projects without sustained and growing financial investment in the scientific enterprise." One might wonder why investments in the research endeavor should be prioritized when many other economic challenges dominate the world scene. The answer is in the treatments that are desperately needed for diseases like ataxias. Considering one in six people worldwide have a neurological disease, there is also an economic incentive. According to a recent interview with our state senator Amy Klobuchar, "neurological disorders cost the United States about $137 billion a year, not counting the toll on caregivers, and the cost is projected to rise to $1 trillion by 2050." Considering the rising costs of healthcare

Continued on page 12

What MRI Can Do for Ataxias…
Continued from page 11

in the U.S. and worldwide, novel neuroimaging methods that can help develop drugs to alleviate the burdens of these diseases on society are worth investing.



MR image from an individual with spinocerebellar ataxia (right) and a healthy individual (left). The atrophy of the cerebellum in the individual with ataxia is apparent from the larger amount of cerebrospinal fluid (bright substance in the image) around the cerebellum.

It is therefore critical to contact our congressmen and women to encourage support for initiatives like the BRAIN initiative and biomedical research in general. According to NIH (*www.nih.gov/science/brain/*), input will be sought broadly from the scientific community, patient advocates, and the general public during the planning process for the BRAIN initiative – an opportunity for the ataxia community to have our voices heard.

The NIH Blueprint for Neuroscience Research – an initiative that pools resources and expertise from across 15 NIH Institutes and Centers – will be the leading NIH contributor to the BRAIN initiative. I, as an ataxia investigator, have already benefited from this NIH Blueprint initiative, when I responded to a Request for Applications announced under the initiative and applied for funding to study ataxias with MRS. Through this work we identified biomarkers that can be used to non-invasively monitor the brain chemistry and pathology in several hereditary ataxias. We now work on translating the technology for use in clinical trials in ataxias, the next necessary step in bench-to-bedside translation of this novel technology. Therefore while funding for research is tight, initiatives such as these restore our hope in the future and that we will one day conquer these devastating diseases that affect the little brain. In this endeavor, the support of patient advocacy groups such as NAF and individual patients and families, working together with scientists, cannot be underestimated.

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Free Magazine for Those Affected with Neurological Disorders

Neurology Now is the official publication of the American Academy of Neurology. It is currently available at no cost to individuals with a neurological disorder (including ataxia), their families, and caregivers. To order a subscription, call 1-800-422-2681 or go to *www.NeurologyNow.com*.

There is also the opportunity to have your personal essay printed in the "Speak Up" section of the magazine. This forum is for people who live with neurologic conditions and those who care for them. Submissions should be kept to 600 words and should be sent to *neurologynow@ lwwny.comor* or faxed to (646) 674-6500.

Sharing your story can help raise awareness of ataxia as one of the many neurological diseases that needs more funding for researchers and clinical care information for general neurologists.

From the Desk of the Executive Director

By Michael Parent, NAF Executive Director

Thank you to all who supported the 2013 NAF Annual Membership Drive. We warmly welcome our new and renewing members. Your membership support significantly helps in providing important programs and services to ataxia families. Thank you! Thank you also to our current members who gave a Gift Membership or a donation in response to the drive. If you have not yet done so, there is still time to contribute to the 2013 NAF Annual Membership Drive by going on-line to NAF's web site, *www.ataxia.org* and clicking on "Donate Now." It's never too late to become a member or renew your membership.

We have exciting news about a new patient registry for those with ataxia and those who are "at-risk." The new patient registry will offer a streamline enrollment process for participants (approximately 20 minutes to fully register), has the technological support of a world-class, state-of-the-art software development company and expert IT personnel to assure a secure and robust system in managing clinical research, and now is available to international participants.

The National Ataxia Foundation has formed a cooperative agreement with the Coordination of Rare Diseases (CoRDS) at Sanford Research to host its ataxia patient registry. This partnership will significantly help in moving ataxia research forward. If you have previously registered or have been thinking about registering, we encourage you to register in the new CoRDS ataxia patient registry. To register, contact CoRDS personnel at (605) 312-6423, e-mail *CoRDS@sanfordhealth.org* or go online and visit *www.sanfordresearch.org/cords/cordsregistryform/*. (See article on page 7 for more information.)

A heartfelt thank you to all who had registered in our previous patient registry, the National Ataxia Registry. We are truly grateful to all of you for your commitment in accelerating ataxia clinical research. The new ataxia patient registry will significantly help in this acceleration and continued advancement of research in all forms of ataxia.

International Ataxia Awareness Day (IAAD) is September 25, a day that people and ataxia organizations around the world recognize to help increase ataxia awareness. Help us increase ataxia awareness by telling a friend, co-worker, or neighbor about ataxia. Support or create an IAAD event, participate in a Walk n' Roll for Ataxia event, or get involved with the Virtual Walk n' Roll. Ask your local or state elected officials to declare September 25 as IAAD or wear ataxia apparel. NAF offers an IAAD awareness kit as a guide to help you promote International Ataxia Awareness Day in your community. You can find the kit on NAF's web site, *www.ataxia.org*, under "Events." Please let us know about your IAAD activities so we can share with others in a future issue of *Generations* by e-mailing your story to at *joan@ataxia.org*.

Plans are underway for the 2014 National Ataxia Foundation's 57th Annual Membership Meeting (AMM), which will be held at Bally's in Las Vegas on March 21–23, 2014. We are very excited about the program and speakers for the 2014 conference, which will be hosted by the Western Region Support Groups. We look forward in seeing you in Las Vegas.

If you are interested in making a reservation for an ADA room at Bally's during the conference, please directly contact the National Ataxia Foundation. We will begin accepting ADA reservations on August 7 at noon (CDT). You may either e-mail *lori@ataxia.org* or call (763) 553-0020.

Along with the AMM, plans have also begun for the Fifth International Ataxia Investigator's Meeting (AIM), "AIM 2014: Advancing Toward Therapeutics." This scientific conference for

Continued on page 14

From the Desk of the Executive Director
Continued from page 13

ataxia researchers will begin prior to the 2014 AMM and will assemble an international roster of world-leading investigators to address the multi-disciplinary nature of ataxia, to define better the pathogenic basis of ataxia, and to explore routes to therapy. The conference will focus on the most recent scientific advances and emerging translational approaches toward therapy.

The AIM 2014 co-lead organizers are Harry T. Orr, PhD, University of Minnesota, and David Lynch, MD, PhD, University of Pennsylvania.

The overall objective of the AIM 2014 conference will be to create a forum for presenting the latest developments in translational research on ataxia, encourage cooperation and collaboration among researchers and to help accelerate worldwide ataxia research. Senior and junior investigators from around the world will be attending this international scientific conference on ataxia. As with the past AIM, there will be opportunities for AMM attendees to interact with investigators through a Thursday afternoon poster session and at the Friday afternoon Birds of a Feather sessions.

Researchers around the world are beginning to submit their research proposals to NAF for funding in late December. We are excited by the quality of these research studies and the promise they bring in furthering our efforts to help end ataxia. Over the past two years NAF has received more than 140 ataxia research proposals from 13 countries. To help support these promising studies for funding, the NAF Annual Ataxia Research Drive will begin on October 15. More details on this important drive will be forthcoming.

Thank you and have a wonderful summer. ❖

New Website Helps Patients Have a Bigger Voice at FDA

With its new Patient Network website, *PatientNetwork.FDA.gov*, the Food and Drug Administration (FDA) Office of Health and Constituent Affairs (OHCA), formerly the Office of Special Health Issues (OSHI), welcomes the unique perspective of patients, family members, caregivers, and patient advocates directly affected by serious disease to the Agency's decision-making processes.

FDA's Patient Network supports people who are looking for reliable information about medical products and their approvals, clinical trials, and other treatment options. The new website contains information on the drug and device approval process, clinical trials, investigational drugs, off-label drug use, and new FDA approvals – all written in plain language that is easy to understand.

To enhance usability and transparency, FDA has developed a "Get Involved" page, which offers several interactive functions, including e-newsletter signup, live chats, a calendar of public meetings, webinars on medical product regulation, a clinical trial search, and information on how you can apply to the FDA Patient Representative Program.

The FDA Patient Representative Program is a unique opportunity for members of the public to apply to become Patient Representatives and act as liaisons between the public and FDA. These individuals serve on FDA's Advisory Committees and are invited to ask questions on behalf of the patient community. Patient Representatives also present at FDA meetings and workshops. Those interested in becoming a Patient Representative may apply online through the Patient Network website.

For more information on FDA's Patient Network, visit *PatientNetwork.FDA.gov* or e-mail *PatientNetwork@fda.hhs.gov*.

Improvement with Ataxia Physical Therapy

By Theresa Gonzales
Orange County ASG of Southern California

I'd like to share with you my experience with ataxia in the past eight months. I worked with Dr. Tom Clouse on physical therapy techniques in January, and what I learned from him encouraged me to take the "t" out of "I can't" – very life changing and confidence building.

