Generations

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From Mouse Models to Biomarkers: NAF Funded Ataxia Research Continues

Again this year, 10 ataxia research projects received funding from the National Ataxia Foundation. Over 40 applications were submitted and each received a thorough review with two reviewers scoring each application in two categories: the merit of the science and the relevance to ataxia. As in past years, excellent scientific studies on ataxia were submitted, but because of the rigorous review process, the best science was funded in keeping within the limitations of the research funds available to NAF.

NAF is grateful to the many groups, families and individuals who held fundraising events, the individual and corporate donations and contributions given in memory or honor of loved ones that were designated to research. These dollars translate into ataxia research studies that take place all over the world. This year's awardees included three Young Investigator Awards, two Fellowship Awards, and five Research grants. The research is being completed in the United States as well as in Australia, Germany and Italy.

Research grants are intended to be used as seed monies in early or pilot phases of studies and ongoing investigations that demonstrate a need to attract future funding from other sources. In a recent questionnaire sent to researchers who received funding from NAF, of the 27 who responded, 17 were able to secure additional funding because of the preliminary research funds they received from NAF. A quote from one of the researchers, "I very much appreciate the work of the NAF, and their help in promoting ataxia research. I could not have obtained my R01 (an NIH grant) without NAF support that helped me get the needed preliminary data."

The research projects involve basic science and translational research. NAF continues to fund the National Ataxia Registry, an important tool to facilitate clinical trials for ataxia treatments. Everyone in the United States who has any type of ataxia or who are at risk for ataxia, are encouraged to enroll in the patient registry by going to *www.NationalAtaxiaRegistry.org* and following the instructions.

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NAF continues to be a world leader in ataxia research funding. Your continued contributions and fundraising efforts make that happen. Thank you.

Research Grants

Giorgio Casari, PhD
San Raffaele University
Milan, Italy

Disclosing the mitochondrial connection to Purkinje dark cell degeneration in the SCA28 mouse model

Spinocerebellar ataxia type 28 (SCA28) is a novel form of juvenile-onset, slowly progressive, autosomal dominant cerebellar ataxia characterized by unbalanced standing, gait incoordination, nystagmus, ophthalmoparesis and pyramidal signs. Several disease causing mutations have been identified in the AFG3L2 gene. The encoded protein, AFG3L2, resides in the mitochondrion. The cerebellum is the neuronal tissue mostly and specifically affected by AFG3L2 dysfunction. In fact, a mouse affected in the *Afg3l2* gene shows progressive ataxia due to degeneration and loss of Purkinje cells (PCs). The appearance of morphologically altered mitochondria correlates with the onset of motor impairment. We found that SCA28 PCs degenerate by cell shrinkage, cytoplasm darkening, atrophy, and chromatin condensation, but lack of DNA fragmentation. These pathological findings have been documented also in SCA5 and SCA7 and are due to different causes. Peculiarly, in the SCA28 mouse this type of degeneration originates for the first time from mitochondrial dysfunction. The proposed specific aims tackle important key steps to dissect the molecular pathogenesis of SCA28 and propose for the first time preclinical approaches to SCA28.

Dr. Giorgio Casari

Joseph P. Sarsero, PhD
Murdoch Childrens Research Institute
Victoria, Australia

Generation of an improved humanized mouse model of FRDA containing a long GAA trinucleotide repeat expansion

Friedreich's ataxia (FRDA) is an inherited progressive disorder of the nervous system and muscles that results in the inability to coordinate voluntary muscle movements. Improper heart function is also a common and life-threatening condition of the disease. The genetic defect that causes FRDA results in reduced levels of an essential protein termed frataxin in all cells of the body. Prior to evaluating new therapies in patients it is important that they be tested in appropriate biological models of the disease. Animal models that are generated by the "knockout" of specific genes often manifest the main symptoms of the corresponding human disorder, however such models rarely recapitulate the precise molecular cause that underlies human disease. Accurate "humanized" mouse

Dr. Joseph P. Sarsero

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models of disease are designed to contain an entire human gene of interest and harbor the specific disease-causing mutation as found in patients. Such mice do not only manifest the main symptoms of a disorder, but also provide the correct underlying molecular cause of the disease. We will utilize our expertise in handling the gene responsible for FRDA, and our current preliminary mouse models of FRDA, to generate an improved humanized FRDA mouse model that more accurately reflects disease symptoms and the underlying molecular cause of the disorder. This will be an important resource for the study of the pathophysiology of the disease and for the evaluation of novel therapeutic interventions.

