

Generations

The Official Publication of the National Ataxia Foundation

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Promising Ataxia Research Receives Funding for 2009

The response to the National Ataxia Foundation's invitation for ataxia investigators to submit research applications was the greatest it has been in NAF's history since the Foundation began providing research funding.

NAF's four grant programs for 2009 included: Research, Young Investigator, Friedreich's Ataxia Special Projects and Fellowship awards. Each of these programs has a different dollar amount or a specific focus but all have the same requirement: the research must be for new and innovative studies that are relevant to the cause, pathogenesis or treatment of ataxia, both hereditary and sporadic.

When all four categories are combined, a total of 49 well-written and thorough research projects were submitted and reviewed utilizing 33 experts in ataxia to read and score the applications. The reviewers' scores and comments were then submitted to a research review committee to make recommendations to the NAF Board of Directors for their final approval for funding.

There were many excellent projects submitted and only because of the limitations in funds were some not granted funding. However, the National Ataxia Foundation is proud to announce its most recent funding of nine excellent projects for FY2009. Some grants are for two years so those projects will continue to receive

funds during 2010. It is exciting to note that six different countries are represented, nine different types of ataxia are being studied and one project has the potential to identify a new ataxia gene.

It is because of the generous donations of individuals and private foundations, as well as family fundraisers, that NAF funded the following research:

Research Grant Awards

Stefan Kindler, PhD

*University Medical Center,
Hamburg, Germany*

**Spinocerebellar Ataxia 2: Cellular
and Molecular Action of Normal
and Mutant Ataxin-2**

Ataxia, an unsteady and clumsy motion of the limbs and torso, is a common disability accompanied by severe loss of quality of life and often premature death. Different types of inherited spinocerebellar ataxias (SCAs) are caused by mutations in distinct genes. In several diverse forms of SCA, these mutations lead to expansions of so-called polyglutamine (polyQ) stretches in the corresponding gene products, termed proteins.

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Proteins are organic compounds composed of a chain of different amino acids, including one called glutamine. They are the main molecular working units of cells and participate in practically every cellular process often via regulated



Dr. Stefan Kindler

interactions between particular proteins. Each protein possesses a precise three dimensional structure that enables it to fulfill its specific cellular function. Most structural alterations thus lead to functional deficits. Spinocerebellar ataxia type 2 (SCA2) is caused by a polyQ stretch expansion in a protein named ataxin-2. This alteration may compromise the structure and cellular interaction pattern of ataxin-2 and disrupt its physiological function thereby causing the death of particular brain cells, which finally results in uncoordinated muscle movements.

Our research aim is to identify proteins, which interact with normal ataxin-2 in cells. These data will help to determine the cellular function of ataxin-2. In addition, we will analyze whether polyQ expansion changes the interaction pattern of ataxin-2. Identified differences may help to understand the cellular mechanism by which the altered protein leads to the development of the disease.

In the long term, our studies are aimed at designing new therapies to delay or prevent the progress of ataxia in individuals affected by SCA2.

Puneet Opal, MD, PhD

*Northwestern University Medical School,
Chicago, IL*

**Cellular Mechanisms Underlying
SCA1 Pathogenesis**

Spinocerebellar ataxia type 1 (SCA1) is an inherited disease that causes progressive instability of gait or ataxia. Unfortunately, there is no treatment for this relentless disease and those afflicted succumb to complications of cerebellar and brainstem dysfunction.

This disease is caused by an expansion of glutamines (glutamine is an amino acid) in the disease causing protein, ataxin-1. Recent evidence suggests that mutant ataxin-1 causes alterations in gene expression.

In searching for genes directly down-regulated by mutant ataxin-1, we have identified the angiogenic/trophic factor VEGF (Vascular Endothelial Growth Factor) that is also significantly decreased in the brains of the SCA1 mouse model.

This proposal tests the hypothesis that low levels of VEGF in SCA1 contribute to the cerebellar dysfunction and degeneration characteristic of this disease.

Our long-term goal is to use these insights to elucidate mechanisms that will help reverse pathology of this otherwise incurable disease.



Dr. Puneet Opal

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**Support these research efforts and the work of the Foundation
by becoming a member or by making a donation at www.ataxia.org.**

Promising Ataxia Research...
Continued from page 3

Shirley Rainier, PhD

University of Michigan, Ann Arbor, MI

**Spinocerebellar Ataxia:
Three Novel Genetic Forms**

There are many different types of inherited ataxia. Seventeen ataxia genes have been identified. We evaluated three large families that have distinct forms of ataxia. In the first



Dr. Shirley Rainier

family, ataxia and involuntary movements begin very rapidly (sometimes overnight) and then worsen slowly over years. In the second family, progressive tremor begins in childhood and is followed by worsening ataxia in adulthood. In the third family, progressive ataxia involving speech, walking, and the arms begins in adulthood. Genetic testing of each family shows that there are no mutations in ataxia genes that are available for analysis.

The proposed investigation will perform genetic analysis of each family to discover the

location of the mutant gene causing ataxia. Discovering new ataxia genes will increase our knowledge of the molecular processes that cause ataxia. This will increase our ability to develop or discover treatments for ataxia.

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Liana Veneziano, PhD

National Council of Research, Rome, Italy

**Looking for Gross Rearrangements of
CACNA1A Gene in Episodic Ataxia
Type 2 (EA2) Patients by Comparative
Genomic Hybridization (CGH) Arrays**

This project focuses on the study of a rare disorder, Episodic Ataxia type 2 (EA2) due to mutations of CACNA1A gene encoding for the core protein of one type of calcium channels particularly abundant in brain.

The study is aimed at increasing the rate of EA2 molecular diagnoses. EA2 is due to protein changes decreasing calcium influx into the cell. Many problems remain unsolved, among which the low rate of EA patients in whom a molecular diagnosis is attained (20-30%) is seriously limiting the chance to study clinical and therapeutic aspects in appropriately sized group of patients.



Dr. Liana Veneziano

The present project proposes to verify if gene rearrangements, not detectable with the routine methods, can increase the detection rate. This goal will be reached by using a new methodology, Comparative Genomic Hybridization (CGH) arrays, that measures DNA copy number variations at multiple loci simultaneously, which can be used for a screening of CACNA1A gene rearrangement in a sample of 40 EA patients in which gene point mutations were excluded. ►►

CFC Number

The National Ataxia Foundation's Combined Federal Campaign (CFC) number is 10752.

This program provides a convenient way to donate to the Foundation, and provides great benefit to those with ataxia.

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

The accomplishment of this task will increase the number of molecularly diagnosed patients undergoing clinical trials for new therapies.

Theresa A. Zesiewicz, MD

University of South Florida, Tampa, FL

A Pilot, Randomized, Double-blind, Placebo-controlled Phase I Study to Determine the Safety and Tolerability of a Compound in Treating Spinocerebellar Ataxia Types 1, 2, 3, and 6

This will be a pilot, multi-site, prospective, double-blind, randomized, placebo-controlled trial to examine the safety and tolerability of a compound in treating spinocerebellar ataxia types 1, 2, 3, and 6. This study will also assess the



Dr. Theresa Zesiewicz

effectiveness of this compound on gait and imbalance, quality of life; and activities of daily living (ADL) in patients with spinocerebellar ataxia. The study will have two phases. During the first phase, patients will be randomized to take the compound or placebo for eight weeks. For the second phase, patients will switch and take either the compound or the placebo, whichever they did not take during the first phase. Neither the patient nor the study personnel will know when the patient is taking the real medicine.

Deadline

The deadline for the summer issue of *Generations* is May 15. Contact information appears inside the front cover.

Post-Doctoral Fellowship Awards

Smita Agrawal, PhD

University of Minnesota, Minneapolis, MN

Alternative Splicing in SCA1

Spinocerebellar ataxia type 1 (SCA1) is a genetic neurodegenerative disorder caused by mutation in the SCA1 gene, which encodes for the ataxin1 protein. This mutation involves the expansion of a translated CAG repeat that encodes a polyglutamine tract in ataxin1. At the pathological level, the most common feature is the progressive degeneration of cerebellar Purkinje cells in SCA1 patients.

Previous studies suggest that in addition to the expansion of the polyglutamine tract, other domains of ataxin1 are also important for development of neuropathology in SCA1, including phosphorylation of serine 776. The RNA-binding capabilities of ataxin1 and its interaction with various modulators of transcription suggest that it plays a role in RNA transcription.

A recent study demonstrates that ataxin1 interacts with RBM17, an RNA splicing factor and this interaction is enhanced in the presence of mutant ataxin1. We hypothesize that this enhanced interaction of RBM17 with the mutant ataxin1 may cause changes in RNA splicing in downstream target genes, which in turn may contribute to onset of the disease. We have examined the splicing patterns of cerebellar RNA from SCA1 mutant and control mice and detected widespread changes in splicing patterns



Dr. Smita Agrawal

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between the two transgenic mice models before pathological effects are apparent. This further strengthens our hypothesis.

In this proposal, we aim to identify and validate key target genes and pathways affected due to alternative splicing before onset of SCA1 pathology due to mutant ataxin1-RBM17 interaction. To this end, we first propose to conduct a genome wide exon expression analysis on two additional well characterized SCA1 mice models in order to shortlist the candidate target genes and identify putative pathways for therapeutic targeting. These hits will then be validated using standard quantitative RT-PCR techniques and a cell based assay system that we have developed.

Finally, the long-term goal of the project is to generate an RBM17 gain-of-function transgenic mouse model to further investigate the role of RBM17 in causing SCA1 pathology. The identification of genes and pathways downstream of mutant ataxin1 that might be altered due to splicing changes will provide mechanistic insights into the onset of SCA1 pathology. In addition, these genes could also become potential targets for development of SCA1 therapeutics.

Getting Married?

If you are getting married, you can support the National Ataxia Foundation by registering with the *I Do Foundation*.

From honeymoons to invitations to wedding gifts to charitable wedding favors, the *I Do Foundation* allows couples and their guests to make wedding-related purchases that generate donations for charity. Their charity registry service makes it easy for guests to make donations in lieu of gifts.

These services are available free of cost at www.IDoFoundation.org. Please select NAF as the beneficiary of your charitable wedding.

Thomas M. Durcan, PhD

*Montreal Neurological Institute,
Quebec, Canada*

Investigate the DUB Activity of Ataxin-3 and its Effect on Parkin Stability and Activity

Machado Joseph disease (MJD)/Spinocerebellar ataxia-3 (SCA3) is the most common dominantly inherited ataxia worldwide. Screening for the disease causing gene led to the identification of ataxin-3, a gene identified as containing an expanded polyQ tract (>50Q) in MJD. Further studies identified ataxin-3 as a deubiquitinating enzyme, with this activity to remove Ub chains from a substrate protein residing in its N-terminal Josephin domain. Moreover, ataxin-3 contains 3 ubiquitin interacting motifs (UIMs), permitting ataxin-3 to bind Ub and ubiquitinated proteins. Both the UIMs and the Josephin domain indicate that ataxin-3 plays a role within the Ub proteasome system (UPS). Yet, until recently little has been determined about the role of ataxin-3 in the UPS and if the presence of the polyQ expansion in MJD could affect the normal function of ataxin-3 in the UPS. To first understand the role of ataxin-3 within the UPS, it was critical to first identify a substrate that ataxin-3 could deubiquitinate.