Dr. Clouse taught me techniques and exercises to practice walking without a walker and other techniques that I will mention later. After our sessions, I would be very tired from not really having any physical exercise strengthening for over 20 years, and this was very frustrating in my physical progress. Dr. Clouse suggested joining the YMCA. I never thought this was possible with ataxia. I jumped at the thought, qualified for financial aid, and have been an active member for seven months now. The YMCA is very accessible and I am able to use their nautilus equipment if I am very careful.


Theresa Gonzales

My legs, especially my calves, have really become a lot stronger. One concrete example is to be able to get up to a standing position, no hands and no help, from a low level couch using the techniques that he showed me. Also, I don't get cramps anymore in my lower legs. I have even been able to walk at more extended lengths than I use to. I use the shopping cart as a walker and I have been able to go shopping for lengths of 30 minutes to one hour at many of the local stores. Because I have more stamina, I have even been able to cook again and help more in the kitchen – it feels great to be useful again at home.

These are real, concrete, positive physical improvements that I have experienced with this progressive condition; and without any medication and no side effects.

I strongly encourage you to check out Dr. Clouse's website, *www.walkingwithataxia.com*, and also *www.youtube.com/watch?v=Br72k-LLXsc*. I enthusiastically encourage you to contact Dr. Clouse if you are willing and able to, and to invest in the time he teaches to learn methods of physical therapy for ataxia. The rewards are worth the hard work and really gives a boost to self-confidence and positive self esteem.

Editor's Note: Please consult your physician before beginning any new exercise program. Results of any exercise program may vary and testimonials given are not claimed to respresent typical results.

❖

CFC Number

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

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

After the Diagnosis

By David W. Shere

In 2007, I was diagnosed with a myriad of neurological problems.

First, a poor quality MRI said I had a "mass" in the center of my brain. I'm not even Catholic. Why is there a mass in my brain?

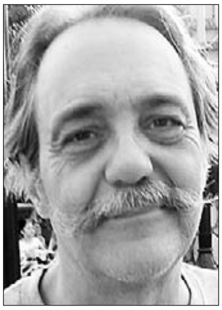
We were told we should try another MRI in six weeks. So for six weeks I was convinced I had this "thingy" in my brain. I fretted briefly but my faith sustained me during those weeks. Fast forward six weeks.

Turns out, the first MRI machine was made by Mattel. (Okay, not really, but the MRI wasn't done well.)

Second, I was diagnosed with Multiple Sclerosis (MS). I showed all the signs, but eventually, that was changed to Cerebellar Ataxia, the "plus" variety. I guess the "plus" makes it kind of like that store at the mall called Bed, Bath and Beyond. "Ataxia PLUS," "Bath and BEYOND," what's that all about?

That said, Cerebellar Ataxia is like a cousin to Parkinson's Disease or a second or third cousin to MS. Lots of the same symptoms, such as: balance problems, speech problems, swallowing trouble, fatigue, neuropathy, and inability to dance the funky chicken

For those freshly diagnosed with neurological disorders, I offer the following advice:



- Get a solid diagnosis. It's your disorder. If you have faith in your current neurologist, great, but if you want a second opinion, it's up to you.
- If you need to go on Social Security Disability, get your documentation well in order, including a letter from the doctor treating your condition. It can mean the difference between approval or denial on the first application try.
- Master it, don't let it master you.
- Keep moving in spite of it instead of giving into it.
- Keep your sense of humor. It's good medicine. When I have hand tremors I take solace in the fact that I can wave "bye bye" better than anyone else on the block!

In summation, to borrow from a famous Winston Churchill commencement address, the great man rose and walked to the podium and said six words: "NEVER, NEVER, NEVER, NEVER GIVE UP!" With that, he sat back down.

God bless and keep on keeping on! ❖

Ataxia Does Not Define Me

By Denise Drake

Although Friedreich's Ataxia is an inherited disorder, I've never blamed anyone for my disease. I accepted long ago that this disease is what happened to me, and I could choose to deal with it or not. The ability to make decisions is what is most important to me. We all make them. I choose to live my life the same way you choose to live yours.

I have a disease that keeps me from walking, not from living. This disease is not my life. Yes, it forces certain adaptations and can be discouraging, but it doesn't define who I am. ❖

Planning Around Government Assistance Programs

By Mary Anne Ehlert

Mary Anne Ehlert is the founder and President of Protected Tomorrows, an advocacy company that provides comprehensive life planning that addresses the educational, residential, financial, legal, health care, government benefits, employment and recreational needs of the individual with special needs. For more information on working with an advocate near you to help you with life planning, contact info@protectedtomorrows.com or visit www.protectedtomorrows.com. If you have specific questions, please feel free to e-mail Mary Anne at mehlert@protectedtomorrows.com, or call Protected Tomorrows at (847) 522-8086 and the receptionist will direct your call to the appropriate individual.

So you have just found out that your child has special needs. You know that there are programs out there for your child, but you are not sure where to start. You may wonder what the government provides, what it will cost you and how you are going to sort through all the information. A special needs planner with a benefits department will bring clarity to a very complex system.

Knowing what assistance your child qualifies for will make a difference in the type of care your child will receive now and in his adult years. A special needs planner will help you to assess your situation and clarify options. She will refer you to her benefits department, who will act as your liaison, utilizing their experience to effectively navigate through the system.

Your biggest resource for funding for your child will come from government assistance programs. The types of government assistance and your child's eligibility for these programs can be very confusing. Let's break down the types of assistance into four general categories:

Entitlements

We are entitled to SSDI/SSA and Medicare because we bought these benefits by having money taken out of our paychecks throughout our working years.

Needs-Based

SSI and Medicaid are available regardless of whether or not you paid into the system. Because these benefits are not purchased, the eligibility requirements are based on your income level and your assets.

Cash

SSDI, SSA and SSI are all programs that provide cash to meet daily living expenses and to supplement any other benefits. Each have their own eligibility requirements.

Goods and Services

These benefits come in the form of medical and residential assistance. These services are vital to your child's future as an adult. The programs include Medicare and Medicaid.

Now, let's look at each program individually:

Social Security Disability (SSDI) and Social Security Administration (SSA)

When a working person becomes disabled, he or she will receive disability based on how much they have paid into the system and if they are substantially and gainfully employed. This is called the "income rule." SSA is your retirement pay, which can be taken as early as age 62. It is important that you always save your social security statements for review. They tell you a lot about not only your own benefits, but what your family receives when you die.

Continued on page 18

Planning Around Government Assistance Programs
Continued from page 17

Medicare

Medicare begins two years after Social Security recognizes your disability. Medicare does not pay for prescriptions unless you have Medicare Part D. This benefit also follows the income rule when determining eligibility. That amount changes from year to year, and your special needs planner will help you to determine what that amount is so that your child will not be disqualified from other benefits.

Supplemental Security Income (SSI)

This program is for those who are not entitled to the benefit but need it. This benefit is subject to both the income rule and the asset rule. The current accepted assets that you can have are your house, a car, a prepaid funeral and $2,000. If the person receiving benefits exceeds this by any amount, they are disqualified from receiving benefits. A special needs planner will help you put strategies in place to help your child qualify for these benefits.

Medicaid

Medicaid typically goes with SSI. As with SSI, Medicaid is subject to the income and asset rules. You can have both health insurance and Medicaid. Medicaid pays for deductibles and co-pays that your health insurance does not cover. But the most beneficial reason for your child to qualify for Medicaid is to gain access to funding which will provide for your child's programs, workshops and residential housing.

A special needs planner and her benefits department can also help you through the complicated application process. They can provide information about the proof you will need to show your child is disabled. Your special needs planner can help you through the questions they will ask and guide you through your visit to the social security office. Her benefits department may also act as your representative for your child.

Helping you obtain benefits for your child is where a special needs planner will be most valuable. She will be able to interpret your social security statement and let you know what your child can qualify for. She will be able to help you through the application process, and she will be familiar with the programs available in your state. Finally, she will be able to keep up with the law changes and new programs as they come along. She will bring order to the chaos. You shouldn't have to navigate this maze alone.

❖

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

Humor

By Pete Meyerhoff

As an ataxian you probably don't encounter too many humorous situations connected to your disability. If you do, share them with the rest of us. We all could use a laugh.

This is what happened to me:

I am 87 years old with Sporadic Ataxia. To keep busy and have the satisfaction that I still make a difference to someone, I teach low-level math required to earn a General Education Degree (GED) at a neighborhood school for adults. The GED is a path to a job.