S.H. Subramony, MD
University of Florida
Gainesville, FL

New Initiatives for Clinical Research on Ataxia

This proposal is requesting continuation of funding for "New Initiatives for Clinical Research on Ataxia" a project funded by NAF last year. The original intention of the funding was to reinvigorate clinical research in the field of ataxia primarily by establishing a new patient registry on behalf of the National Ataxia Foundation. In addition, it was hoped that the grant would revive the clinical research network in the USA by establishing an Ataxia Clinical Research Coordinating Center (ACRCC) at the University of Florida. There has been considerable progress with regard to these aims. The PI worked closely with a volunteer group (estimated contribution close to $50,000) from the HP-EDS company to generate the software needed to establish a web based ataxia registry (*www.nationalataxiaregistry.org*). The National Ataxia Registry (NAR) is actively recruiting subjects with over 700 subjects in contact and over 220 already confirmed and activated since it became functional this spring, an activity that is mostly done under the direction of our coordinator, Phuong Deleyrolle. The PI helped in the application to NIH that resulted in a $1 million grant from the NIH to Dr. Ashizawa as the principal investigator for a nationwide natural ▸▸

Dr. S.H. Subramony

history and genetic modifier study of SCA 1,2,3 and 6. The ACRCC is coordinating the activity of 10 clinical centers that are participating in the study, including two unfunded centers (Harvard and Johns Hopkins). In order to maintain this momentum, the ACRCC will have to succeed in maximizing patient recruitment to the NAR as well as to the natural history study. As the NIH grant comes up for renewal later this year, demonstrating the success of the clinical consortium to complete additional pilot studies will also be important. The consortium has initiated or discussed several clinical studies including drug trials (varenicline, CoQ 10, lithium, riluzole), imaging studies, cognitive studies and gene discovery studies. This continued funding request is aimed at maintaining these achievements so that we can obtain competitive grants to accomplish the overarching goal of successful therapy for ataxias.

Roberto Testi, MD

Laboratory of Signal Transduction, Department of Experimental Medicine University of Rome Institution, Rome, Italy

Evaluation of lead compounds that prevent frataxin degradation in a Friedreich's ataxia mouse model

All proteins of our body are constantly made and routinely degraded, and frataxin is no exception. Therefore, in principle, understanding how frataxin is degraded, might suggest a method to prevent its physiological degradation. This might be exploited therapeutically to extend the bioavailability of residual frataxin in Friedreich's ataxia patients. We discovered how frataxin is degraded and found a set of small drug-like molecules that prevent frataxin degradation and increase frataxin levels in cells derived from Friedreich's ataxia patients. Within this project we therefore plan to validate the efficacy of these compounds in an animal model of the disease. Successful compounds might be candidates for future clinical trials.

Dr. Roberto Testi

Chih-Cheng Tsai, PhD

University of Medicine & Dentistry of New Jersey – Robert Wood Johnson Medical School, Piscataway, NJ

Nuclear events affected by Ataxin-1

In this proposal, we report our finding that ataxin-1 (ATXN1), a protein whose mutant form causes SCA1, and its related factor Brother of ataxin-1 (BOAT1), are integral components in a very important and conserved cell signaling pathway, called Notch. In both vertebrates and invertebrates, the Notch pathway is known to use similar mechanisms to control the development and functioning of multiple tissues or organs, including the nervous system. Building on the connections that we have established between Notch and ATXN1 / BOAT1, we propose to investigate whether the Notch pathway is disrupted in the brain tissues targeted by SCA1, and whether ATXN1 and BOAT1 influence the Notch pathway differently. We hope that the outcome of our research will lead to new ways for treating SCA1.

Dr. Chih-Cheng Tsai

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Research Fellowship Awards

Maria do Carmo Pereira da Costa, PhD
University of Michigan
Ann Arbor, MI

Developing an SCA3 therapeutic: small molecules that reduce levels of mutant ataxin-3

Spinocerebellar ataxia type 3 (SCA3) or Machado-Joseph disease (MJD) is a neurodegenerative disease of late onset and the most common form of ataxia worldwide. SCA3 is part of a group of diseases, the polyglutamine (polyQ) diseases, caused by the same type of genetic mutation, an expansion of a triplet CAG repeat in the respective genes.