Recent studies in our lab identified parkin, an E3 ligase, as a novel substrate for ataxin-3 mediated deubiquitination. Parkin plays an opposing role to ataxin-3 in the UPS, possessing the ability to form Ub conjugates on substrate proteins and itself. Moreover, mutations in parkin account for a common familial form of PD. Identification of parkin as a substrate for ataxin-3 mediated deubiquitination was of interest to us as a result of previous studies, in which patients with MJD presented with overlapping symptoms of PD, suggesting a potential overlap between both diseases.

For this study, we propose to examine further how ataxin-3 and parkin functionally interact ►►

and how this could potentially lead to parkinsonian symptoms in MJD patients. Previous studies observed ataxin-3 interacting directly with parkin through two interaction domains, facilitating direct deubiquitination of self-ubiquitinated parkin. Moreover, ataxin-3 was observed to deubiquitinate parkin in real-time, targeting Ub linkages as they are forming on parkin. Furthermore, by targeting Ub conjugates



Dr. Thomas Durcan

on parkin, ataxin-3 appears to regulate parkin levels with over expression of ataxin-3 causing a decrease in parkin levels and vice versa. Yet, what remains unclear is what Ub linkages are targeted by ataxin-3 to regulate parkin levels.

The best characterized linkages studied are K48 linkages, observed to target substrate proteins for degradation and K63 linkages, observed to protect proteins from being targeted for degradation.

In this study, we hypothesize that parkin self-ubiquitinates using primarily K63 Ub linkages, consistent with other studies. Moreover, we speculate that ataxin-3 targets K63 linkages leading to a shift in the ratio of Ub linkages on parkin towards K48 linkages, with increased targeting of parkin for degradation. To examine this in detail, a combination of in vitro ubiquitination assays and mass spectrometry analysis will be performed.

In addition to providing the first insight into how ataxin-3 deubiquitinates a substrate protein and the linkages targeted by ataxin-3, we propose to examine how ataxin-3 mediated deubiquitination of parkin can affect its stability and activity towards other substrate proteins using both in vitro and in vivo assays. By examining the effect of ataxin-3 on aspects of parkin function and stability, this study will help us under-

stand how parkin and ataxin-3 functionally interact for the first time. Given that both proteins play opposing roles in the UPS and play a role in PD and MJD respectively, it is imperative to understand how the disease form of ataxin-3 could affect parkin function. Such findings could possibly provide an explanation for the overlapping parkinsonian symptoms observed in many MJD patients and delineate a novel mechanism in the pathogenesis of MJD.

Young Investigator Award

Leeanne McGurk, PhD

*University of Pennsylvania,
Philadelphia, PA*

**The Identification of Putative
Drug Targets for SCA3 using
*Drosophila Melanogaster***

The cerebellum, which is found at the back of the brain, is the major center for motor control. Patients that suffer from degeneration of the cerebellum show a progressive loss of motor control and balance. This symptom, called ataxia, is observed in many neurological diseases that include the spinocerebellar ataxias (SCA).

There are around 30 different subtypes of SCA, each



Dr. Leeanne McGurk

of which are due to distinct mutations. Of the 30, SCA3 is the most prevalent. Therapeutic strategies to prevent the degeneration in SCA patients have proven unsuccessful. Due to the nature of the mutation, which is present in the ataxin3 gene, designing a good strategy is difficult.

Promising Ataxia Research...
Continued from page 7

There are many proteins that ataxin3 affects and strategies have so far targeted some of those proteins. Unfortunately the results generated by clinical trials contradict each other and no strategy, as yet, has proven to be 100 percent successful.

In order to identify new drug targets for SCA3 the mechanisms by which mutant SCA3 confers toxicity needs to more greatly understood. We aim to reveal new genes (potential drug targets) that generate ataxia. To do this we will use the fruit fly. It has been well established that mutant ataxin3 can cause degeneration of the fruit fly eye and our preliminary data suggests that mutant ataxin3 can also cause an ataxia-like behavior in flies.

We want to determine which of the proteins that ataxin3 interacts with causes the ataxia-like behavior. There are approximately 650 proteins

that directly interact with ataxia causing proteins and ataxia associating proteins. We have found that 200 of these genes are present in *Drosophila*. We will prevent the proteins from being made in the ataxia-causing neurons and we will assess whether the flies suffer from ataxia. We aim to show that these proteins can prevent the ataxia-like behavior in the SCA3 model by increasing the amount that is present in the brain. We will not only do this in the SCA3 fly model but also in the fly models of other neurological diseases such as Friedreich's ataxia.

Finally, we want to screen a database of drug molecules that have the ability to increase the amount of our candidate proteins, and test whether they will be suitable therapeutic strategies by feeding them to our SCA3 fly model.

As well as providing insight into the mechanisms involved in the progression of SCA3, the findings of this project can directly translate into data that is beneficial to clinical advancement of the disease. ▶▶

Film of 2008 AMM Available

Independent filmmaker Jonathan Higgins recently released a production capturing major events from NAF's 51st Annual Membership Meeting in Las Vegas, NV in March 2008. The film is entitled "Ataxia: Finding a Cure for an Incurable Disease" and was made to promote education and awareness about ataxia as well as medical research. The film contains footage of major events at the meeting as well as interviews with specialists, patients, and family members.

Higgins was awarded a grant from the National Film Board of Canada Filmmaker Assistance Program which enabled him to enlist the talents of a visual and audio editor as well as gain access to state-of-the-art editing equipment.

To purchase a copy of the film, contact Higgins at higgins0466@rogers.com.

TISSUE DONATION

**If you are interested
in helping ataxia research
by donation of tissue
after death, please contact
Dr. Arnulf Koeppen for
information and details.**

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Friedreich's Ataxia Special Projects Award

Filip Lim, PhD

*Universidad Autonoma de Madrid,
Madrid, Spain*

Richard Wade-Martins, PhD

University of Oxford, United Kingdom

Manipulation of Frataxin Expression in Neurons

Although skin and blood samples from patients with inherited diseases have been extremely useful, laboratory studies and drug screening in certain cases, many ataxias such as Friedreich's ataxia (FA), are principally neurological diseases, and the lack of human neuronal cell models may substantially delay the development of treatments



Dr. Filip Lim

which are effective in the nervous system.

To remedy this situation we have focused our research on how to control levels of frataxin (the molecule which is reduced in FA), specifically in neurons. Our two groups in Madrid and Oxford have collaborated in FA research since 2004 and our present work consists of three closely linked projects: 1) developing FA gene therapy in animal models; 2) understanding how the normal and diseased frataxin gene is regulated in neurons; 3) novel human neuronal cell models for FA.



**Dr. Richard
Wade-Martins**

These projects not only attempt to develop new therapeutic approaches such as gene therapy, but also serve to improve our understanding of FA and generate new research tools, which in turn will accelerate the identification of FA treatments, both by ourselves as well as by other research groups. ❖

Research Survey Participants Needed

You and your family members are invited to participate in a survey titled "Perceptions and Values Regarding DNA Contribution to Genetic Biobanks: Survey Design, Generation and Testing."

The survey asks about how you value particular factors in DNA contribution for future genetic research. Families living with rare genetic conditions have high stakes in future DNA biobank practices therefore the ataxia community is encouraged to respond to this survey.

Eligibility to participate is NOT limited to the diagnosed person. Persons at risk and family members not at risk are invited, too.

Your identity will not be submitted with the survey, therefore your responses are completely private and anonymous. Please call the nurse scientist conducting the study to leave contact information. The survey will be privately mailed to you and your family. Postage for the survey's return is provided.

Your participation provides important information that informs development of safe and fair practices for biobanks that collect and store your DNA for future research.

Call Pamela Williams, JD, MS, RN toll-free at 1-866-931-3630 for more information.

From the Desk of the **Executive Director**

The National Ataxia Foundation recently held its 52nd Annual Membership Meeting in Seattle, Washington on March 20-22. The meeting was a great success and we are truly thankful to the Seattle Area Ataxia Support Group and the British Columbia Ataxia Society for co-hosting this outstanding conference.

These NAF annual membership meetings represent the largest gathering of ataxians in the world. Many of the states in the United States were represented, along with registrants as far away as Australia and Hong Kong. At the conference, world-leading ataxia scientists and clinicians gave presentations on cutting-edge ataxia research along with speakers who provided valuable information on topics ranging from "Nutrition and Ataxia" to "Wheelchair Yoga."

Kyle Bryant, the founder of Ride Ataxia, gave a heartfelt presentation at the Friday Night Reception, and great fun was had by all at the Saturday Night Banquet with a live band and entertaining raffle activities. I hope you were able to attend this wonderful meeting where learning, sharing, networking, and having fun is what these meetings are all about.

Meeting old friends and developing new friendships is an important part of these meetings. I must share with you a story told to me by a wonderful woman who attended the conference. Her parents had offered her and all her family members a vacation on a cruise ship. While she was overwhelmed by their generosity, she had asked her parents that, rather than a cruise, would they consider sending her to the NAF Annual Membership Meeting? I believe this speaks volumes on how important these meetings are and the impact they have on all of us.

If you missed this year's annual membership meeting, start planning for next year's meeting being held on March 12-14, 2010 in Chicago, Illinois at the Hyatt Regency O'Hare. The Chicago Area Ataxia Support Groups will host the 2010 meeting and plans have already begun to make this a memorable event. More information about the 2010 annual membership meeting will be available in future issues of *Generations*, on NAF's web site, www.ataxia.org, and in NAF E-Blasts.

At the 2009 conference various NAF highlights for 2008 were presented. I would like to share with you a number of these highlights:

- Over the past 10 years NAF has awarded funding to 128 promising ataxia research studies in 11 countries.

- In March 2008 NAF hosted its second International Ataxia Investigators Meeting (AIM).

Approximately 120 world-leading ataxia clinicians and scientists from 12 countries participated in this four-day conference.

- In 2008 NAF made funding commitments for 12 promising ataxia research studies. These studies are being conducted in the United States, Germany, Canada, Netherlands, Spain, and the United Kingdom.

- In 2008 NAF, FARA, and Ride Ataxia II combined forces for the second year in a row and awarded funding totaling \$250,000 for two \$125,000 Kyle Bryant Translational Research Awards.

- In 2008 NAF received its fifth consecutive 4-Star rating out of a possible 4-Stars from Charity Navigator, America's largest independent evaluator of charities in the U.S. Only 3% of all nonprofit organizations evaluated by Charity Navigator have been awarded this honor. ►►



Michael Parent

- The 2008 NAF Annual Membership Meeting was held in Las Vegas, Nevada, breaking previous attendance records with nearly 650 registered attendees. NAF members came from around the United States and there were international attendees from France, the United Kingdom, Switzerland, Germany, Canada, and Australia.

- In 2008 NAF provided programs and services in all 50 states and in 63 foreign countries.

- NAF saw significant activities on its web site, www.ataxia.org, in 2008. During the year, NAF's web site had 10,782,962 "hits" compared to 7,690,093 in 2007, a 40% increase. Visitors to the site came from 120 countries and totaled 948,872 compared to 691,088 visitors in 2007, a 37% increase.

- In 2008 NAF continued to update and develop new ataxia publications and published and distributed its 48-page quarterly news publication throughout the world.

- In 2008 NAF received 7,663 telephone calls and responded to 11,459 letters and 35,162 e-mails.

- NAF continued in 2008 to attend and participate in various conferences including the National Society of Genetic Counselors, the Society of Neuroscience, American Academy of Neurology, and the NIH Office of Rare Diseases Coalition of Patient Advocacy Groups. In addition, NAF was represented at various Abilities Expos across the nation.

- In 2008 NAF continued to update and add additional sections to its web site on a weekly and most often daily basis to provide up-to-date and accurate information.

- NAF chapters, support groups, and ambassadors continued to play a vital role in 2008 in providing local support, addressing educational needs, and networking for local ataxia families.