Rose Meyerhoff, Pete Meyerhoff, and "J"

One of my students (who I will call "J") told me that he wanted very much to become a police cadet. He had failed the math part of the test twice and they gave him only one more chance. He is in his early thirties and evidently they like him a lot otherwise he would not be able to take the test again. "J" was to take his third test on Monday. He asked me if I was willing to tutor him at my home. So we worked all day Friday, Saturday, and Sunday. Math is not his thing.

On Monday he took the test and passed. We were jubilant.

To express their gratitude, he and his two supervisors wanted to take me out for lunch. We arranged a date which happened to coincide with my senior co-op's open house. We have 99 units so there was a lot of activity up front. It was a nice day.

I met my party of three, "J" and his two bosses, in our vestibule. All wore full police uniforms, handcuffs and all. The supervisors even had guns. There were two squad cars at the front curb. To assist me, two of them grabbed me by my armpits and led me to the waiting squad cars. I was helped in with a head-duck. Meanwhile the whole co-op is wondering: "What is going on?"

Our next co-op newsletter explained it all.

What Happened to Pete?

Three uniformed police helped Pete and his walker get into one of two squad cars parked in front of the co-op. A lot of co-op members watching this might have gotten the wrong idea. Pete was taken to lunch at a local restaurant to thank him for helping "J" pass his math GED and get a job as a police cadet.

Everybody is happy!

And I am still allowed to live there. ❖

Editor's Note – If you have a humorous story that you would like to share, please submit it to joan@ataxia.org for consideration for publication in a future issue of Generations.

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 sire and follow the easy steps to make NAF your charity of choice. Then use GoodSearch as you would any other search engine.

By using *GoodSearch.com*, you'll make a difference in the lives of those with ataxia!

Move YOUR Way for Rare Disease Day

Rare Disease Day is a worldwide awareness effort on February 28 each year to draw attention to all rare diseases. Together, rare diseases affect millions of people. This year the National Ataxia Foundation joined the National Organization for Rare Disease (NORD) and other advocacy groups around the world to show the general public and decision-makers that more support is needed for rare diseases like ataxia.

Though ataxia is a group of physically limiting neurological disorders, many in the ataxia community fight the progressive effects of the disease by staying as physically active as possible. Some cycle on adaptive cycling equipment, others work out at the gym, and others work their muscles in the pool or in a stander. The photos on this page are some of the ways the ataxia community supported this event.

See more ways Move Your Way for Rare Disease Day was recognized on Facebook at *https://www.facebook.com/MoveYOURWay*.

Together we MOVE to cure ataxia! ❖

Cheri Bearman and her yoga class with teacher Joanne Snow are "Moving Their Way" for Rare Disease Day in Fort Wayne, IN. 150,000 people in the United States have ataxia. Cheri is one of them.

The Lunzer Family "Moving Their Way" during a Rare Disease Day celebration at River Valley Health Club, Stillwater, MN.

The Davis/Franklin family and friends are "Moving Their Way" through exercise with personal trainer Tamara Mingo.

Emily Penn, Justin Amos Hernandez, and David Henry "Riding Their Way" in Texas for Rare Disease Day.

Macy's "Shop for a Cause"

Purchase a Macy's "Shop for a Cause" discount card today for $5 and help the National Ataxia Foundation.

Your special Macy's "Shop for a Cause" discount card gives you access to a special one-day-only sales event at Macy's stores nationwide on Saturday, August 24. Card holders receive a 25% discount on regular, sale, and clearance items, including home. You can even save on most brands usually excluded! Card holders will also save 10% on electronics, watches, furniture, and rugs. Exclusions apply. Card holders are also eligible to register to win a $500 Macy's gift card. NAF will sell the cards until August 16.

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

Matching Gifts

Many employers will match your gift to the National Ataxia Foundation through a Matching Gifts Program. This valuable benefit will allow you to have twice the impact on the lives of families affected by ataxia when you make a donation to NAF.

Please check with your company to see if this benefit is available to you. If they do, please give generously and encourage your co-workers to also contribute. Thank you.

Remembering NAF in Your Will

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

Please consider remembering NAF in your will. Thank you.

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.

The NAF Board of Directors along with the
Western Regional Support Groups would like to invite you to attend the

National Ataxia Foundation
57th Annual Membership Meeting
March 21-23, 2014

Join us in Las Vegas for the Annual Membership Meeting!

Bally's Las Vegas is pleased to provide the facilities for the 2014 AMM. Standard room reservations at Bally's can be made online at *www.totalrewards.com/hotel-reservations?propCode=BLV&groupCode=SBNAF4*

For guests that prefer to phone in their reservations call the Reservation Center at 1-800-358-8777 and ask for the National Ataxia Foundation's group rate. Callers may also use your group code to identify the group, **SBNAF4**. A credit card is required at the time of booking and a deposit equal to one night's room and tax will be charged. Notice of cancellation must be received 72 hours prior to your arrival date, in order to receive a full refund of your deposit. Parking and valet is provided at no additional fee. **Request rooms in the North Tower to be closest to meeting rooms and registration.**

Please note all ADA rooms must be booked through the NAF office starting on August 7 at noon CDT by contacting (763) 553-0020 or *lori@ataxia.org*. Calls or e-mails prior to noon CDT on August 7 to book an ADA room cannot be honored.

Reservations in the block at group rate will be available until **Tuesday, February 18, 2014**. The NAF group rate is $99 + tax Sunday – Thursday, $149 + tax Friday - Saturday nights. Please note there is limited availability on discounted rate rooms

For more information on Las Vegas, visit *www.lvcva.com*. For the latest information on conference registration, program schedule, and area information, visit *www.ataxia.org*.

2014 NAF Annual Membership Meeting "Support Our Conference" Campaign
https://naf.myetap.org/fundraiser/14AMM/

THE NATIONAL AT

56th Annual Men

“Driving Together

Detroit, Michigan

Christopher Marsh and friends

Mary Fuchs and Charlotte DePew

Camille Daglio and Lori Shogren

Special thanks to photographer Randy Dombrowski for taking the photographs you see on these pages

Robert Chan and Davic

Dancing and having fun at the Saturday night Banquet

There were hugs ga

Sunday morning speakers included (left to right) Michael Parent; Sarah Ying, MD; Susan Perlman, MD; Laura Ranum, PhD; and Armin Alaedini, PhD

AXIA FOUNDATION

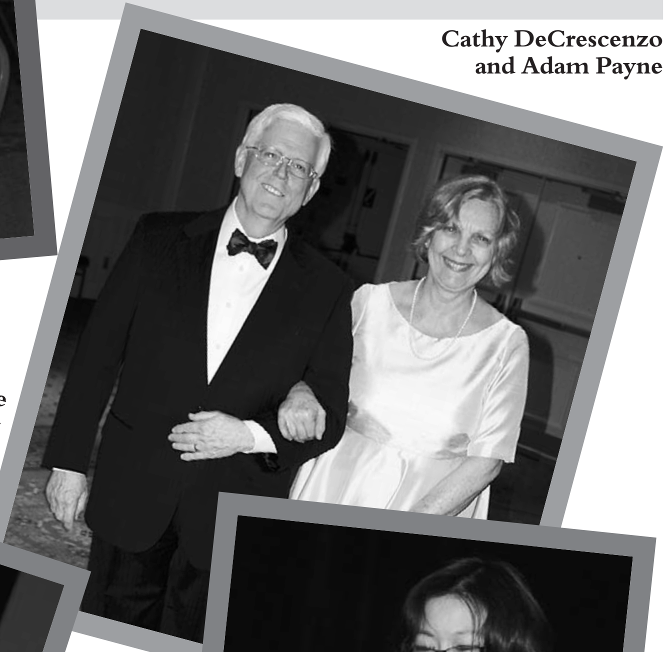
nbership Meeting

Towards a Cure"

March 15-17, 2013

Cathy DeCrescenzo and Adam Payne

Guangbin Xia, MD, PhD and Joe DeCrescenzo



Grand Entrance to the Banquet

Below: Debra Simpson and Michael Parent

d Zilles

Dr. Sarah Ying at a Q&A Session

lore at the 2013 AMM

(Left to right) Guangbin Xia, MD, PhD; Katherine Hermann; Jeremy Schmahmann, MD; Sarah Ying, MD; Jessica Harding; and Franziska Hoche, MD

Our Honeymoon Trip to South America

By Kory and John Macy

We were looking for something to do for our honeymoon that was accessible and fun. Most places had accessibility but few or no activities that were. We were really frustrated so I typed in accessible travel in South America. I found a trip in Ecuador. It met all of our requirements and I have always wanted to go to South America. After a year of planning, we were off. I have AOA2 and use a wheelchair and John has CP and uses crutches.

Kory and John Macy in South America

We arrived in Quito late. The old airport is in the middle of the city, very busy and chaotic. We could not believe how close we were to the residential buildings. Finally we got our bags, met our guide and were off to the hotel for a good night's sleep.