Though many efforts are underway to develop and test therapeutic strategies for polyQ diseases, no preventive treatment is yet available for any of these diseases. The neuropathological features shared by polyQ diseases suggest that common biological pathways could be targeted in an effort to develop class-wide therapeutics. However, the specific way through which the expanded polyQ proteins, encoded by the mutated genes, can cause neuronal dysfunction remains unclear. Thus, targeting the causative mutant polyQ proteins by regulating their synthesis or clearance is a strategy that will act upstream of any possible altered cellular mechanism caused by the mutant polyQ proteins.

Dr. Maria do Carmo Pereira da Costa

Taking into account this therapeutic strategy, in particular for SCA3, we sought to identify small molecules that reduce the levels of mutant ataxin-3, the SCA3 disease protein. We performed a High Throughput Screening (HTS) assay of 2,880 FDA approved drugs and natural compounds. Currently, we found some promising molecules and we intend to test their efficacy in neuronal cells derived from a transgenic SCA3 mouse model and then test the best molecule in the same mouse model. If the promising molecule shows to be efficient to reduce the levels of ataxin-3 species in the transgenic SCA3 mice and consequently improves their motor impairment, it will present a good candidate for clinical trials in patients with SCA3, and potentially in patients with other polyQ diseases.

Sara Lagalwar, PhD
University of Minnesota
Minneapolis, MN

Inhibition of ataxin-1 phosphorylation: screening potential therapeutics of SCA1.

Spinocerebellar ataxia-type (SCA1), like Alzheimer's disease and Parkinson's disease, is a progressive neurodegenerative disorder. A common mechanism of these diseases is that a protein normally found within our neurons is modified genetically or chemically to become pathogenic.

In the case of SCA1, the protein in question is ataxin-1. Ataxin-1 has a region within it that typically contains 35 or fewer glutamine residues in normal individuals. Individuals with SCA1, however, often have a genetic mutation which leads to ataxin-1 protein containing greater that 35 (and as many as 200) glutamine amino acid residues. As a result of this mutation, the normal function of the protein is likely compromised. Ataxin-1 is expressed in the Purkinje neurons of the cerebellum, the brain cells that coordinate balance and movement. Expression of mutant ▸▸

Dr. Sara Lagalwar

ataxin-1 leads to degeneration of Purkinje neurons, and subsequent loss of motor and balance coordination.

Recently, an amino acid residue found in both normal and mutant ataxin-1, termed serine 776, was found to undergo a chemical modification termed phosphorylation, that may be more crucial to disease progression than the mutant glutamine region. In fact, in transgenic mice studies, phosphorylation of serine 776 was found to be necessary for mice to get the disease. Mice expressing a continuously phosphorylated form of normal ataxin-1 showed the same pathological and behavioral symptoms as mice expressing the mutant ataxin-1 protein. These studies indicate that the detrimental effects of the mutant glutamine expansion may be to structurally facilitate phosphorylation of serine 776 or perhaps to activate the signaling mechanisms within Purkinje neurons that lead to phosphorylation of serine 776.

Therefore, we recognize that molecules that inhibit phosphorylation at serine 776 have therapeutic potential for SCA1. To begin to find potential inhibitors, we began by identifying the enzyme that phosphorylates ataxin-1 at that site. Once identified, we undertook a large drug screen of +250,000 small molecules compounds to find specific inhibitors of ataxin-1 serine 776 phosphorylation. The molecules discovered in the drug screen as positive hits will then be ascertained through computer modeling for their activity and ability to penetrate into the brain. We will then further screen the positive hits in progressively more complex model systems, as described in this proposal, in an effort to find a small molecule inhibitor of ataxin-1 serine 776 phosphorylation that can be safely taken up into the brain with little side effects.

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Second Annual Virtual Walk n' Roll for Ataxia

In celebration of International Ataxia Awareness Day (IAAD) on Sept. 25

Please join the National Ataxia Foundation in some fun and camaraderie to raise awareness and funds during the second annual Virtual Walk n' Roll for Ataxia. Contributions will be used to support ataxia research and important NAF programs.

To join the Virtual Walk n' Roll, please visit the event website, *www.ataxia.org/11Virtualwnr*. Click "Register" on the event website to become a participant and receive a personal fundraising page created just for you.

Here, you can upload pictures, write a personal greeting, and set your personal fundraising goal. You can then forward your fundraising page link to your family and friends, and ask them to "sponsor" you to help you meet your fundraising goal.

Check your fundraising page often to watch your sponsorship thermometer rise. Your miles will be combined with the participating collective as the group "virtually" heads off across the country to visit NAF's Ataxia Researchers and Ataxia Research Centers!