These and other programs and services are made possible because of dedicated volunteers and through support from NAF's generous donors. We are truly grateful for all your help and support. Thank you. ❖

How To Explain Ataxia

During the National Ataxia Foundation's Annual Membership Meeting in Seattle, chapter and support group leaders and ambassadors met to share their success stories in fundraising and ataxia awareness raising. Information on other aspects of serving as a National Ataxia Foundation volunteer leader in their own local settings was also provided.

In addition, Dr. Susan Perlman from the UCLA Ataxia Clinic was present to answer medical questions that are often posed to NAF volunteer leaders.

One of the questions that Dr. Perlman answered was, "How can I explain the disease of ataxia to the non-medical public?"

Her answer was well received and is reprinted here:



Dr. Susan Perlman

"I have a problem with poor balance, clumsy coordination, and slurred speech. It's called ataxia. The balance center in my brain (the cerebellum) is not working well. This can be

caused by a genetic problem, an immune problem, a toxin that a person is exposed to, or a stroke or injury. In some cases the doctor does not know what caused it and then the physician continues to look for a cause.

My ataxia may continue to slowly get worse, but I can partially control it with physical therapy and medications. Even though ataxia may look like multiple sclerosis or some of the other movement disorders, the causes are different, the treatments are different, and the research organizations that are working for cures are different. Ataxia is its own unique disorder.

The best place to get information about ataxia and the research that is taking place to find cures is at www.ataxia.org."

NAF Merchandise

BOOKS

Three Wheels by Rebecca Cummings Baldwin
True personal, heart-warming story of a woman with ataxia. A portion of the proceeds supports the NAF. Paperback. \$15.99

Ten Years to Live by Henry Schut
The story of the Schut family's struggle with hereditary ataxia. Paperback, photos. Also available in Korean. \$8.75

Living with Ataxia by Martha Nance, MD
Compassionate, understandable explanation with ideas on how to live with ataxia. Paperback. \$14

Healing Wounded Doctor-Patient Relationships by Linda Hanner and contributor John J. Witek, MD
Offers demonstrations of how effective dialog can help move patients and doctors to productive relationships. Paperback. \$10

Friedreich's Ataxia Research Cookbook
Julie Karjalahti of Savage, Minnesota has published this cookbook to raise money for FA research. Includes recipes from around the U.S. \$12

Recipes and Recollections by Kathryn Hoefler Smith
Full of delicious recipes and recollections, this book is perfect for fund raisers. Proceeds go towards FA research. Paperback. \$10

Managing Speech & Swallowing Problems by G.N. Rangamani, PdD, CCC-SLP
A basic guide to understanding and managing speech and/or swallowing problems. \$7.50

Evaluation and Management of Ataxic Disorders, an Overview for Physicians by Susan L. Perlman, MD
A guide for physicians treating ataxia patients. Paperback. \$5

VIDEO / CD

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

"Together There is Understanding" VHS or DVD
Continuation and expansion of "Together There is Hope." 50 minutes. VHS \$20 or DVD \$25

SHIRTS / MISCELLANEOUS

2009 Annual Membership Meeting T-Shirt **NEW!**
Gray, long-sleeved with "Climb Every Mountain" logo. Sizes medium to XXX-large. \$10

Past Annual Membership Meeting T-Shirts
Meeting t-shirts from past annual membership meetings. Various styles, sizes and colors. \$5

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

NAF Polo Shirt
Royal blue w/ white embroidered NAF logo. \$27.50

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" Sweatshirt
White. Sizes small to XXX-large. \$20

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 Logo
Eco-friendly, reusable grocery tote bag. Made in the USA of quality material. \$5

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Caregiver's Corner

NAF has permission to reprint the following excerpts from the "The Comfort of Home" series.

Good Nutrition and Healthy Meals On a Budget

Good Food Is Key to Good Health

Good nutrition requires effort, knowledge and some planning. To some degree, it's as much about what you don't eat as what you do eat.

It starts with changing how you view your plate: Instead of making meat the center of the meal with vegetables as side dishes, make vegetables and grains the main course and reduce your meat portion to a side dish. The recommended meat portion should be no bigger than a deck of cards – much smaller than the typical meat course.



The Food Pyramid

According to the current USDA food pyramid, adults should eat 2-2½ cups of vegetables every day and 1½-2 cups of fruit a day for a total 3½-4½ cups. Making sure you have at least one fruit or vegetable dish at each meal accomplishes that goal. Add two fruit snacks between meals, and the goal is surpassed. This isn't hard to do, but it takes a little planning.

If you're having trouble getting the person in your care to eat fruits and vegetables, start by buying produce in season – it costs less and tastes best. To make it easy, buy veggies that are easy to prepare or that can be eaten raw. When steaming vegetables, don't overcook them – they should be crunchy, if the person does not have difficulty chewing. Also, stock up on frozen veggies. Cook them in the microwave for a quick and easy dish. Packages of baby carrots and celery sticks make quick snacks. When buying fresh produce, only

buy what can be consumed in a few days.

To lower your sodium intake, prepare meals using fresh ingredients. Packaged and processed foods are the source of most sodium in the American diet. When buying canned vegetables, buy those labeled "no salt added."

At meals, include a green salad at dinner each night, and add colorful, in-season vegetables. Make a salad the main course at lunch every few days by adding a little chicken. And go light on the salad dressing and leave off the croutons, which contain a lot of calories. Try a veggie stir-fry or soup as the main dinner course or a bean-and-grain casserole.

Menus for Every Condition

Help for planning low-cost, nutritious meals:

- Get personalized eating plans and advice on making smart choices in every food group at www.mypyramid.gov.
- Get menus, recipes and tips on buying and serving healthier food at <http://snap.nal.usda.gov> (in English and Spanish), as well as find information on whether the person in your care qualifies for food stamps.
- Find over 100 low-cost, nutritious and delicious recipes at <http://recipefinder.nal.usda.gov>.
- If you're preparing food for a heart patient, go to www.americanheart.org and type "delicious decisions" into the search window, then click on Browse Recipes.
- If you're preparing food for a person with

Continued on page 14

Good Nutrition and Healthy Meals...
Continued from page 13

diabetes, go to www.diabetes.org and click on Recipe of the Day. From there you can access other recipes.

- To locate a Senior Nutrition Center in your area, call 1-800-677-1116.

Saving \$\$\$\$

Simple tips for saving money on food purchases:

- \$ Plan meals, create a list from that meal plan, then shop from that list – it'll help you to stick to your budget.

- \$ Look for coupons, sales and store specials. For even more savings, sign up for the store's discount card.

- \$ Don't shop when you're hungry. Shopping when full makes it easier to stick to your list.

- \$ Buy store brands. They usually cost less and are of similar quality.

- \$ Compare prices. Even if you have a coupon, other brands may still be cheaper.

- \$ Buy larger quantities when items are on sale, divide them into smaller portions, and freeze them.

- \$ Check sell-by dates, and buy the freshest food possible.

Taking Care of Yourself

Studies have found that caregivers often don't eat as well as they should. In addition, they have higher rates of heart disease than non-caregivers.

In addition, poor eating habits contribute to obesity, which in turn contributes to heart disease and diabetes. Diabetes itself contributes to high levels of heart disease and stroke. Waist-line measurements have been shown to predict a variety of diseases. Women with waists larger than 35 inches and men with waists over 40 inches are considered at highest risk. Studies show that waist size is a better predictor of premature death than overall weight.

Try to eat fewer calories. An easy way to do this

is to give up sugary snacks and drinks. These are considered "calorie-dense" foods. Calorie-dense foods pack a lot of calories in a small package – think chocolate. For example, 8 ounces of broccoli is 65 calories; 8 ounces of chocolate chip cookies is 1,070 calories!

For reliable and easy-to-understand information on nutrition, changing your diet, easy-to-follow eating plans and quick, tasty and healthy recipes, go to www.AmericanHeart.org. It is a free, one-stop shop for heart-healthy nutrition.

Tip

Remember to check with the doctor before starting any special diets, especially for the person with a swallowing impairment. If diabetes is an issue, ask your doctor for an eating plan. The doctor, pharmacist, or registered dietitian will know what effect medicines have on what the person in your care can eat.

Inspiration

"Of all the medicine created out of the earth, food is the chief."

Sir Robert McCarrison, MD, British Nutritionist

Meals on Wheels

The person in your care may be eligible for Meals on Wheels, a nationwide program that delivers prepared meals to seniors. The qualifications vary from program to program, but generally, to be eligible, a person must:

- Be age 60 or older.
- Be unable to use kitchen appliances.
- Have no motivation to prepare food and no caregiver to help cook.
- Have become homebound in the winter months.
- Be recuperating from a serious illness or surgery.

To find the closest program to you, contact Meals on Wheels at (702) 548-5558, visit www.mowaa.org, e-mail mowaa@mowaa.org or contact your local Area Agency on Aging or Visiting Nurses Association. ❖

Ride Ataxia III Travel Journal

Starting on March 16, 2009, a robust group of 70 Ride Ataxia III participants departed from Portland, Oregon, on an unforgettable journey. The group traveled 200 miles by cycle, encountering steep hills and battling brutal weather conditions including rain, hail and wind along the way. The event concluded on Thursday, March 19, 2009, as the riders arrived at the Doubletree Hotel – Seattle Airport for the start of the National Ataxia Foundation’s Annual Membership Meeting. Meeting attendees and supporters celebrated the Ride Ataxia III group’s triumphant arrival with a warm and congratulatory welcome.

Kyle Bryant, Ride Ataxia founder prepared a travel journal throughout this year’s event to document the adventure. The following are his observations and reflections.

Weather and Bridges

Monday, March 16, 2009

Craziest day ever! But let me start from the beginning.

This morning we had a nice sendoff ceremony at OHSU. Three doctors/researchers told us a little about what they do for ataxia. We heard from Dr. Maylie and Dr. Nutt both from OHSU and we heard from Dr. Schut who is the Medical director for the National Ataxia Foundation. All three gentlemen gave very nice talks about what they do and all three stressed how important it is to have funds from groups like ours to help get research off the ground.

We then took off through downtown Portland and once again it became apparent how many people we had on this trip. It was pretty fun to travel through downtown turning heads as a huge, strong team.

When we got out of town, we hit the highway and it immediately started pouring rain. It started getting a bit miserable but as soon as my clothes soaked through, my body heat warmed the water that was next to my skin and I started warming up. We had heavy rain, light rain, sunshine and rolling hills until lunch.

After lunch we ran into more ridiculous weather...much more rain...and hail for about

five minutes. We crossed some railroad tracks and three of our teammates fell pretty hard at the tracks, one requiring minor medical attention but our SAG team took care of business and everything is fine.

At mile 51 we crossed the Lewis and Clark Bridge from Oregon to the state of Washington... Everyone had been talking about this bridge and how scary it would be... the bridge lived up to the hype. The Bridge was about two miles long and it had a small bike lane on the shoulder. It was pretty darn steep on either side so it was a slow climb followed by a screaming down hill.

“
**It was pretty
 fun to travel
 through downtown
 turning heads
 as a huge,
 strong team.**
 ”

We crossed the bridge in a group of four: me, Mike Bryant, Uncle Steve and Sean Roberson. When we reached the halfway point of the bridge (the highest spot) the rain began to turn very heavy and was between rain and snow, the wind was blowing very hard and the bridge began to sway a bit. The trucks to our left were causing the guard rail to rattle as if it were going to fall off. Then we began our descent. We landed on solid ground as soon as possible and as soon as we got off the bridge, the sun came out... Mother Nature was playing tricks on us.