The next day we drove to the Amazon. It was a beautiful drive. We stayed at a lodge in the Napo Province. The staff were really helpful, even though they barely spoke English. It was in an isolated spot and the views were spectacular. Everything was universal design so we were able to get everywhere. The buildings were made out of bamboo with thatched roofs. The food there was amazing and so much that we had to ask them to make the portions smaller. At night it was so dark, you could not see your hand in front of your face. It was so scary that we kept the bathroom light on. After lunch we visited a typical indigenous community called Rukullakta. There we learned about how the indigenous people from this area keep their traditions. We ate food that they prepared, saw some typical dances and John had a shaman (indigenous doctor) perform a limpieza (cleansing of the body and the soul).

The next day we went for a quick walk on an Amazon secondary rainforest path to observe native medicinal plants. We both had to use off-road wheelchairs. Our guide, the leader of an indigenous community, was very knowledgeable. We learned a lot and we enjoyed it. After lunch, we went to a zoo. Its original intent was to be an animal rescue. We felt sad because the cages were too small and muddy. We met an indigenous artist who had us make necklaces out of seed and plant fibers found in the forest. He and his children had great patience with us as we struggled. The end result was two beautiful necklaces.

The next day we visited a cacao collection center operated by Kallari Association, which is a self-governed coalition of Amazon organic farmers and artists that produce and export organic fair trade cocoa beans. They produce their own chocolate as well. We saw how ⏩

the bean was collected, fermented and dried before it goes on sale. The collective works with the locals to grow the high quality kind because they will make more money. We had lunch in a local town at the top of one of the rivers that go into the Amazon, then we went to Tena, the capital of the province. We sat in its parks and observed how people live in town. It looked like a town in the United States but everything was in Spanish.

The next morning we traveled to the Anzu River, where we took a raft. The river was very calm (class II) and there were some rapids. We saw some indigenous people on the river banks. We went swimming in the Anzu River. Before we left the Amazon basin, we went to a local food market. We saw local people and local foods. We drove to Baños de Agua Santa which is a cute little town on the edge of the Amazon. This town lies at the bottom of the Tungurahua, an active volcano. We walked around at night and enjoyed the night life. Next morning, we went to a local food market and tried some local juice and fried dough. We drove to Riobamba in the Andes. When we arrived we spent the afternoon discovering the town, plazas, colonial area and the people.

The next day we drove to a local leather manufacturer where they tan, color, and sew leather products. Then we drove to Cuenca which is surrounded by four rivers. After breakfast we started our tour of the city. We visited the main squares, plazas, churches of Cuenca and a Panama hat manufacturer. Downtown Cuenca was also declared Human Heritage by UNESCO. (United Nations Educational, Scientific and Cultural Organization). About 18 miles west, we visited Cajas National Park. The park is 110 square miles and is 5,000 meters (3.10 miles) above sea level, cold and beautiful. After the park, we visited the Inca ruins, There were not many of them here. Then we went to Chordeleg, which makes silver pieces.

The next day we drove to Guayaquil. On the way we admired the changes in vegetation from the highlands to the coast. We observed the different banana, cacao, and rice plantations. It is the biggest city in Ecuador. We walked along the boardwalk and then we took a boat ride around the city.

Kory and John Macy in the Galapagos Islands

The next day we flew to the Galapagos Islands. It was a short flight. We had lunch and then we went to the beach and watched the sea lions. They are protected animals and they walked right up to us. They put John in an off-road wheelchair and I sat in a beach wheelchair. The next day we went to a park on the other side of the island. We observed different vegetation and also saw some tortoises. Some other activities we did were a speedboat ride around the island where we saw blue footed boobies, masked boobies, marine iguanas, dolphins, and more sea lions as well as Kicker Island and a swim in the Pacific Ocean. We visited an information center that explained the history, current problems and solutions with the island.

We finished our trip by flying to Quito to meet up with Juan. We had dinner and went to bed, ending the trip with a tour of the city with its many beautiful churches.

For more information, please contact us at *kstab77@yahoo.com*. ❖

NAF Merc

BOOKS

— ATAXIA RESOURCES —

Healing Wounded Doctor-Patient Relationships

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

This book is packed with information that anyone who 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, MD

This illustrated book provides a compassionate, easy to understand explanation of ataxia with ideas on how to live well with ataxia. Second edition published in 2003. $14

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

by G.N. Rangamani, PhD 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. Includes helpful suggestions. Second edition 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 Hoefer Smith*

Dedicated to the memory of her daughters who had Friedreich's ataxia, Kathryn Hoefer 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

VIDEO/CD

Ballads of a Family Man CD

10 songs in memory of Billa Ballard. $5

"Together There is Understanding" VHS or DVD

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

SHIRTS / MISCELLANEOUS

Original NAF IAAD T-Shirt

Features "globe" logo shown on front page.
Sizes S, 3X only. Limited quantities available. $10

NAF Baseball Cap (White or Blue)

Velcro closure. Navy embroidered logo. $10

NAF 50th Anniversary Coffee Mug

Blue marble and gold. $3

NAF Wheelchair/Walker Pouch

Zippered black pouch with "National Ataxia Foundation, logo, and web URL printed in white on the front. 9.5"W x 5"H x 1"D. $5

NAF Grip n' Sip Water Mug

Blue with "National Ataxia Foundation, logo, and web URL printed in white on the side. 3.5"W x 9"H with 13" sipping straw. $5

chandise

SHIRTS/MISCELLANEOUS

International Ataxia Awareness Day T-Shirt
Available in youth L, and adult small to XXX-large. $10

Past Annual Membership Meeting (AMM) T-Shirts
Limited years and sizes available. You pick the size and we'll pick the AMM. $1 each while supplies last!

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-Sleeve T-Shirt
Blue. Sizes small to XXX-large. $15

"Ataxia is Not a Foreign Cab" Sweatshirt
White. Sizes small to XXX-large. $20

"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 $5

Magnetic Power Clip
Strong magnet for super holding power featuring rubber grips. $3

"Know Ataxia" Backpack
20"x16" drawstring backpack features gray reflective strips, drawstring straps, and two carry handles at top. $5

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

ORDER FORM

Description	*Qty.*	*Size*	*Each*	*Total*

SUBTOTAL: ____________________

Shipping within U.S.:	**Add $5.00**
Shipping outside U.S.:	**Add $15.00**

ORDER TOTAL: ____________________

PLEASE ALLOW 4-6 WEEKS FOR DELIVERY

NAME: ______________________________

ADDRESS: ______________________________

CITY ______________ ***STATE:*** ____ ***ZIP:*** ________

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*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: ______________________________

Tissue Donation Program for the SCAs and Sporadic Ataxia

The National Ataxia Foundation is committed to ataxia research from basic science research that strives to better understand the disease mechanism, to translational research, or what is sometimes called "bench-to-bedside." Translational research seeks to facilitate the development of treatments.

In addition, the National Ataxia Foundation understands that the study of postmortem human brains is crucial to a better understanding of ataxia. Many people with ataxia are interested in learning about donating brain tissue after death. The NAF sees this as a courageous and selfless act by the donor and family members.

Currently, Dr. Arnulf Koeppen facilitates the Tissue Donation Program for Friedreich Ataxia.

If you have Sporadic or Spinocerebellar Ataxia and want to learn more about brain tissue donation, please contact the National Ataxia Foundation at *naf@ataxia.org* or (763) 553-0020. ❖

Friedreich Ataxia Tissue Donation

Donating tissue for medical research is a deeply personal decision. If you have Friedreich Ataxia (FRDA) and are interested in learning more about donating tissue, please contact Dr. Arnulf Koeppen directly at the following address:

Professor of Neurology and Pathology
VA Medical Center
113 Holland Ave., Albany, NY 12208
Telephone: (518) 626-6377
E-mail: *Arnulf.Koeppen@va.gov* or
akoeppen@nycap.rr.com

If you have another form of ataxia and are interested in tissue donation, please e-mail *naf@ataxia.org*. Thank you for your support of this important research initiative.

Toe Wedge Helps with Balance

Dear Ataxians,

Twenty-some years ago my husband and I were in a high-speed head-on collision with a drunk driver. I lost my balance due to injuries I sustained from the crash. I combed through the ataxia newsletter *Generations* looking for advice. I found good suggestions for prescription drugs which helped my balance greatly.

The greatest help of all however, I discovered when watching football! I heard of a kicker who injured his big toe but was still able to kick. I asked my podiatrist and he explained that the kicker used a "Cluffy wedge." That wedge puts thickness under your big toe so the toe believes it's making contact with the ground. He said that 70% of your weight is balanced by your big toe. (I put smaller hammer-toe wedges under my other toes to help solidify the other 30%.)

If I was able to keep only one aid, I would keep the toe wedges and give up every other aid! I highly recommend that you try these as soon as possible and evaluate if they might be helpful for you. (It is important that the wedge is placed under the joint connecting the big toe to your foot.)