If you wish to contribute to the Virtual Walk n' Roll without becoming a participant, please click "Make a Donation" on the event website to help the group meet its fundraising goal.

Please help the Foundation spread the word about this event. Our journey starts now – let's get walking and rolling!

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Young Investigator Research Awards

Jana Boy, PhD
University of Tuebingen
Tuebingen, Germany

Assessment of riluzole treatment as a therapy for SCA3

Spinocerebellar ataxia type 3 (SCA3) or Machado-Joseph disease (MJD) is a family disorder leading to progressive degeneration of brain cells in affected patients. SCA3 patients suffer from progressive movement deficits and are wheelchair bound in later disease stages. Up to now, no curative therapy is available for this disease. In a recent study, a group of neurologists at the University hospital of Rome (Italy) treated a group of different ataxia patients with Rilutek and compared them with untreated patients. Rilutek is a drug already approved and successfully used for the treatment of a different brain disease called amyotrophic lateral sclerosis (ALS). After just eight weeks of treatment, behavioural deficits of treated ataxia patients clearly regressed. However, among the treated group were patients suffering from different kinds of ataxias and the treatment was only carried out for just two months. It is, therefore, important to confirm whether Rilutek may also be beneficial in a long term treatment and also suitable for patients suffering from SCA3.

We plan to answer both questions using a novel mouse model of SCA3 which we were able to generate recently. As the lifetime of laboratory mice is much shorter than that of humans, analyses in mouse models of diseases allow to follow the progression (and also regression) of disease symptoms in a time-lapse manner. We will treat our mice with Rilutek at different concentrations and starting at different time points. We will then analyze treated and untreated mice with specific methods which allow us to even quantify both the disease progression/regression and even the efficiency of the treatment with Rilutek. We hope to confirm that Rilutek is also suitable as potential drug against SCA3 and that its effect is not just symptomatic but that Rilutek is even able to cure this severe disease.

Dr. Jana Boy

National Ataxia Registry Is Online Now

The National Ataxia Foundation is pleased to announce that the web-based National Ataxia Registry (NAR) is up and running!

An essential component for rare disease research is the availability of people with these diseases to participate in drug trials and other research.

Even if you are registered on another patient registry, you are encouraged to sign-up on this new ataxia patient registry for individuals in the United States with any type of ataxia or who are at risk for ataxia.

Go to *www.nationalataxiaregistry.org* to register. If you have questions or encounter problems, please contact the Research Coordinator by e-mail at *nationalataxia registry@neurology.ufl.edu*, or leave a voicemail message with your name and phone number at (352) 273-9195.

Thank you for your willingness to sign up on the National Ataxia Registry.

Isabelle Iltis, PhD

University of Minnesota
Minneapolis, MN

Magnetic Resonance Imaging and Spectroscopy of the brain in patients with Friedreich's Ataxia and Ataxia with Oculomotor Ataxia type 2: searching for non-invasive biomarkers

Currently, following up diseases such as Friedreich's Ataxia (FRDA) and Ataxia with Oculomotor Apraxia type 2 (AOA2) is complicated by the lack of an objective and non-invasive measure of disease progression. A biomarker would ideally be such a measure and reflect directly the mechanisms underlying the diseases.

Our goal with this project is to identify biomarkers that will ultimately allow the monitoring not only of disease progression, but also of the efficacy of future therapies. We propose to achieve this goal by using Proton Magnetic Resonance Spectroscopy (1H MRS), a technique derived from MRI, that allows non-invasive measurements of concentrations of chemicals in the brain providing insights into the composition and function of brain cells.

Dr. Isabelle Iltis

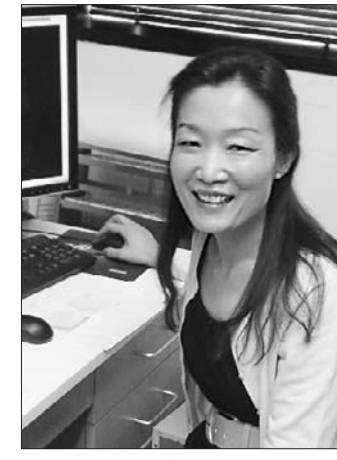
To identify biomarkers in AOA2, we propose to scan both patient and control volunteers at 3T (a magnetic field increasingly available in hospitals and clinical centers in the United States and Europe) and also at 7T, a higher field dedicated to research that allows higher measurement sensitivity. In FRDA, the spinal cord is affected; therefore, we propose to implement 1H MRS of the spinal cord at 3T, as we hope in future studies that robust biomarkers will be identified in measurements from the spinal cord of patients affected with this disease.