Continued on page 16

Ride Ataxia III Travel Journal
Continued from page 15

Cold

Tuesday, March 17, 2009

We left this morning from our hotel at about 9 a.m. in a downpour. Today was a short day (40 miles) but the weather made it seem like much more. We can all deal with the wetness at this point but today was particularly cold... Most of us went for several hours without feeling in our toes. The only way to warm up was to ride as hard as we could to get the heart pumping and the circulation going to the extremities.



A big crowd was on hand to welcome the riders to the site of the annual meeting

After our lunch stop quite a few groups of us rode past a loose dog who was not friendly. Several people were chased at high speeds. Luckily nobody got hurt and the dog had fun today with lots of people to chase.

When we finally reached our destination, we thawed our fingers and toes and headed to dinner at the historic train depot in Centralia, Washington. We were honored to have the mayor of Centralia along with the operator of the train depot, Pollo Enriquez, with us at dinner. The city generously provided the space to us free of charge.

Our dinner was once again catered by Outback Steakhouse and their volunteer crew. The food was fantastic. Outback has been a HUGE supporter of the ride this year. They are an

organization dedicated to service and community. Thank you, Outback.

Triumph

Wednesday, March 18, 2009

Today started slowly and painfully for many of us. Personally, during the first half mile of the day, I was unsure that I was going to be able to last all day because of the pain in my knees. However, we pushed through the pain and loosened up. The weather was relatively nice today and we had a slight tailwind to help us along.

We rode for about 20 miles through a town and down some country roads. Then we hit a bike trail and we were cruising. The tail wind and the smooth surface helped us reach high speeds with little effort. We rode this trail all the way to lunch at mile 28.

Shortly after lunch the trail ended and we missed a turn... we got lost for about a half hour. When we finally found our way back, we were cruising again at high speeds.

The day dragged on toward the end and the knees began to stiffen and the pain returned but we struggled through to the end. I am so proud to have finished the ride today because I really did not think it was possible when I began.

We had one last team dinner at an Outback Steakhouse restaurant. The food was fabulous and we shared a few stories from the road, people talked about their favorite parts of the ride and we had a lot of fun remembering what happened over the past few days.

Victory

Thursday, March 19, 2009

We rolled in to the hotel this afternoon as a huge group. We were welcomed by a crowd of smiling faces. Ron Bartek, President of FARA, said a few words and then Mike Parent, Executive Director of NAF, said a few words and then we honored each rider with a medal. I am extremely proud of our team and the personal accomplishments of each person. ▶▶

Editor's note: Many of the Ride Ataxia III participants shared their reflections about the event noting the following memorable challenges and triumphs from their experience:

“Ride Challenges

- The storm when going over the bridge
- The final hill
- Rain, sleet, cold, wind
- Nothing challenging compared to living with FA
- The bridge and the very last hill (mountain)
- Traffic
- The rain and cold
- The hill
- The last hill, the bridge and crazy rain and wind storm

Ride Triumphs

- Spending time riding with my family
- Riding with my friends and the last dinner where everyone shared their stories
- Getting up that last hill with riders falling all over each other
- The people, the camaraderie, and the teamwork, taking care of each other, being certain nobody got left
- Meeting my riding buddy for all four days
- Going over that huge bridge
- All the friends I made
- All of it
- The last quarter mile riding together

Share Your Story

Generations is published quarterly by the National Ataxia Foundation to inform readers about research, chapters and support groups, events and other topics related to ataxia.

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

- Family participation
 - The people! Everyone was so supportive and so much fun – everyone there had a person they cared about with FA (or some of us have FA) everyone was doing their best, you became instant friends for life – it was amazing!
 - Doing the ride with my son
 - That darn bridge
 - The flat trails with conversation
 - All of the people
 - Meeting everyone and being as one
 - Riding at the end and seeing all the people who will benefit from the treatment that will come
- P.S. – I will never forget that bridge.” ❖

Living with Ataxia in British Columbia?

Are you and/or your child living with ataxia in British Columbia? If so, you are invited to join a new study being conducted by Dr. Patrick MacLeod, a pediatrician and geneticist at the University of British Columbia, in collaboration with the British Columbia Ataxia Society, about the number and location of individuals with ataxia in B.C.

Your participation is voluntary and would include a short questionnaire about you and

your diagnosis of ataxia that would take less than one hour of your time. You may be contacted again in the future by a researcher or by the British Columbia Ataxia Society.

If you are interested, you are invited to contact Valancy Miranda, the graduate student involved in the study, in order to get more information about participation. Please call (604) 875-3496 or e-mail vmiranda@cw.bc.ca.

Ataxia Questions & Answers

The National Ataxia Foundation (NAF) receives hundreds of requests for information as well as specific questions about ataxia symptoms and treatments. NAF provides over 20 fact sheets about the various types of ataxia, tissue donation, cognition and emotion as it relates to cerebellar disorders, and many other topics of concern for those with ataxia and their family members. These fact sheets are written in collaboration with members of NAF's Medical and Research Advisory Board members and updated when new information becomes available.

There are some very specific questions, however, that have been asked that are not covered in any fact sheets. We thought it would be interesting for the readers of Generations to read the questions with answers from members of NAF's Medical and Research Advisory Board.

Question: Can having your teeth capped with silver as a small child cause ataxia?

Answer: Not as far as we know.

Question: Can a person have an SCA type 5 but a very, very, low level?

Answer: No, there is some misunderstanding.

Question: If the duration of the symptoms of ataxia is from 10 to 15 years, what happens after that?

Answer: One cannot make a prognosis; it depends on too many factors.

Question: Is there a correlation between asthma and ataxia symptoms?

Answer: There is no connection between asthma and ataxia.

Question: Will cerebellar atrophy cause intermittent growling and gurgling in intestines or stomach?

Answer: Cerebellar atrophy does not cause the stomach to gurgle in any direct way.

Question: Is it okay for someone with ataxia to get a flu shot?

Answer: Older or very young ataxans are recommended to get the flu shot, just like their non-ataxan counterparts, unless there is some

pressing reason not to such as allergy to flu vaccine, a bad reaction in the past, or immune system problems.

Question: Can gastric bypass surgery cause ataxia?

Answer: If a patient has gastric bypass surgery but can consume a nearly normal diet, there is no reason that an ataxia should occur. If ataxia does occur, it is likely because gastric bypass surgery can reduce the absorption of vitamins, especially B1, B12, and E.

Question: Have you heard of success with hyperbaric therapy in ataxia?

Answer: It has been used for several neuro-degenerative diseases, but after optimistic reports, has faded from the scene.

Question: Is hypnosis effective for treating ataxia?

Answer: We are not aware of any research reports regarding the effects of hypnosis on ataxia symptoms. In general, biofeedback, relaxation, perhaps hypnosis, and a number of other things that may relax the mind or body are unlikely to be harmful and may have temporary benefits. A patient with ataxia will be on his or her own to make a decision about having these treatments, and should use common sense in choosing this, or any other unproven treatments. ❖

The National Ataxia Foundation 52nd Annual Membership Meeting

"Climb Every Mountain"

Seattle, Washington – March 20-22, 2009

The 2009 Annual Membership Meeting was hosted by our Seattle, WA area Ataxia Support Group and the British Columbia Ataxia Society. This was the first year that this conference has been co-hosted by an international ataxia support group. Many thanks to both support groups for all your efforts in coordinating this event and congratulations on a highly successful Annual Membership Meeting. Nearly 500 people attended the 52nd conference from around the world. Thirty-eight U.S. states were represented along with attendees from Australia, Canada, Hong Kong, and Switzerland.

Thursday, March 19, marked the arrival of the riders of Ride Ataxia III. Over 100 people gathered to welcome the riders! Congratulations to Kyle Bryant, founder of Ride Ataxia, and to all the other participants for their courageous efforts. Kyle was presented with a plaque dedicated to Ride Ataxia III and all of the riders were recognized with a medal for their participation in the bike ride, which started in Portland, OR. We would really like to thank all those that supported Ride Ataxia III in their effort to raise ataxia awareness and funds for important ataxia research.

Friday morning started out a little different this year. Instead of smaller breakouts we started our general session program this morning. The most popular or requested topics which would have been breakout sessions in the past were incorporated into our general session program. Mike Parent, NAF's Executive Director, started out the meeting with his welcome and accepted the

key to the City of SeaTac, WA from Mayor Ralph Shape on behalf of Arnie Gruetzmacher, AMM Chairman, who could not be present. Thank you so much, Mayor Shape, for your participation at our conference and for this most outstanding honor that you have given to us. Laura Ranum, PhD (University of Minnesota) then presented a general overview of ataxia and was followed by Corrie Smith, MS, CGC (University of Washington), who presented an overview of Genetics and Gene Testing. Harry Orr, PhD (University of Minnesota) gave an overview of the current ataxia research being done and was followed by S.H. Subramony, MD (University of Texas, Galveston), who gave us an update on the ataxia patient registries that are available.

The Nintendo Wii demonstration room opened Friday morning and continued on Saturday. This was a wonderful opportunity for attendees to experience the fun, interactive, physical therapy aspects of the Nintendo Wii game system.

Friday afternoon allowed attendees the opportunity to meet others by type of ataxia in smaller groups in order to get personal questions answered by ataxia investigators and to share experiences with others through the very popular Birds of a Feather sessions.

On Friday evening the Seattle Area Ataxia Support Group and the British Columbia Ataxia Society hosted a light hors d'oeuvres reception

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Annual Meeting Review
Continued from page 19

that was well attended. Delicious food and great company were enjoyed by all. At the reception, Theresa Zesiewicz, MD, FAAN (University of South Florida) gave an update of the clinical trial she is conducting on a compound for SCAs. Then Kyle Bryant, founder of Ride Ataxia, reflected on his own experience with ataxia and how he copes with its challenges. The work that Kyle and his fellow Ride Ataxia participants put into their cycling fundraising event is a great demonstration of his “can do” attitude. One of the goals of Ride Ataxia is to introduce cycling



NAF Executive Director Mike Parent (left) presents a plaque dedicated to the riders of Ride Ataxia III to Ride Ataxia founder Kyle Bryant

to ataxians who otherwise would never have tried it through the 2009 Ataxian Athlete Initiative. The winner of the Terra Trike Cruiser, Nadia Robertson, was announced and introduced that evening and encouraged to start her own Ride Ataxia adventure.

Ride Ataxia III raised over \$220,000 for ataxia research that will go towards a translational research grant in Kyle Bryant’s honor. Additional funds will be added by NAF and FARA.

At the reception Mike Parent, NAF’s Executive Director, presented a plaque to Dr. Michael Wilensky for his 25 years of service on the

Medical Research Advisory Board for NAF.

Saturday continued with the general session program with many new and familiar medical professionals and researchers. Thomas Bird, MD (University of Washington) started out the General Sessions by discussing the multi-discipline approach or “Seattle Experience” for an ataxia patient. Gregory Carter, MD, MS (University of Washington) talked about the rehabilitation aspects of ataxia. Kristie Spencer, PhD, CCC-SLP let us know about helpful Speech and Swallowing techniques. Michael Wilensky, MD (private practice, New Orleans, LA) then discussed medications to consider for an ataxian patient.

Saturday afternoon was filled with more general session presentations. Marek Napierala, PhD (University of Texas) presented on his study of targeting DNA structure for Friedreich’s ataxia therapy followed by Henry Paulson (University of Michigan), who presented the Poly-glutamine ataxias. Ralph Miller demonstrated wheelchair yoga. Sid Gilman (University of Michigan) then brought us up to date on sporadic ataxia.