Jan Snyder, Plymouth, MN ❖

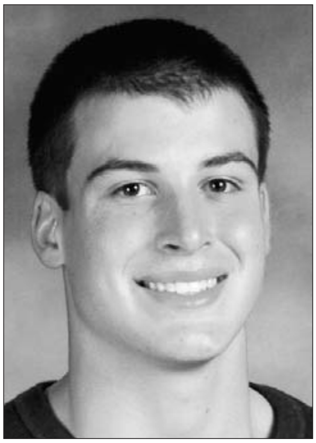
True Strength

Written by Lucas Medeiros, age 16
Submitted by James Coyne

This was written by my grandson. It touches home in many places. Luke had only known his Nana, Janet R. Coyne, in a wheelchair. This never stopped him from playing as if there were no disability involved. Nana passed away on September 21, 2008. My daughter Stacy Leger also has SCA 3. Her son Landon was written up years ago in "Generations" as a young ataxia hero. He still tells me he has a Google page, and I don't.

I have always wanted to be strong, simply because I did not want to be classified as weak. I wanted to be strong because that was cool, because everyone in my family was stronger than me, and I didn't like that. That was my whole reasoning behind it, but now, after thinking about it, I realized that I was right about the necessity of being strong, but I was wrong about the reasons, and what true strength really was.

Nana Janet R. Coyne



Lucas Medeiros

True strength is not about the muscles, it has nothing to do with who hits the hardest, or can lock away the most emotions. It is the ability to endure in the face of the most powerful adversary, life.

My grandmother was living proof of true strength. She had ataxia. It's a disease that hardly anyone even knows about, and it took the strongest person I know. This disease shut down her body, piece-by-piece, until she could barely mumble what used to be words, except her brain was fully functional. She thought like a normal person, except she couldn't do anything about it. She became a prisoner in her own body. Every time she stood, she fell, but then stood again in defiance not to submit to this disease. As if getting back up after life has given you its worst wasn't enough of a testament for true strength, she did it while smiling the entire time. I cannot put into words the amount of strength, determination, and willpower it took to live 64 years with this disease. In her final weeks of life, her doctors told us that it was amazing that she was still alive, that her stage of ataxia was so progressed that pure strength that was the only thing keeping her alive. That is when I learned what true strength really was. I do not know anyone that had the strength she had, and I never will.

Life is not fair; it births some with a silver spoon in their mouth, and others with dirt. Some people are lucky enough to be healthy, but no one can avoid all of the things life throws at you. Eventually, you must deal with them. No matter what your condition is, you must be strong, and push forward through any obstacle. You must be able to get back up when life knocks you down. To not sweat the small things in life, to be thankful for what you have, but more importantly, fight for it, for yourself.

I now know why I want to be strong, and that is because ataxia is hereditary, although it is unlikely for me to have it, because my mother does not, there is still a chance. I could get tested, but refuse to learn that I might go through the same thing my grandmother went through, if I do have ataxia, I only hope that I have learned how to become truly strong, as strong as my grandmother. ❖

Everyone Has a Story, and Here's Mine

By Christopher Marsh, Metro Area Chicago Support Group Leader

My real name is Christopher. "Topher" is my nickname. I have SCA2. I grew up in Tonawanda, NY (a suburb of Buffalo).

School was decent. I did not become symptomatic until after high school. I was a "B" student. When I graduated, there were about 1,000 students in the whole school.

On the net, I sound like Martin Lawrence, but in real life, I sound like Wayne Brady. It's funny to me.

My life was like most, very athletic and active, until I was in my early 20's. I've had a few apartments, driven, worked mostly as a waiter, had a live-in girlfriend, married and got a college degree.

Christopher Marsh

In 1999, we had a son, named Payton (after Walter, running back for the Chicago Bears, #34 baby). He was born seven weeks premature, very ill and diagnosed with CP. But he had something the doctors couldn't figure out. He had all the ataxic symptoms. He was like a rag doll with a heartbeat. My neurologist, Dr. Christopher Gomez, thought that my little P-nut had ataxia. In 2000, after a few organs shut down, he passed away at 19 months. Three months later my wife left me. I did some research and about 87% of marriages end when a tragedy of such magnitude occurs.

I live in Chicago now. My brother brought me out here. He'd been asking me to move here for a while, and I always had a reason to say no. In the summer of 2003, I told my brother yes.

I'm primarily an advocate now. When I first moved here, I filmed a movie called, "It's About Living." It's a documentary about chronic illness. I run two support groups, this one (my pride and joy and my baby), and one in the city.

My father has ataxia too, along with two uncles, one aunt, and a couple of cousins. It's hit my family kind of hard. It's tough seeing a loved one progress with something like this. I've been watching as my father gets worse every year since I was in middle school. That's the single, most difficult, thing about coming to the AMM every year. Everyone is a little bit worse than the last time you saw them.

You know, ataxia really stinks. It's unkind, and totally unfair. If you would have told me I'd be in a wheelchair and unemployable by the time I was 40, I would have fallen on the floor laughing at you. Attitude is everything and a bad one is not going to help your plight. I try to do something big and fun every month. Be light, get out there, have fun, crack jokes, make friends, smile and be around others that are doing the same for as long as you can.

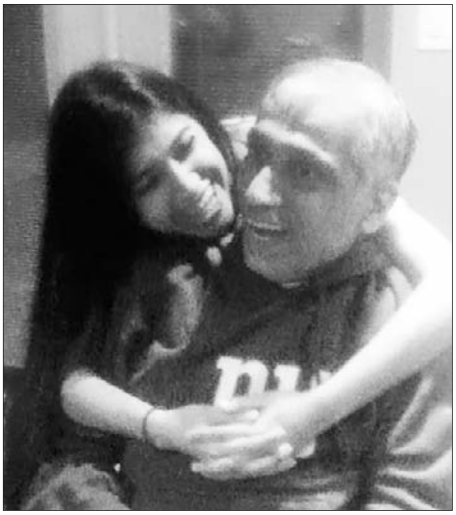
Be light, and groove. *Topher* ❖

My Dad, My Hero

By Priya Mansukhani, age 16

My dad, Arun Mansukhani, married my mom at the age of 27 in 1989. They had an arranged marriage and did not know each other very well when they got married. My mom never had a boyfriend – he was her first for everything. My dad showered her with love, attention, and kindness and from those moments she fell in love with him. For them, the future seemed bright, they were in love, happy, and my dad was gaining success as an electronics engineer for Magnavox.

My mom began to notice small events that, at the time, seemed insignificant. For instance, he wasn't able to put a nail on the wall or would stumble here and there. They did not know how to approach the situation, so they took precautions and headed to the doctor. Blood tests were taken, physical exams, and everything came out fine so life continued on.


Priya (left) and Arun Mansukhani

After couple of years, my parents went to the bar together. When walking, a security guard stopped my parents with the suspicion that my dad was tipsy. My parents were offended, but thankfully, were able to convince the guard that he was in fact completely sober. The idea that someone thought he was drunk, when in reality he was not, bothered my dad. It seemed unusual and odd that someone would think this without reason, so another doctor's appointment was scheduled. At the appointment, he shared his difficulty about how some of life's daily tasks seemed less easy to accomplish. After hearing examples, the doctor suggested a visit to the neurologist. For a while, life consisted of constant meetings with physicians and neurologists.

With feedback from many, my parents were told that my dad was diagnosed with ataxia. At the time, it seemed that this condition would not play such a large role in their lives – it would just be something on the side. They knew that somewhere along the way it may get tough, but they had no idea of when my dad's condition would get a lot worse or when it would take a toll on their lives.

As time passed, they started a family and had me, Priya. I remember coming back from school, in fourth grade, and every day he would be sitting there in front of the door in his wheelchair, awaiting my arrival. Each and every day, I would run to the mailbox and carry the heavy mail in for him. Out of routine, I would set it on the table, where I would do my homework and he would look through the unopened envelopes. His inability to walk did not affect how helpful he was to me in different aspects. When I would do math homework and struggle, he would sit there and examine the problem and within minutes help me understand how to solve it. I would observe him and his actions. Sometimes I used to do this. It is kind of interesting to study someone who is totally different from you physically. Dad's eyes would move intensely across the page. A minute later, Dad's eyes would meet mine. He would tell me that I made a mistake. With his words, I would take the paper away from him and correct the answer.

Continued on page 34

My Dad, My Hero
Continued from page 33

Growing up, I would also play the piano. When, my fingers press on the keys, music would fill our ears. Each time I played, he never failed to sit right next to me and listen to my music, nodding his head to the beat.

Often, I would sit next to him as he fell asleep on the couch while watching his passion, football, read him a book, or hold his hand and listen to music. For us, that was enough. My dad could not walk, and that was the way I had grown up. He couldn't teach me how to ride my bike or play catch with me at the park or give me piggyback rides. However, those spaces were filled in other ways, in ways that gave us a unique bond. We would listen to his favorite music and talk about the 80's and his childhood. We would sit on the patio and enjoy the buzzing of bees and summer air. We would sit in silence and just enjoy the beauty in the stillness. My Dad loved me more than I can ever imagine. For me he would do anything. And for him, I would do anything. I realized early on that because he was the way he was, I am who I am today. His condition gave me compassion and made me realize what an amazing man he was. Through the struggles to complete daily tasks, he would still try to fold the laundry, do the dishes and even give me milk at 4 p.m. each day, for as long as he could. I learned from him the willpower everyone should have, the strength I should have in life. He taught me that even if things do get tough, there is a way to get around it and move forward.

Dad sits in a wheelchair, silently reading his magazine. Quietly, I walk in to the couch, open my book, and start to read. Minutes later, I close my book. My eyes fall on Dad. All of a sudden, a tear trickles down my face. More follow and I soon find myself crying. I ran up to him and hugged him tight, never wanting to let go of him and what we had together.

My relationship with my dad was simple and pure. I loved my Dad, and still do endlessly, just the way he was. ❖

Please Support the 2013 NAF Annual Membership Drive

The National Ataxia Foundation depends on the support of our members to continue to bring quality programs and services to the ataxia community. The NAF Annual Membership Drive has begun. If your membership has lapsed or you are currently not a member, please join today. If you are a current member, thank you for your support. You may also consider giving a Gift Membership to a friend or family member.

Why Become a Member?

Membership fees help the National Ataxia Foundation provide programs and services that strengthen and support the entire ataxia community. NAF members have the choice to become an individual, household, patron, or lifetime member, as well as a professional member.

What Are Membership Benefits?

Becoming an NAF member provides you with discount registration fees when attending the annual membership meeting (AMM), as well as receiving NAF's quarterly news publication *Generations*. Members who attend the AMM tell us that the discounts they receive more than cover the cost of their annual membership.

How Do I Become A Member?

Becoming a member is easy. You can become a member by filling out the membership form on the back page of this issue of *Generations*, or you can become a member by going online at *www.ataxia.org* and clicking "Donate Now."

Thank You

Thank you to all who have so generously given to the 2013 NAF Annual Membership Drive.

Chapter and Support Group News from Around the Country

Delaware Support Group supports the DeCrescenzo Family Hot Dog Sale

By Joe DeCrescenzo

The DeCrescenzo Family organized a hot dog sale in the Boscov's Department Store. Joe, Cathy, their two daughters, and four friends from church helped. Two other members of our DE Support Group also made financial donations.

We were set up on the second floor, and open from 11 a.m. – 3 p.m. The store dictated the selling price: hot dogs $1, soda $1, and chips 50¢. Despite the low prices, we collected $640 in donations.

How 'bout a hot dog?

Tarheel Ataxia Support Group

By Ron Smith

We had a great meeting on May 4 with a good turnout at White Deer Park in Garner, NC. John Fisher, along with his Support Dog Roscoe, did a presentation on Support Dogs.

Denver Area Support Group

Our support group meeting on April 20 had about 50 individuals, ages eight to 80, with nine first-time members. Introductions ranged from humorous to emotional with mutual understanding and support from the group.

Announcements included: report on the Detroit AMM, importance of registering in a patient registry, how to view AMM sessions, planning progress for the 2013 RWnR on September 8, and Dr. Tom Clouse (*www.walkingwithataxia.com*) in Denver, May into mid-June.

Nanette Redman volunteered to start organizing social activities between quarterly meetings. The first event, Ataxia Dance Celebration on May 11 at The Church, a Denver nightclub reserved just for our group, from 7 – 9 p.m. Other possibilities include outdoor adventures (e.g. National Sports Center for the Disabled).

Our speaker, Dr. Abbie Collins, summarized the Detroit AMM focusing on new research

Continued on page 36

The Tarheel Ataxia Support Group at their May 4 meeting ***(photo by Greyson Brown)***

Chapter and Support Group News
Continued from page 35

findings. Her handout and talk were excellent.

The May 11 dance was a great success with about 50 attending. Everyone thought it was wonderful fun and we need to do it again sometime.

At our next meeting on July 20, topics will include Social Security, disability, Medicare, and Medicaid.

The Denver Area Support Group's dance on May 11 was a big success.

Central PA Support Group

By Mike Cammer, NAF Ambassador

Central PA Support Group held their first meeting on Saturday, April 27, at the Muhlenberg Community Library in Laureldale with 15 people in attendance and an awesome presentation by Kristen Konestsky from United Disabilities Service (UDS). UDS is a non-profit organization that helps people with disabilities live safer and more independently in their own homes. They offer services such as service dog programs, custom wheelchair seating, and home medical equipment along with adult enrichment programs and independent living services. They assist people throughout Central PA and beyond. For more information call 1-888-UDS-4235 or visit *www.udservices.org*.

I followed up with a summary of the NAF Annual Membership Meeting mostly focusing on the wellbeing and physical fitness presentations and encouraging others to attend the next meeting in Las Vegas if they could. It's a great way to network with other ataxians as well as learn about the most up-to-date information in ataxia research. I met some awesome people and it was an overall rewarding experience!

We also discussed getting the word out about the NAF to more places. Someone mentioned sending pamphlets out to doctor's offices. My wife, Larissa, and I agreed to do it to help spread the word about ataxia awareness and the Central PA Support Group.

Our next support group meeting will be held on July 27 from noon to 2 p.m. at the Muhlenberg Public Library in Reading. For more information, contact me at *michael.cammer62@hotmail.com* or Chris Rakshys, support group leader at *rakshys@ptd.net*.

Members of the Central PA Support Group: (standing, left-right) Karen Stickle, Harry Schmidt, Joan Govan, Jennifer Leader, Mike Cammer, Chris Rakshys, and Donna Klotz; (seated in front) Karen Garrett

Central New York Support Group

By Ed Lueck for Mary Jane Damiano

The Central New York Ataxia Support Group met on Saturday, April 13. Nine members were present. Our guest speaker was Marc Alessi. He conducted a walk for ataxia on Saturday, May 25. It was called, "The Walk for Dave." The event was in memory of Marc's father, Dave Alessi, who died of ataxia about two years ago. *https://naf.myetap.org/fundraiser/13Walk4Dave/* ▸▸

Northeast Florida Ataxia Support Group

By Mac Kelso

The Northeast Florida Ataxia Support Group met at Baptist South Hospital on May 11 at 1:45 p.m. with 14 attendees. Cory Hannan opened by introducing Daryl Walters, a new member to our group, and his friend, Roger Walden. Daryl already knew some of the members from the Tampa's Ataxia Awareness Cruise.

Cory announced the Second Annual Cruising to Create Ataxia Awareness, scheduled for January 27, 2014. If interested, call Jessica at (813) 289-5800 ext. 6543 for your reservation. Cory presented his "New Member's Welcome Packet" to the group. The information in the packet will definitely help new members. Cory spoke of a new ataxia study from the University of Florida focusing on SCA1 and SCA3 for at-risk family members without symptoms that are prevalent in their families. Dr. S.H. Subramony will be the Clinical Investigator in the study.

The final topic was the Jacksonville "Walk n' Roll" September 21 from 10 a.m. to 2 p.m. at Jacksonville Landing. It will include a ¾-mile "Walk n' Roll," entertainment, food, drinks, and guest lecturer Dr. Subramony. Registration will be $20, which includes an Ataxia Awareness T-shirt. Sponsors are welcome and will have their company logo printed on the T-shirt for a $500 donation to NAF.

Special recognition goes to Sonia Hannan for her healthy snacks served up after the meeting.

The group will meet at Corky Bell's in Palatka for an off-site meeting on July 20 at 1 p.m. for good food, fun, and socializing. The next proposed on-site meeting is August 24 at 1:45 p.m. in the Azalea, Begonia, and Camellia Rooms at Baptist South.

Greater Atlanta Ataxia Support Group

By Dave Zilles

The Greater Atlanta Ataxia Support Group held their meeting on May 18 at the Emory Rehabilitation Center. Welcome to Bill and Betsy Lowery, new members. We discussed the NAF Annual Meeting in Detroit. The meeting was quite interactive with lots of discussion around the various types of ataxia and personal experiences.

Our annual picnic was on June 8 at Lake Lanier, where we all got together and had a fun social gathering. The Support Group provided the hot dogs and hamburgers and the members brought their own drinks and a dish to share.

We are planning our Third Annual Walk n' Roll for September 21 to recognize International Ataxia Awareness Day.