Saturday’s banquet was a most enjoyable experience for all who attended. The 50/50 raffle was great fun with over 80% of conference attendees participating to raise more than \$2,950. Congratulations to the winners of the raffle. Thank you to everyone who donated items for the silent auction and to those that participated in this event which raised over \$5,000. Thank you so much to the Raucous Band who provided such great entertainment and dancing music!

On Sunday morning the general session program continued with Susan Perlman, MD (UCLA) who discussed how to manage your ataxia and your neurologist through a multi-disciplinary approach. David Lynch, MD (University of Pennsylvania) gave an update on the FRDA clinical trials. Timothy Maher, PhD (Massachusetts College of Pharmacy and Health Sciences & Massachusetts Institute of Technology) discussed nutrition and ataxia. ►►

Arnulf Koeppen, MD (VA Medical Center, Albany, NY) then presented on what we can learn from brain tissue donations, followed by Ryan Boudreau, PhD (University of Iowa) who discussed RNAi Research. Grisel Lopez, MD (National Genome Research Institute, NIH) then discussed the clinical trial that is currently underway for lithium treatment for patients with SCA 1. George Wilmot, MD, PhD (Emory University) gave the closing presentation of the conference with his review of what we had learned throughout the weekend.

Each day's general session was followed by a question-and-answer session facilitated by Drs. Orr, Wilensky, Gilman, and Wilmot which included the presenters of each day. Please watch future issues of *Generations*, as we publish some talks so you all can learn what they had to say. Also, you can get a copy of these presentations on our website www.ataxia.org.

This was an excellent and exciting meeting! Thank you again to the fabulous job done by the Seattle Area Ataxia Support Group and the British Columbia Ataxia Society!

A Special Thank You

The National Ataxia Foundation would like to extend a special thank you to all the attendees, speakers, facilitators, exhibitors, donors and the numerous volunteers of the NAF 2009 "Climb Every Mountain" Annual Membership Meeting held in Seattle, WA. The NAF would like to especially thank the NAF Seattle Area Ataxia Support Group and the British Columbia Ataxia Society for all their efforts. It was a pleasure working with Milly and Tony Lewendon, Louise Frank, Brenda Dixon, and Fiona Jackson on this conference.

Many thanks to Marcia Kohl, who volunteered as our on-site nurse this year. Your services are so much appreciated. We would also like to thank this year's sponsors. Thank you to the VIBE, Nintendo and Athena Diagnostics. Thank you to Milly Lewendon, who gathered items for the goody bags for this year's conference.

The "Climb Every Mountain" conference had nearly 500 attendees! We appreciate your participation in making this conference so successful. Thank you so much for the wealth of information and knowledge that was brought to the conference by all the speakers, facilitators and exhibitors. The information and skills taken away from this conference by the attendees is invaluable and worth more than any words can say.

Thank you to the Doubletree Seattle Airport Hotel and the Seattle Southside CVB for their service and hospitality throughout this event. ❖

Top Three Lists

Registrants rated their top three highlights from the 2009 National Ataxia Foundation Annual Membership Meeting:

- 1) RNAi
 - 2) Dr. Zesiewicz
 - 3) Birds of a Feather
-
- 1) Meeting other "Ataxians" for the first time
 - 2) Birds of a Feather
 - 3) Q&A Sessions
-
- 1) Genetics of Ataxia
 - 2) Birds of a Feather
 - 3) Q&A Sessions
-
- 1) Birds of a Feather
 - 2) Research – SCA
 - 3) Old Friends
-
- 1) Reception & Dinner
 - 2) Informal hall meetings
 - 3) Birds of a Feather
-
- 1) Presentations
 - 2) BOF
 - 3) Auction
-
- 1) Ride Ataxia
 - 2) Seeing people I've met before
 - 3) Birds of a Feather

Here is what was said by meeting attendees...

Quotes from the 2009 NAF Annual Membership Meeting

On Birds of a Feather

“We had a great group – much sharing.”

“Excellent – Really great opportunity to connect and share.”

“As a first timer, I found the Birds of a Feather very helpful.”

On General Sessions

“Very informative and helpful.”

“All outstanding and very helpful.”

“Speakers were very well organized. I’m very appreciative of them and their time. The PowerPoint presentations were very helpful to understand what was being talked about and the PowerPoint papers were extremely nice/handy for taking organized notes and to be able to take home and share! Thank you!”

On Reception and Banquet

“Band was great!”

“Can’t say enough about Kyle.”

“Saturday was awesome! Food was amazing! Great Band! Raffle was very entertaining! J Kissies.”

“I really liked the Friday Reception menu – not messy, substantial, plentiful, with a very nice presentation... If it’s cheaper do it every year!”

General Comments

“Good Location! Major airport for easy non-stop flight availability and easy access to hotel. All meeting rooms close in. Reasonable prices in hotel. Good elevator access.”

“Great job for entire meeting.”



Annual Membership Meeting Provides Information from A to Z

From A (ataxia) to Z (Dr. Zesiewicz) the medical and research information that was presented at this year’s Annual Membership Meeting was so comprehensive that it included information that began with every letter of the alphabet. This is a list of the articles, some of which will be published in future issues of *Generations*.

Ataxia ... **B**rain tissue donations bring us closer to answers in ataxia ... **C**linical trials taking place and how to participate in a clinical trial ... **D**ysphagia, which is difficulty in swallowing, and some strategies for coping ... **E**mpowered patient needs to be an informed patient ... **F**riedreich’s ataxia research includes targeting DNA structure ... **G**enetics and gene testing ... **H**uman Genome Project was explained ... **I**debenone clinical trials for Friedreich’s ataxia

... **J**oin ataxia patient registries ... **K**nowledge is required before effective therapies are discovered ... **L**ithium clinical trials for SCA1 ... **M**edications available for treating symptoms of ataxia ... **N**eurologists and how to educate and manage them ... **O**ccupational therapy can be beneficial ... **P**olyglutamine ataxias ... **Q**uality research funded ... **R**ehabilitation strategies for those with ataxia ... **S**poradic ataxia and its many causes ... **T**argeted HDAC inhibitors to increase cellular frataxin levels ... **U**nknown dominant mutations still represent a substantial percentage of SCA (20%) ... **V**ertigo or dizziness can be treated ... **W**alking aids such as single point and quad canes and walkers ... **X**-ray beam is used in brain tissue research ... **Y**oga can be helpful for mind and body ... **Z**esiewicz.



Sunday's panel of presenters (left to right) David Lynch, Susan Perlman, George Wilmot, Arnulf Koeppen, Timothy Maher, and Ryan Boudreau

Below: Raffle winner accepts her prize



Below: Board members and guests visit the Silent Auction room



Registrants enjoy the Saturday banquet



Special thanks to photographer David Garcia, with his wife Rita (pictured above), for taking all the photographs you see on these pages



Wilson and Mary Romero enjoy the Saturday banquet

THE NATIONAL ATAXI
52nd Annual Meeting

"Climb Every"

— Seattle, Washington —



Banquet attendees dance to music performed by the Raucous Band

Banquet attendees dance to music performed by the Raucous Band



Below: Attendees participate in Wheelchair Yoga

Members of the British Columbia Support Group pose for a photo during the Saturday evening banquet



Below: NAF staff member Sue Hagen (center) sells raffle tickets at the banquet



Nadia Robertson (center) accepts an award for a new Terra Trike Cruiser through the Ataxian Athlete Initiative



Dr. Michael Wilensky (left) accepts a plaque from NAF Executive Director, Michael Parent for 25 years of service to NAF's Medical Research Advisory Board

Ralph
Yog

STAXIA FOUNDATION
Membership Meeting

“Mountain”

March 20-22, 2009

Kisses
were a
hot item
at this
year's
raffle



Below: NAF's Lori Shogren and Mike Parent with volunteers Louise Frank, Kyle Bryant and Milly Lewendon pose with one of the raffle winners



Raffle winner
accepts his prize

Registrants make
conversation between
presentations



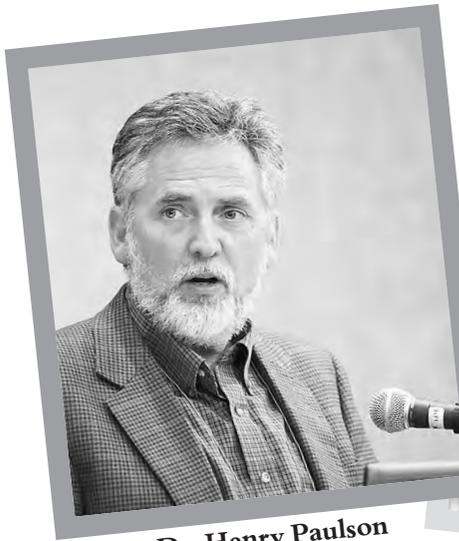
Miller presents "Wheelchair
a" with the help of Mary Vida



Banquet attendees dance to music
performed by the Raucous Band



Dr. Harry Orr and NAF
meeting coordinator Lori Shogren



Dr. Henry Paulson



Dr. Thomas Bird



Dr. Timothy Maher



Dr. Theresa Zesiewicz



Dr. Grisel Lopez



Dr. Kristie Spencer



Dr. George (Chip) Wilmot



Dr. Susan Perlman



Dr. Marek Napierala

Life in the

BALANCE



By Alayne Novalany

I took the title for my article from a well-written book by Thomas Graboys, MD, whose memoir gives an eminent physician's view of life, love, and loss while suffering from an aggressive form of Parkinson's disease and dementia. Anyone who has the disease called ataxia knows well that it is mainly about lack of balance, and coordination.

I would like to take this opportunity to explain just what ataxia is, as I feel that it is a subject that very few people know about. Perhaps some of you have heard of Bob Allison, who played for the Minnesota Twins in the 1960's. He was diagnosed with ataxia in 1989 and died of complications due to the disease in 1995. There is a research center at the University of Minnesota in his name.

The definition of the word "ataxia" is uncoordinated movement. The disease ataxia is a progressively neuromuscular degenerative disease, caused by the dysfunction of the cerebellum, a part of the brain. The symptoms are most commonly lack of balance, problems with walking, talking, slurred speech, and difficulty with handwriting, hand coordination, choking, and swallowing. There is no alteration in brain power or personality. There is, as of yet, no treatment or cure.

Despite all the struggles, my husband Joe has been my rock, my strength, and my sense of humor throughout the acceptance of this disease in my life and in living with it daily.

I have found that ataxians are a special group of people. They listen to every word you say, because they know how hard it is sometimes to speak. Everything they say is important. They

have been through so much in life. There is no time to waste on gossip or unimportant matters. Everything they do, from the time they get up until bedtime, is a challenge and a process of finding a way around a problem.

I have heard the phrase "beating ataxia" and I think that this is a positive approach.

We can certainly improve our situation with exercise: strengthening muscles does compensate somewhat for the imbalance.

On to my story... I first noticed a decline in my handwriting on the first of March 2007 and the next day saw my doctor, who confirmed that I had ataxia and sent me to see a neurologist for blood tests and an MRI.

On the 26th of March, the neurologist told me that all they could find was a slightly convoluted MRI but I definitely had some symptoms of ataxia. I was due to go on a trip on the 29th of March with my son James, who was already traveling and was going to meet me in Moscow. I wrestled around in my mind whether or not I could do this. My second son Drew said "If you don't get yourself on the plane, I'll go!" That did it!

Joe took me to the Minneapolis airport and I flew to Dulles, where I walked to the gate for London. In London, I found a super young chap who took me in a wheelchair to the gate for the flight to Moscow. A person with disabilities need not feel bad about wheelchairs in airports. It was two miles from one place to the next. I could not have done it any other way.