The meeting ended with our refreshments and a chance for us all to get together and talk about what has been happening in our lives and to get to know each other a little better. We find this is extremely important for new members, especially if they have not been around other people with ataxia and want to learn more. ❖

Members of the Greater Atlanta Ataxia Support Group

NAF Directory of Chapters, Support Groups and Ambassadors

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

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

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

Social Networks

NAF BULLETIN BOARD
Moderator – Atilla and Bear
www.ataxia.org/forum/toast.asp

NAF CHAT ROOM
Moderator – Della (ddpokernut@yahoo.com)
www.ataxia.org/connect/chat-rooms.aspx

NAF FACEBOOK GROUP
www.facebook.com/group.php?gid=93226257641

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

NAF YOUTUBE CHANNEL
www.youtube.com/user/NatlAtaxiaFound?feature=mhum

Chapters, Support Groups and Ambassadors

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— ARIZONA —

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

Martha Elliott
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(805) 987-2490
E-mail: DOCElliott268@gmail.com
www.ataxia.org/chapters/Camarillo/default.aspx

— COLORADO —

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E-mail: cldepew77@comcast.net
www.ataxia.org/chapters/Denver/default.aspx

— CONNECTICUT —

TRI-STATE SUPPORT GROUP LEADER

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

AMBASSADOR

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

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

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— GEORGIA —

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Continued on page 40

NAF Directory
Continued from page 39

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Continued on page 42

NAF Directory
Continued from page 41

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Calendar of Events

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

SUPPORT GROUP MEETINGS

— Saturday, July 20, 2013 —

Denver Area Ataxia Support Group Meeting

Time: 1 – 4 p.m.

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

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

Middle Tennessee Area Ataxia Support Group Meeting

Time: 2 p.m.

Location: Amerigo Restaurant, Cool Springs, TN

Details: For more information, contact Vicki Tyler at (615) 646-3024 or *tyler2@comcast.net*.

Northeast Florida Ataxia Support Group Meeting

Time: 1 p.m.

Location: Corky Bell's in Palatka

Details: Off-site meeting for good food, fun and socializing. For more information contact Steve and Carole Brown at (352) 591-5095 or *bike4brown@aol.com*.

Tarheel Ataxia Support Group Meeting

Time: 1 – 3 p.m.

Location: Piedmont Plaza One's Kitty Hawk Room, 1920 W. First St., Winston-Salem, NC 27104

Details: For more information or to RSVP contact Jerry Hauser at *deaconwfu@msn.com*.

Twin Cities Ataxia Support Group Meeting

Time: 10 a.m.

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

Details: Please join us and make new connections. For more information contact Lenore Healey Schultz at (612) 724-3784 or *cshultz.lenore@yahoo.com*.

— Saturday, July 27, 2013 —

Central PA Ataxia Support Group Meeting

Time: Noon – 2 p.m.

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

Details: For more information contact Chris Rakshys at (610) 395-6905 or *rakshys@ptd.net*.

New Hampshire Ataxia Support Group Meeting

Time: 10 a.m. – noon

Location: The Stop & Shop Conference Room, (second level accessible via the elevator located to the left of the bakery side entrance to the store) 7 Kilton Rd., Bedford, NH 03110

Details: Join us and help us help each other. For more information contact Jill Porter at (603) 626-0129 or *jilleporter@comcast.net*.

— Sunday, July 28, 2013 —

Los Angeles Ataxia Support Group Picnic/Concert

Details: Hollywood Bowl picnic/concert "Chicago" the fully staged musical. Tickets $15 and they will sell out, so book early. For more information or to purchase tickets contact Sherry McLaughlin at (626) 791-1558 or *ccherilynmc@yahoo.com*.

— Saturday, August 10, 2013 —

Central MN Ataxia Support Group Meeting

Time: 10 a.m. – noon

Location: Liberty Savings Bank (1st Floor Community Room), 111 Seventh Ave. S., St. Cloud, MN. Entrance in the rear of building for mobility issues.

Details: For more information contact Marsha Binnebose at (320) 248-9851 or *marshabinnebose@yahoo.com*.

North Texas Ataxia Support Group Meeting

Time: 10 a.m. – noon

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

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

— Wednesday, August 14, 2013 —

Willamette Valley Ataxia Support Group Meeting

Time: 11:30 a.m. – 1 p.m.

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

Details: For more information contact Ivy Stilwell at (541) 812-4162 or *istilwell@samhealth.org*.

Saturday, August 17, 2013

Orange County Ataxia Support Group Meeting

Time: 2 – 4 p.m.

Continued on page 44

Calendar of Events
Continued from page 43

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

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

Twin Cities Ataxia Support Group Meeting

Time: 10 a.m.

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

Details: Please join us and make new connections. For more information contact Lenore Healey Schultz at (612) 724-3784 or *cshultz.lenore@yahoo.com*.

— Saturday, August 24, 2013 —

New Hampshire Ataxia Support Group Meeting

Time: 10 a.m. – noon

Location: The Stop & Shop Conference Room (second level accessible via the elevator located to the left of the bakery side entrance to the store), 7 Kilton Rd., Bedford, NH 03110

Details: Join us and help us help each other. For more information contact Jill Porter at (603) 626-0129 or *jilleporter@comcast.net*.

Northeast Florida Ataxia Support Group Meeting

Time: 2 – 4 p.m.

Location: Baptist South Hospital. Azalea, Begonia and Camellia conference rooms.

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

— Saturday, August 31, 2013 —

Detroit Area Ataxia Support Group Meeting

Time: 1 – 4 p.m.

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

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

— Saturday, September 7, 2013 —

JHU Ataxia Support Group 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: Joseph Savitt, MD, PhD, Parkinson's Disease and Movement Disorders Center of Maryland. For more information contact Bailey Vernon, Health Educator at (410) 616-2811 or *bvernon1@jhmi.edu*. Please RSVP if planning to attend.

Los Angeles Ataxia Support Group Meeting

Time: 2 p.m.

Location: Azusa City Library

Details: For more information or to RSVP contact Sherry McLaughlin at (626) 791-1558 or *ccherilynmc@yahoo.com*.

West Central Florida
Ataxia Support Group Meeting

Time: 12:30 – 3 p.m.

Location: The Morsani Center, 13330 USF Laurel Drive #1013, Tampa, FL 33612

Details: For more information contact Cindy Steever-Ziegler at (239) 878-3092 or *scsteever@msn.com*.

— Sunday, September 8, 2013 —

Los Angeles Ataxia Support Group
Picnic/Concert

Time: Concert starts at 7 p.m.

Details: Hollywood Bowl picnic/concert "A Night with ABBA." Top Swedish tribute band will take us back to the disco era. For more information or to RSVP contact Sherry McLaughlin at (626) 791-1558 or *ccherilynmc@yahoo.com*.

— Wednesday, September 11, 2013 —

Willamette Valley Ataxia Support Group Meeting

Time: 11:30 a.m. – 1 p.m.

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

Details: For more information contact Ivy Stilwell at (541) 812-4162 or *istilwell@samhealth.org*.

— Thursday, September 12, 2013 —

Tri-State Ataxia Support Group Meeting

Time: 6:30-8:30 p.m.

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

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

— Saturday, September 14, 2013 —

North Texas Ataxia Support Group Meeting

Time: 10 a.m. – noon

Location: Las Colinas Cancer Center, 7415 Las Colinas Blvd., Irving, TX. The parking is free and the building is handicap accessible. ⏩

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

— Sunday, September 15, 2013 —

Central PA Ataxia Support Group Picnic

Time: 11 a.m. – 3 p.m.

Location: Warwick County Park, 191 County Park Rd., Pottstown, PA 19465

Details: For more information contact Mike Cammer at (610) 873-1852 or *michael.cammer62@hotmail.com* or Chris Rakshys at (610) 395-6905 *rakshys@ptd.net*.

— Saturday, September 21, 2013 —

Twin Cities Ataxia Support Group Meeting

Time: 10 a.m.

Location: Langton Place in Roseville at 1910 West County Rd. D, Roseville, MN 55112. Central location and easy to access.

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

INFORMATIONAL AND AWARENESS EVENTS

— April–October, 2013 —

One Mountain at a Time

Details: This year, from April through October, I, Alana Moehlman, will be attempting what is called a "thru-hike" of the Pacific Crest Trail (PCT) to raise awareness and funds for the National Ataxia Foundation. The PCT is a long-distance hiking and equestrian trail closely aligned with the highest portion of the Sierra Nevada and Cascade mountain ranges to the east of the U.S. Pacific coast. The trail is approximately 2,663 miles long and passes through 25 national forests and seven national parks. Please join me on my journey from the deserts of southern California north to the Cascades of Washington state and into Canada. What a difference we could make if everyone contributed one penny per PCT mile, amounting to $26.63 per individual contribution! I will be keeping a journal along the way which can be found at *www.trailjournals.com/alanamoehlman*. Please pass this information on to friends and family to help get the word out and help raise funds for NAF! *https://naf.myetap.org/fundraiser/13mountain/*

— Friday, July 19, 2013 —

Annual KML 3 x 3 Soccer Tournament

Time: 4 p.m.

Location: Kettle Moraine High School, 3399 Division Rd., Jackson, WI

Details: Proceeds benefit the National Ataxia Foundation. For more information contact Barry Washburn at *ewashburn@nconnect.net*.

— Friday-Sunday, August 2-4, 2013 —

Abilities Expo

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

Location: Reliant Center, Houston, TX

Details: Admission is free. *www.abilitiesexpo.com*

— Saturday, August 24, 2013 —

Macy's "Shop for a Cause"

Details: Just in time for "Back to School" shopping! One-day-only sales event at Macy's stores nationwide. Card holders receive a 25% discount on regular, sale, and clearance items, including home. Even save on most brands usually excluded. Card holders will also save 10% on electronics, watches, furniture, and rugs. Exclusions apply. Card holders are also eligible to register to win a $500 Macy's gift card. All Macy's Card orders must be received by August 16. For more information please contact NAF at (763) 553-0020. All proceeds benefit the National Ataxia Foundation.

— Sunday, September 8, 2013 —

Denver Third Annual
Run, Walk n' Roll for Ataxia
IAAD Event and Fundraiser

Location: Denver's City Park between Colorado Blvd. and York St, along 17th St.

Details: The event is a non-competitive 3K run/walk and shorter routes for "rollers" or less ambitious runners and walkers. All proceeds benefit the National Ataxia Foundation. For more information visit the event website or contact Charlotte DePew at (720) 379-6887 or *cldepew77@comcast.net. www.ataxia.org/walk/denver*

— Saturday, September 14, 2013 —

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

Time: 9 a.m.

Location: Wolfe Park in St. Louis Park, MN

Details: Wolfe Park is kid and pet friendly. All proceeds benefit the National Ataxia Foundation. For more information visit the event website or contact Terry Sweeney at (612) 763-9320 *mnataxiawalk@yahoo.com. www.ataxia.org/walk/minnesota*

Continued on page 46

Calendar of Events
Continued from page 45

— Sunday, September 15, 2013 —

Dining to Fight Ataxia
IAAD Event and Fundraiser

Details: The Delaware Support Group is inviting friends, family members, and associates throughout the state and southeast Pennsylvania to dine with them at selected participating restaurants that have agreed to donate a percentage of purchases to the National Ataxia Foundation. For more information contact Joe DeCrescenzo at (320) 388-6810 or *jdecr@comcast.net*.

— Friday-Sunday, September 20-22, 2013 —

Abilities Expo

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

Location: Boston Convention and Exhibition Center, Hall C, Boston, MA

Details: Admission is free. *www.abilitiesexpo.com*

— Saturday, September 21, 2013 —

Atlanta Third Annual Walk n' Roll for Ataxia
IAAD Event and Fundraiser

Time: 9 a.m. - Noon

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

Details: All proceeds benefit the National Ataxia Foundation. For more information visit the event website or contact Greg Rooks at (404) 822-7451 or *rooksgi@yahoo.com*. *www.ataxia.org/walk/atlanta*

Detroit Fifth Annual Walk n' Roll for Ataxia
IAAD Event and Fundraiser

Time: Registration 10 – 11 a.m., 11 a.m. Walk n' Roll

Location: William G. Miliken Park, 1900 Atwater (between Orleans and St. Aubin) Detroit, MI. Parking on St. Aubin in lot.

Details: All proceeds benefit the National Ataxia Foundation. For more information or to volunteer contact Tanya Tunstull at (313) 736-2827. *www.ataxia.org/walk/detroit*

Jacksonville Walk n' Roll for Ataxia
IAAD Event and Fundraiser

Time: 10 a.m. – noon

Location: North Bank River Walk, 201 East Coastline Dr., Jacksonville, FL

Details: All participants present at the event who donate $20 or more in support will receive a free "Walk n' Roll" t-shirt. All proceeds benefit the National Ataxia Foundation. For more information visit the event website or contact Cory Hannan at (904) 314-2061 or *coryhannan@hotmail.com. www.ataxia.org/walk/jacksonville*

— Wednesday, September 25, 2013 —

International Ataxia Awareness Day (IAAD)

Details: The "International Ataxia Awareness Day" (IAAD) is an international effort from ataxia organizations around the world to dedicate September 25 as International Ataxia Awareness Day. Each participating country, state, or individual may have a specific plan for this event. For more information on organizing an event in recognition of IAAD visit *www.ataxia.org/events/international-ataxia-awareness-day.aspx*.

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

— Saturday, September 28, 2013 —

Third Annual Bingo for Ataxia
IAAD Event and Fundraiser

Time: 5:30 p.m.

Location: Berlin Fire House, 214 North Main Street, Berlin, MD

Details: All proceeds benefit the National Ataxia Foundation. For more information contact Joanne or Dana Simpson at (410) 251-2478 or *dsimpson2478@yahoo.com*.

Central Massachusetts
Third Annual Walk n' Roll for Ataxia
IAAD Event and Fundraiser

Time: Registration 9 – 10 a.m. Walk starts at 10 a.m.

Location: Lamanski Park (aka Rocketland), Auburn, MA

Details: Event registration is free and all registrants receive a complimentary event T-shirt. All proceeds benefit the NAF. To volunteer or for more information, visit the event website or contact John Mauro at (508)736-6084 or *johnmauro@verizon.net*. *www.ataxia.org/walk/auburn*

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

Time: 8 a.m.

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Location: Shoreline Park in Long Beach, CA

Details: All proceeds benefit the NAF. For more information visit the event website or contact Daniel Navar at (323) 788-7751 or *danieln27@gmail.com*. *www.ataxia.org/walk/longbeach*

NCASG Fifth Annual
Walk n' Roll for Ataxia and Fitness Faire
IAAD Event and Fundraiser

Time: 11:30 a.m. – 2:30 p.m.

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

Details: All proceeds benefit the NAF. For more information visit the event website or contact Joanne Loveland (925) 735-7037 or *joanneloveland@gmail.com*. *www.ataxia.org/walk/lafayette*

North Texas Trail Walk n' Roll & Picnic
IAAD Event

Time: 10 a.m.

Location: Mike Lewis Park, 2600 Block of North Carrier Parkway, Grand Prairie, TX

Details: Join us for a "fun" picnic get together for members of the group and any family they choose to invite. There are plenty of good paved trails, ponds, and other recreation areas and the entire park is very accessible. Each family will bring their own lunch/drink and picnic thing they want to have/do for themselves. For more information contact David Henery at (817) 491-4573 or *cheve11e@sbcglobal.net*.

San Diego Seventh Annual
Walk n' Roll for Ataxia
IAAD Event and Fundraiser

Time: Registration 7-8 a.m.; Walk n' Roll 8 a.m.

Location: Tuna Harbor Park, Downtown San Diego

Details: Free T-shirt for the first 200 participants. All proceeds benefit the NAF. To volunteer or for more information visit the event website or contact Earl McLaughlin at (619) 447-3753 or *emclaugh@cox.net*. *www.ataxia.org/walk/sandiego*

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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 March through May 2013. We are sorry that we cannot separate the memorial contributions from those made in honor of someone, as sometimes the person making the contribution does not let us know if the contribution is a memorial or in honor of their friend or family member.

Joseph Arce
Daniel Balogh
Soleil Banguid
Jeffery Barberi
Blair Bassler
Jack Bates
John Bates
Jerry Bender
Carl Beyer
Dorothy Biniek
Nancy Brooks
Louise Brown
William Chwee
Patricia Crandall
Eleanor Creel
Russell Crystal
Robert Currier, MD
Carole Degenfelder
Raffaela Deluca
Grace Demeo
Dawn Dizon
Nan Dodds
Trinity Falk
Masserant Family
Aleksandra Fawcett
Kevin Fleming
Rita Fleming
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Kathy Gardner
Callie Girod
Betty Lou Graham
Jay Greenblatt
James Hankins
Jim Hankins
George Hicks
Warren Holmes
Krista Humes
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Quincie Kelly
Chad Kiviaho
Elaine Koissian
Jamie Kosieracki
John Lane Sr.
Dean Laugerman
Pauline Le
Erica Lehrer
Harriet Lewis
Joyce Lokken
Walter Lowry
Carly Magnuson
Martha Makohon
Brent Masserant
Alyssa McClure
Ilse McGrath
Mr. & Mrs. R. McMullin
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Janet Riley
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2600 Fernbrook Lane, Suite 119
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Is your address correct? Are you receiving more than one issue of *Generations*? If there are any changes that need to be made, please call NAF at (763) 553-0020 or e-mail *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 # ______
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41-2