Via a taxi ride, I met my son James in Moscow

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Life in the Balance
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at the hotel. We went to a Russian restaurant for entertainment that evening.

The next day I walked with James as my “human cane” from 11 a.m. to 7 p.m. We saw the Kremlin and took a three-hour walking tour of Red Square. In the evening, we enjoyed the hot tub at the hotel.

On April 1st, we took a bus tour of the city and had fish and chips in a British pub. I think James took me to every museum in Moscow. Breakfast was always hard, because it was buffet style, but James would just get all my food for me.

On the evening of April 3rd, James and I boarded the Trans-Siberian Railway. We had to have special visas for Russia and China. We traveled in a first class compartment, which is tiny. I have photos of James trying to handle the luggage, which was very funny.

We had six nights in total on the train, an experience I will never forget. We ate a lot of bread and cheese, washed little, and laughed a lot.

The time zones constantly change on the train, so you never know what time it is.

The train makes many stops, but for only a few minutes, and at one stop I got off. Our visas, passports, money, etc. were on the train. Lo and behold, the train started moving, and anyone with ataxia knows you cannot jump on a moving train. James very quickly summed up the situation, put an arm round my waist, and jumped onto the train with me. How he did this I’ll never know, but I was unhurt.

We passed Lake Baikal, the largest freshwater lake in the world. We ate omul, the fish from there, passed the Gobi Desert with its camels, cattle, and mustangs.

In the middle of the night, they took the train into a warehouse, put it up on a mechanical lift, and changed the wheels, as the tracks are a different width in China than they are in Mongolia.

Next we found ourselves in Beijing, where we ate duck in a restaurant with a hole in the floor for a toilet! We stopped on the highway and the taxi driver put the hood of the car up to pretend to have a problem while we took pictures of the Bird’s Nest Olympic Stadium.

James and I strolled into the Forbidden City, with its multitude of rooms. We found ourselves in Tiananmen Square, took pictures of Mao Zedong, and more photos of the 2008 Olympic Clock. With James’s help, I climbed the thousands of steps, went through rocky pathways and caves to the Summer Palace, 30 minutes from the Forbidden City. A young Chinese girl was sitting there and saw that I was quite handicapped and applauded my efforts and gave me the thumbs-up sign.

We then went to the Hutong area and rode rickshaws, climbed the Great Wall, visited jade factories, and saw the most amazing Chinese acrobats. We ended that day with a wonderful Chinese massage back at the hotel.

On the 13th of April, we flew to Shanghai and stayed in the Jing Mao Tower, 72 stories high. We went to the top of the Oriental Pearl, three football fields high, and crossed the Hung Po River to the Bundt Business Center. On the 16th of April, I said goodbye to James at the Shanghai Airport. I flew alone from Shanghai to Chicago and back to Minneapolis.

A trip roughly around the world and, as James said, he walked every step of the way with me, literally. I am lucky to have three wonderful children, two boys and a girl. I think, on looking back, it made me even more determined to succeed. When I was in Red Square in Russia, James and I sat on a bench in the park and ate hot dogs from a stand while I explained to him about the ataxia. We felt very sad for a moment, but there is a determination to go on and make the best of things.

In reading this article, my hope is that others who get the chance to travel, will do it. You can do most things by believing in yourself. ❖

Caregiver's Corner

NAF has permission to reprint the following excerpts from the "The Comfort of Home" series.

Back Safety and Transfers: Golden Rules to Be Safe

Being a caregiver puts you at risk for back injuries. Many occur when lifting, moving, transferring or changing the position of the one in your care. Improper movements can cause injury to the person being moved, such as abrasions to skin, strains, sprains and tears – even fractures. Learn how to avoid harming yourself and the one in your care.

First – Take Care of YOU

Maintain good posture, and exercise to strengthen your back and stomach muscles. If you are overweight, lose weight. Excess weight puts extra stress on back and stomach muscles and on joints. One pound of extra weight puts four extra pounds of stress on knee joints.

The Golden Rule...

First, consider the task at hand. Think about what you are capable of, what assistance you might need and to what degree the one in your care can assist you. Then, eliminate hazards such as clutter, throw rugs, or excess furniture. When planning on the space you need to move, pivot, or transfer, allow for more space than you think you need.

Remember these tips:

- Let the person you are helping do as much as he can do safely.
- Never allow the person you are helping to put his arms around your neck.
- Have the person PUSH off rails, chair arms, etc. (No pulling)
- Avoid sudden jerking movements; move slowly and communicate what you are doing and need the person to do. Remember, if the person in your care does not move often, he may become lightheaded with a change in position –

move slowly!

- Have all equipment you need ready and in working order, such as a transfer belt, chair, wheelchair, commode, or Hoyer lift. If transferring to or from a bed, wheelchair or commode with locking brakes, make sure they are locked.
- If, during a transfer, you start to "lose" the person, do not try to hold him up. Doing so will probably result in injury. Instead, lower him slowly to the floor and call for assistance.

Tip

If you're not sure about the proper body mechanics for lifting and transferring, ask a therapist or nurse to show you how.

Transferring from a Wheelchair to a Car

Be sure the car is parked on a level surface without cracks or potholes.

- Open the passenger door as far as possible.
- Move the left side of the wheelchair as close to the car seat as possible.
- **Lock the chair's wheels.**
- Move both footrests out of the way.
- Position yourself facing the person.
- Tell him what you are going to do.
- Bending your knees and hips, lower yourself to his level.
- Grasp the transfer belt around his waist to help him stand while straightening your hips and knees.
- If his legs are weak, brace his knees with your knees.
- While he is standing, turn him so he can be

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Back Safety and Transfers...
Continued from page 29

eased down to sit on the car seat. GUIDE HIS HEAD so it is not bumped.

- Lift his legs into the car by putting your hands under his knees.
- Move him to face the front.
- Put on his seat belt.
- Close door carefully.

In the United States, approximately 37,000 people over age 65 are injured yearly when entering and exiting cars; 40 percent of these injuries were severe, with 25 percent requiring hospitalization.

Source: *Journal of American Geriatrics Society*; April 2008

**Taking Care of Yourself—
Get that Needed Sleep...**

You can easily become exhausted, sleep deprived, and depressed if you don't get enough sleep. Not only will you feel overwhelmed, but many physical illnesses have been linked to sleep deprivation. These include a reduction in natural immunity to infections and diseases, an increased sensitivity to pain, appetite changes and weight gain, and an increased risk of diabetes, to name just a few.

Caregiving demands can easily extend to 24 hours a day in many cases, if proper thought and preparation is not considered. Plan ahead, so you don't become sleep deprived, because when it occurs, judgment and mood changes can impair your problem-solving abilities.

Here are some things you should do to assure proper rest and "down time":

- Plan ahead for adequate relief and support.
- Be realistic—no one can be a caregiver 24 hours a day.
- Learn to listen to your body; recognize fatigue early and plan to rest.
- Openly express how you are feeling to those who support you.

- Join a caregivers' support group.
- Remember ... alcohol, excessive caffeine, lack of exercise and lack of a routine all make exhaustion worse.

Inspiration

"I've learned that people will forget what you said, people will forget what you did, but people will never forget how you made them feel."

Angela Mayou

Resource for You

The American Academy of Orthopaedic Surgeons offers a free booklet, "Lift It Safe," on lifting procedures for home-based caregivers. Call 1-800-346-2267 or visit www.aaos.org.

Assistive Devices...

Tools to Help Prevent Injury

These devices can be very helpful in making a lift or transfer easier and in preventing injuries, however, these items require a prescription, and the caregiver should be trained by a therapist or nurse before using them.

- *Transfer belt* – Placed around the waist of a person and used to secure the person while walking; gait belt.
- *Transfer board (sliding board)* – A polished board used to slide a person when moving from one place to another; for example, from bed to wheelchair or commode.
- *Trapeze* – A metal bar suspended over a bed that the person can grab to pull up in bed or to assist with turning in bed or coming to a seated position.

- *Mechanical lift* – Also called a hydraulic lift or known as a Hoyer lift. A canvas sling is placed under the person as he lies in bed, then attached to the lift with straps. The caregiver starts the lift (electronically or by hydraulics), which secures the sling around the person and lifts him off the bed. The position of the sling can then be adjusted and the person transferred into a chair.

REMEMBER ... Get proper training before using a transfer belt, transfer board, trapeze or mechanical lift. ❖

Ataxia Management

There is currently no cure for the ataxias. But there are management strategies that can be implemented.

The National Ataxia Foundation maintains a website with valuable and reliable information to assist those affected by ataxia and their caregivers. You can learn more about the disease, symptoms, research, and medical advances in ataxia as well as find links to many organizations that can assist in all aspects of life with ataxia. Spending time at www.ataxia.org can provide a wealth of information.

How can ataxia be managed?

Although ataxia can't be cured, treatment will often improve a person's capabilities and quality of life. Many people go on to enjoy their lives if their disabilities are properly managed. In general, the earlier treatment begins, the better the chance that the treatments will be successful.

There is no standard therapy that works for every individual with ataxia. Once the diagnosis is made and the type of ataxia is determined, a team of health care professionals will work with an individual and his or her family/caregiver to identify specific impairments and needs, and then develop an appropriate plan to improve quality of life.

A comprehensive management plan will often involve a combination of health professionals with expertise in the following:

- **Physical therapy** to improve walking and gait, strengthen muscles, stretch spastic muscles, and prolong the use of the arms and legs;
- **Occupational therapy** to develop compensating tactics for everyday activities such as dressing, eating, self-care and participating in day-to-day activities;
- **Speech therapy** to address swallowing disorders and slurred speech;
- **Counseling and behavioral therapy** to

address emotional and psychological needs and help individuals cope emotionally with their disabilities;

- **Medications** to control tremors, relax muscle spasms, alleviate pain, treat diabetes or heart problems, reduce spasticity, assist with sleep disorders;
- **Surgery** to correct anatomical abnormalities such as spinal curvature;
- **Braces and other orthotic devices** to compensate for muscle imbalance, improve posture and walking, and increase independent mobility and address foot deformities and scoliosis;
- **Adaptive devices** such as canes, crutches, walkers and wheelchairs for individuals who are not independently mobile; and
- **Communication aids** such as computers, voice synthesizers, or symbol boards to allow impaired individuals to communicate with others.

Through education, timely involvement of other specialists, and medical treatment of specific symptoms, the quality of life of any person with ataxia can be improved considerably.

If you have more questions, please contact the National Ataxia Foundation at (763) 553-0020 or naf@ataxia.org. ❖

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Thank you for searching and shopping.

My Ataxia Story

By Doe Shorey

I remember often being picked last for teams in primary school sport activities. I remember being a clumsy person. I remember trying to walk in heels keeping my legs together. I so wanted to look like my peers – a bit taller, slimmer and in control of things like high heels.

The truth is I was, and still am, most often described as a person who was not too good at sports but did like to read. People tended to describe me as brainy and serious. That is how I recall my early years.

With age I came to think that who I am is OK. I discovered I really enjoyed drawing and was happy exploring countries different to Australia and reading books that let my imagination wander. I believed that by working hard I could try whatever I wanted – should I really want.

At age 24, not having enough money or traveling alone for a year did not get in the way of an opportunity for me to see things I had read about. I have great memories – climbing the Eiffel Tower in Paris, relaxing on a Rhine River Cruise in Germany and standing on a glacier at Norway. I felt exhausted while traveling, meeting new people and overcoming language barriers with my phrase book. I happily managed it all.

When I returned to Australia I felt out of place and resolved I needed to do more to meet people other than going to pubs and playing sports. I moved to a different city in an attempt to find what was missing.

I found work quite easily, and often changed jobs. I enjoyed the opportunity to experience different work places, develop new skills and

demonstrate my ability to manage change. I am a qualified social worker and mostly worked with young people to facilitate their goal achievement. I was keen to assist people to achieve their potential. Whatever came my way I managed it well.

I recall starting to go to doctors a lot when I was 28. Another difficult period was emerging. I really did not like going to doctors – I felt that I was responsible for fixing myself and was embarrassed that I was not coping. When doctors responded to my statements that I was

“tired of being tired” I totally accepted that I must be depressed or have hormone difficulties. I suppose I did not initially accept this view as I tried other doctors – they expressed the same view and readily provided anti-depression medication. I tried the medication for a short period, but decided not to seek further medical assistance as I

had been made to feel like my experiences were not real.

But as much as I tried, and no matter how much I tried, I was feeling more tired. I struggled to stay on a treadmill, fell over when jogging, struggled going down stairs, and even getting the courage to try kick boxing proved a disaster as staying standing on one leg when trying to kick was unsuccessful.

I decided that it was too hard to feel good doing what I was doing. I sold all I could and traveled to places I had longed to see 10 years earlier.

As always, my parents supported me in all I planned. I regularly reported my adventures to them – including my falls and climbing difficulties at spectacular locations such as The ►►

“
**But as much as
 I tried, and no
 matter how much
 I tried, I was
 feeling more tired.**
 ”

Great Wall of China and Mount Sinai.

I was happy to share my travel stories, and even found that entertaining others with stories that highlighted my clumsiness contributed to my enjoying the attention. I felt positive, and was determined to finally pursue a new career. I had been keen to work with children for several years, but struggled to find a distance education course that appealed. I found a course titled “Diploma in Play Therapy.” My life felt good.

My parents, being the wonderful people that they are, had asked our family doctor to discreetly check me out when I returned from my travels. She organized X-rays. I remember thinking that, unlike previous experiences, she was very thorough and even the people at the X-ray clinic seemed very nice about not rushing me.

For the first time there was medically accepted evidence that there was a problem. I felt relieved. Checking it further was a priority. I am very appreciative of all the assistance I have received enabling this to happen.

In less than five years I have stopped driving, been contacted about applying for a disability support pension, started to use walking aides, and accepted that the life I had planned is not going to happen.

I’ve been given a label of spinocerebellar ataxia. The view is it is genetic, but where from no one knows.

Ataxia has changed my life, and I believe it will continue to do so. It is not a bad thing. I have a

scooter and walking frame to assist with my mobility and independence. I volunteer to provide health information to people at a hospital, regularly exercise to manage my weight, and study to keep my mind active and alert. I do wonder about my future, but have decided that while I am able to do things I want to enjoy the life I have. Ataxia is yet another change. Unlike other changes, I cannot move away from this one.

Life is mostly good. When it is not I like to remind myself I am responsible for choosing how I react. With the support of others, I feel less alone and able to tackle the future positively. I am always comforted when I read that a problem associated with ataxia is one I have been trying to overcome by working harder. I believe my determination – having very supportive parents, family and friends – keeping positive – and developing strategies that address my changing mobility, balance, speech, bladder control, breathing and eating activities ensures that I am able to manage whatever comes my way.

Since ataxia I have chosen to create and enjoy a future that I am likely to have missed out on if I continued as planned before an ataxia diagnosis.

The following quote I tell myself often to not feel sorry for myself:

“We must be willing to get rid of the life we had planned,

So as to have the one that is waiting for us.”

—Joseph Campbell ❖

Stay in Touch!

News and photos from your support group’s activities and updates about what’s happening in your area regarding ataxia education, support and awareness are important to our readers.

Send stories, events and reports by e-mail to naf@ataxia.org or by mail to the NAF office address listed on page 2. The deadline for the summer issue is May 15.

SCA 1 Study

The National Institute of Health is currently conducting a clinical study on lithium for patients with SCA 1.

For eligibility requirements, recruitment and details on the study, please visit the ClinicalTrials.gov web site at www.clinicaltrials.gov/ct2/show/NCT00683943?term=ataxia&rank=6 or visit NAF’s web site at www.ataxia.org.



Chapter and Support Group News from Around the Country

West Central Florida Ataxia Group

By Crystal Frohna

On January 10th we had our group meeting at Feather Sound Community Church in Clearwater. The meeting was well attended. We served lunch and afterwards got down to discussing ataxia awareness, ways we can promote it to the general public as well as the medical community. I demonstrated some of the ataxia awareness items I purchased from the NAF store and the blue bracelets were particularly popular. I encouraged members to visit the NAF store to purchase items and spread the word!

Next we discussed our IAAD Walk and Roll, which we will be doing September 26th with Dennis Giuzio as Committee Chairman. We discussed public relations efforts, a location and sponsors. Dr. Clouse then advised us that since he moved to Tampa he was now a part of our group, which thrilled us all! We immediately named him Vice President. He then discussed his theories and demonstrated his methodology on several volunteers, and as always the results were phenomenal.

On February 5th we formed a "Steering Committee" consisting of myself, Tom Clouse, Dennis Giuzio, Sue Wier and Arlene Bethelmy, our Secretary. We discussed items of importance, such as the Walk and Roll and developing a new, more professional website. So far we are looking for locations at Busch Gardens or USF with participation by ARC. We are seeking walkers and rollers who will each obtain sponsors donating a dollar amount per mile walked. Dennis Giuzio will be contacting Governor Charlie Crist to see if we can get his involvement and a proclamation for IAAD in Florida

It was exciting for me to have support and other opinions and ideas from other members of the group, because I had been leading it myself for so long and the group has grown so large.

On February 28th we had our group meeting with 39 members present! Ataxians came from as far as Miami Beach, Tallahassee, Orlando and Jacksonville! We are blessed to be able to help so many people in Florida and encourage anyone who doesn't have a support group in their area to join us at our meetings, or at least get on our mailing list so they can get in the "loop."



Members of the West Central Florida Ataxia Group at their January 10th meeting

The highlights were Dr. Clouse, who filled us in on the exciting events going on at Johns Hopkins and the Chesapeake Chapter, and our own Ralph Hassel, who demonstrated an interactive Wii program that works with agility, balance and posture and was truly amazing.

Professor Jeannie Stephenson of the USF Physical Therapy Department was there to watch Ralph's presentation to see if this program would be useful at USF. The Wii program has helped cerebral palsy patients ►►

and we noticed a marked improvement in Ralph's posture, balance and speech since he started working with it. If you are interested, please contact me for info.

Drs. Clouse and Zesiewicz had attended the Medical Conference at Johns Hopkins to learn how the Ataxia Center there was organized and how the Chesapeake Chapter and Johns Hopkins interact. They came back with valuable information not only for the structuring of the new ARC at USF, but also on how our group can be more involved. Dr. Clouse presented his plan for us to have our own regional medical conference in September. We have many talented researchers and neurologists right here in Tampa that we will invite to be speakers. We also hope to give them a better understanding of what it is like to live with ataxia.

N.E. Florida Ataxia Support Group

By June McGrane

Our first Northeast Florida Support Group meeting of 2009 was held on January 31 at the Baptist South Medical Center in Jacksonville. We had a great turnout, which included some new members, and also a breakaway session for ataxians and their caregivers.

We discussed the November 2008 meeting in Clearwater with the West Central Florida Ataxia Support Group. We had a delicious dinner and discussed the research group Dr. Zesiewicz and Dr. Clouse are planning in Tampa. Some of our support group members hope to attend this program.

Our group plans to have a picnic at the Jacksonville Zoo before our next scheduled Support Group meeting May 9th at the Baptist South Medical Center conference rooms.

There are several of our members who attended the Seattle NAF Convention in March this year. We look forward to hearing from them in future meetings.

Denver Area Ataxia Support Group

By Tom Sathre

The spring 2009 meeting of the Denver Area Ataxia Support Group was held March 14 at the Swedish Hospital's Conference Center. Attendees included 18 individuals and one dog.

We held a potluck luncheon and had three speakers. Dr. Barbara Rendé of the University of Colorado at Boulder spoke about the work now going on at the Speech and Language Pathology Labs at her University. She is currently treating one of our group members. Sean McCaffree, whose ataxia was caused by an accident, spoke about how plastic the human brain is. Ben Price, a member of our group, spoke about her new book and showed off her new wheelchair.

Greater Atlanta Ataxia Support Group

By Dave Zilles

The Greater Atlanta Ataxia Support group held their meeting Saturday, February 7, at the Emory University Rehabilitation Center. We had 22 people attend. We were pleased to have Brian Mulvaney from Florida as a guest.

The highlight of the meeting was Dr. Cheryl K. Burdette, a Naturopathic Doctor. Naturopathic medicine combines natural treatments based on evidence that recognizes each person's unique presentation and works to find the source of the disease. She focuses on the treatment of chronic conditions in her work, and the use of hormones as a part of wellness. At Progressive, Dr. Burdette works with MD's, dieticians and DO's to design a treatment plan that helps the individual in a complete and holistic manner. Dr. Burdette gave a very informative presentation on how we can work our diet and other use of vitamins and hormones to treat chronic conditions with a focus on ataxia. She has been working

Chapter and Support Group News
Continued from page 33

with several of the support group members. Dr. Chip Wilmot also spoke to the group. Members also shared news about their family or loved ones.

We have a fund-raising event coming up in the near future: our 50/50 Braves Game Raffle will be held on June 6.

Our next meeting is scheduled for May 16. ❖



Greater Atlanta Ataxia Support Group

NAF Represented at Rare Diseases Clinical Research Network Meeting

As a member of the Coalition of Patient Advocacy Groups of the Rare Diseases Clinical Research Network, the National Ataxia Foundation is able to participate in meetings that provide information on the activities of the Office of Rare Diseases at the National Institutes of Health (NIH).

At the meeting on April 3 in Bethesda, the success of the recently launched program to evaluate patients with disorders that have not been diagnosed was presented. Called the Undiagnosed Diseases Program, it has two goals: 1) To provide answers to patients with mysterious conditions that have long eluded a diagnosis; and 2) To advance medical knowledge about rare and common diseases.

Patients must be at least six months old with

an undiagnosed disease or condition, be able to travel and be referred to the program by a physician, nurse practitioner, or physician assistant. Patients who are accepted into the program are evaluated by many NIH senior attending physicians. Specialties include neurology, pain and palliative care, genetics, pediatrics, ophthalmology and many other areas of medicine.

It is anticipated that not all admissions will eventually result in a diagnosis for the patient, however it is believed that the evaluations will provide valuable information for medical researchers that may be used to identify previously unrecognized rare diseases.

For more information, call (866) 444-8806 or visit the website at <http://rarediseases.info.nih.gov/Resources.aspx?PageID=31>. ❖

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

National Ataxia Foundation 53rd Annual Membership Meeting

March 12-14, 2010
(Leadership Meeting March 11)

Join us in Chicago for the Annual Membership Meeting!



The Hyatt Regency O'Hare Hotel is pleased to provide the facilities for the 2010 National Ataxia Foundation Annual Membership Meeting. Rooms are available at the **special group rate** of \$149 per night. Please be sure to make your reservations by **February 15, 2010** in order to secure the special group rate. If rooms are available, the special group rate will be extended three days before and three days after the meeting dates.

There are a limited number of ADA rooms available on a first-come, first-served basis in our group block. To reserve an ADA room at the Hyatt Regency O'Hare Hotel you MUST contact the National Ataxia Foundation at (763) 553-0020 or naf@ataxia.org.

If you need ADA equipment be sure and mention this when making your room reservation. Shower chairs, tub bars and toilet frames will be available on a first-come, first-served basis by contacting the Hyatt Regency O'Hare Hotel front Desk upon check in.

To book your stay online, go to https://resweb.passkey.com/Resweb.do?mode=welcome_ei_new&eventID=779322&fromResdesk=true or if you would prefer to make your reservations by phone, please call 1-888-421-1442 or (847) 696-1234 and ask for the **National Ataxia Foundation Conference special rate**.

Watch for the 2010 AMM Registration Form in the Winter 2009-10 issue of *Generations*. Keep checking our website, www.ataxia.org, for the latest information about the meeting.

We look forward to seeing you in Chicago!

Chapters, Support Groups and Ambassadors

The following is a list of National Ataxia Foundation chapters, support groups and ambassadors. The use of these names, addresses and phone numbers for any purpose other than requesting information regarding NAF or joining a chapter or support group is strictly prohibited. We encourage you to contact the chapter or group nearest you.

Chapters

Chesapeake Chapter

Carl J. Lauter, President
3200 Baker Circle, I-117
Adamstown, MD 21710-9666
(301) 644-1836
E-mail: carljlauter@erols.com
Web: [www.geocities.com/HotSprings/Oasis/4988/
www.ataxia.org/chapters/Chesapeake/default.aspx](http://www.geocities.com/HotSprings/Oasis/4988/www.ataxia.org/chapters/Chesapeake/default.aspx)

Louisiana Chapter

Carla Hagler, President
PMB 51056
2250 Gause Blvd.
Slidell, LA 70461
(985) 643-0783
E-mail: ataxia1@earthlink.net
Web: www.angelfire.com/la/ataxiachapter
www.ataxia.org/chapters/Louisiana/default.aspx

Mississippi Chapter

Camille Daglio, President
P.O. Box 17005
Hattiesburg, MS 39404
E-mail: daglio1@bellsouth.net
www.ataxia.org/chapters/Mississippi/default.aspx

Support Groups

Alabama

BIRMINGHAM ATAXIA S.G.
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E-mail: donnelyb6132@aol.com
www.ataxia.org/chapters/Birmingham/default.aspx

Arizona

PHOENIX AREA ATAXIA S.G.
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(480) 726-3579
E-mail: rtg22@cox.net
www.ataxia.org/chapters/Phoenix/default.aspx

TUCSON AREA ATAXIA S.G.

Bart Beck
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E-mail: bbeck15@cox.net
Web: www.geocities.com/azataxiassg
www.ataxia.org/chapters/Tucson/default.aspx

California

LOS ANGELES ATAXIA S.G.

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See Tri-State Ataxia S.G. under New York

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Louisiana

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Continued from page 39

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Virginia

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Chapters, Support Groups and Ambassadors
Continued from page 41

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E-mail Addresses Wanted!

Do you wish you could get updates on what's happening regarding ataxia between issues of *Generations*?

Sign up for e-mail blasts from the National Ataxia Foundation and you'll periodically receive updates on ataxia research, events and other timely issues of interest regarding ataxia.

It's easy to sign up. Simply send your e-mail address to julie@ataxia.org and ask to be put on the E-mail Blast list so you don't miss out on receiving important information from the Foundation.

Calendar of Events

Saturday, May 2, 2009

New England Ataxia Support Group Meeting

Noon-3 p.m. in room 210 of the Yawkey Building at MGH. For more information please contact Donna Gorzela at (978) 475-8072. www.ataxia.org/chapters/phoenix/default.aspx

Saturday, May 9, 2009

Kansas City Area Ataxia Support Group

2-4 p.m. at the Northeast Library, 65 Wilson Ave., Kansas City, MO. For more information contact Lois Goodman at (816) 257-2428 or Jim Clark at clarckstone9348@sbcglobal.net. www.ataxia.org/chapters/KansasCity/default.aspx

Los Angeles Area Ataxia Support Group Meeting

Westside Center for Independent Living at 12901 Venice Blvd., Venice Beach, CA. Contact Sid Luther for more information at harryluther@sbcglobal.net. www.ataxia.org/chapters/LosAngeles/default.aspx

North Texas Ataxia Support Group Meeting

10 a.m. - noon at the Los Colinas Medical Center, 6800 MacArthur Blvd. at Hwy 161, Irving, TX. Parking is free. Enter through the main building and follow the signs to the classrooms. Contact David Henry Jr. at cheve11e@sbcglobal.net for more information. www.ataxia.org/chapters/NorthTexas/default.aspx

Northeast Florida Ataxia Support Group Meeting

1 p.m. at Baptist South Hospital in Jacksonville (off I-95) in the Azalea and Begonia rooms. For more information contact June McGrane at (904) 273-4644 or jmcgranepvb@bellsouth.net. www.ataxia.org/chapters/NortheastFlorida/default.aspx

SE Pennsylvania Ataxia Support Group Meeting

The SE PA Support Group is no longer meeting monthly. The group will meet the second Saturday of March, May, July, September, and November. You must RSVP to the meetings. To RSVP or for more information contact Liz Nussear at (610) 272-1502 or lizout@aol.com. www.ataxia.org/chapters/SEPennsylvania/default.aspx

West Central Florida Ataxia Support Group Meeting

1-3 p.m. at Feathersound Community Church, 13880 Feathersound Dr., Clearwater, FL. Contact Crystal Frohna at (813) 453-1084 or flataxia@yahoo.com for more information. www.ataxia.org/chapters/TampaBay/default.aspx

Wednesday, May 13, 2009

Willamette Valley Ataxia Support Group Meeting

11:30 a.m. - 1 p.m. at Albany General Hospital, 1046 Sixth Ave. SW, Albany, OR. For more information contact Malinda Moore, CCC-SLP at (541) 821-4162 or malindam@samhealth.org. www.ataxia.org/chapters/Willamette/default.aspx

Thursday, May 14, 2009

Tri-State Ataxia Support Group Meeting

Phillips Ambulatory Care Center (PACC), 10 Union Square E. New York, NY. To RSVP or for more information contact Jeannie Soto-Valencia at (212) 844-8711. www.ataxia.org/chapters/Tri-State/default.aspx

Saturday, May 16, 2009

Greater Atlanta Ataxia Support Group Meeting

At Emory Center for Rehabilitation Medicine, 1441 Clifton Rd. NE, Room 101, Atlanta GA. For more information contact Greg Rooks at (404) 822-7451 or atlantaataxia@gmail.com. www.ataxia.org/chapters/Atlanta/default.aspx

Sunday, May 17, 2009

Chicago Area Ataxia Support Group Meeting

1 p.m. at the Good Samaritan Hospital – White Oak Room, 3815 Highland Ave., Downers Grove, IL. For more information contact Craig Lisack at (847) 496-7544 or caasg2@aol.com. www.ataxia.org/chapters/Chicago/default.aspx ▶▶

**The deadline for
the Summer
issue of
Generations
is May 15**



Tuesday, May 19, 2009**Twin Cities Ataxia Support Group Meeting**

7 p.m. at the Presbyterian Homes of Roseville at 1910 West County Rd. D, Roseville, MN. For more information contact Lenore Schultz at lschultz@bitstream.net. www.ataxia.org/chapters/TwinCities/default.aspx

Friday, May 29, 2009**Abilities Expo – Southern California**

May 29-31 at the Anaheim Convention Center in Anaheim, CA. www.abilitiesexpo.com

Saturday, June 6, 2009**Greater Atlanta Ataxia Support Group Fundraiser**

50/50 raffle at Turner Field during the Atlanta Braves Game. We would like to have at least 50 people participate in this event. 50% of the total funds raised will be split between the Greater Atlanta Ataxia Support Group and the Braves Foundation. We need to turn in our list of volunteers two weeks before the game. Last year's event raised nearly \$700 for the support group and we had a great time! For more information or if you are interested in volunteering please contact Lynn Robinette at (770)982-0275 or lynn.robinette@comcast.net. www.ataxia.org/chapters/Atlanta/default.aspx

Sunday, June 7, 2009**13th International Congress of Parkinson's Disease and Movement Disorders**

June 7-11 in Paris, France. For more information, e-mail congress@movementdisorders.org or visit www.movementdisorders.org/congress/congress09/

Wednesday, June 10, 2009**Willamette Valley Ataxia Support Group Meeting**

11:30 a.m. - 1 p.m. at Albany General Hospital, 1046 Sixth Ave. SW, Albany, OR. For more information contact Malinda Moore, CCC-SLP at (541) 821-4162 or malindam@samhealth.org. www.ataxia.org/chapters/Willamette/default.aspx

Saturday, June 13, 2009**Denver Area Ataxia Support Group Meeting**

1-4 p.m. at the Swedish Hospital and Medical Conference Center (Spruce C), 501 East Hampden Ave., Englewood, CO. For more information

contact Tom Sathre at tom_sathre@amc.org or call (303) 794-6851. www.ataxia.org/chapters/Denver/default.aspx

Kansas City Area Ataxia Support Group

2-4 p.m. at the Northeast Library, 65 Wilson Ave., Kansas City, MO. For more information contact Lois Goodman at (816) 257-2428 or Jim Clark at clarckstone9348@sbcglobal.net. www.ataxia.org/chapters/KansasCity/default.aspx

North Texas Ataxia Support Group Meeting

10 a.m. - noon at the Los Colinas Medical Center, 6800 MacArthur Blvd. at Hwy 161, Irving, TX. Parking is free. Enter through the main building and follow the signs to the classrooms. Contact David Henry Jr. at cheve11e@sbcglobal.net for more information. www.ataxia.org/chapters/NorthTexas/default.aspx

Tuesday, June 16, 2009**Twin Cities Ataxia Support Group Meeting**

7 p.m. at the Presbyterian Homes of Roseville at 1910 West County Rd. D, Roseville, MN. For more information contact Lenore Schultz at lschultz@bitstream.net. www.ataxia.org/chapters/TwinCities/default.aspx

Saturday, June 20, 2009**Orange County Ataxia Support Group Meeting**

1:30-4 p.m. at Orange Coast Memorial Medical Center (in the basement, next to the cafeteria), 9920 Talbert Ave., Fountain Valley, CA. For more information Contact Daniel Navar at dnavar@ucla.edu. www.ataxia.org/chapters/OrangeCounty/default.aspx

Thursday, June 25, 2009**Abilities Expo – Chicago**

June 25-27 at the Schaumburg Convention Center in Chicago, IL. www.abilitiesexpo.com

Saturday, June 27, 2009**Iowa Ataxia Support Group Meeting**

2-4 p.m. at Urbandale Public Library in Meeting Room B in Urbandale, IA. Dr. Robert Rodnitzky from University of Iowa Health Care Movement Disorders Clinic will be the guest speaker. For more information please contact Emily Medina at (515) 633-8620 or emily061578@yahoo.com. www.ataxia.org/chapters/EmilyMedina/default.aspx



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 from November 2008 through February 2009. 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.

Edith Acosta	Brenda Callis	Sandy Dudzic	Anne Gulliver	Robert Keithly
Alexander Family	Edward Callis	Angie Duffy	Madonna Haase	Amy Keller
M/M A. Alibrio	Sharon Cameron	Mary Duffy	Edward Hale	Regina Kelly
Maria Alioto	Barton Carr	Michael Duffy	Jane Haley	M/M W. Kern
Paul Anderberg	James Carr	Diane Dusbiber	Evelyn Hankins	Brian Kohl
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