Mee Whi Kim, PhD

University of Texas Southwestern Medical Center, Dallas, TX

Determination of secondary structure of Ataxin-3 by X-ray crystallography

The main aim of the proposed research is to determine crystal structure of carboxyterminal region of ataxin-3 protein containing polyglutamine expansion regions of different length. Also, crystal structures of complexes of ataxin-3 with relevant protein targets and small polyglutamine binding molecules will be solved. Polyglutamine expansion in ataxin-3 is a cause of spinocerebellar ataxia type 3 (SCA3) autosomal dominant neurodegenerative disorder. Structural information obtained as a result of our work will help to better understand mechanism of mutant ataxin-3 toxicity. This information can also be useful for developing novel therapeutic agents for SCA3 treatment. ❖



Dr. Mee Whi Kim

Deadline

The deadline for submitting materials for the Summer issue of *Generations* is May 13.

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

Donate Used Cell Phones to Help Support Important Programs and Services

National Ataxia Foundation

The National Ataxia Foundation (NAF) is dedicated to improving the lives of persons affected by ataxia through support, education, and research.

Proceeds from the collection and sale of deactivated cell phones will help further NAF's mission in supporting world-wide promising ataxia research and important programs for those affected by ataxia and their families.

For more information about ataxia, visit www.ataxia.org

Thank You for Donating Your Used Cell Phones!

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ReCellular, Inc., is proud to partner with the National Ataxia Foundation. As the world leader in electronics sustainability, ReCellular is committed to recycling all electronic waste to contribute to a cleaner, healthier environment. As such, ReCellular has a strict "zero landfill" policy: cell phones that cannot be reused will be safely recycled. **www.recellular.com**

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4. Print Business Reply Label and tape it to the package.
5. Seal package and place in the mail.

www.ataxia.org

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NAT105

From the Desk of the Executive Director

The National Ataxia Foundation's 54th Annual Membership Meeting, "Bringing the Ataxia World Together" concluded on Sunday, March 20. The meeting was one of the largest-attended NAF annual membership meetings, with nearly 550 attendees. A special thank you to the California host support groups including the Orange County Ataxia Support Group, Los Angeles Ataxia Support Group, and the San Diego Ataxia Support Group for bringing us this outstanding conference. These support groups raised more than $30,000 for this conference.

Michael Parent

We are also truly grateful to all who supported the conference, including our dedicated volunteers, board, and staff, our exceptional speakers, our generous donors and sponsors, exhibitors, and outstanding MCs. A special thank you to the Seattle Area Ataxia Support Group and The FA Project for their support of the AMM travel grant program. Through their support and others, NAF was able to provide 19 travel grants for this year's conference.

The NAF annual membership meetings represent the largest gathering of the ataxia community in the world. This year's conference attendees came from 35 states and 10 other countries including Argentina, Australia, Belgium, Canada, France, Germany, Hong Kong, India, Netherlands, and the United Kingdom. We thank you for being part of this important conference.

The annual membership meetings offer the latest information on ataxia research, clinical trials, and important topics which impact the ataxia community. This year's conference had more than 150 "first timers." Many commented that the conference offers a real sense of community and family. Along with the "first timers," NAF saw families who have attended 26 consecutive annual membership meetings.

This conference was without NAF's long-standing President, DeNiece Roach, who lost her courageous battle with cancer in late December 2010. DeNiece served on the NAF Board of Directors for nearly 32 years and served as NAF's President for 23 years. Many of you knew DeNiece through the many annual membership meetings she attended. In honoring her memory, the 54th NAF Annual Membership Meeting was dedicated to DeNiece Roach.

It really does take a village or community to successfully hold an annual membership meeting. We are truly thankful to all who contributed to the planning of this conference, and to all who participated, contributed, and attended. Thank you!

Begin planning for the 55th NAF Annual Membership Meeting, which will be held March 15-18, 2012 in San Antonio, TX at the Grand Hyatt Hotel. The 2012 conference will be hosted by the Central Texas, North Texas, and Houston Area Ataxia Support Groups. More details will be available in future issues of *Generations*, on our website, *www.ataxia.org*, and in E-Blasts. We look forward in seeing you next year in Texas.

I Am the Strength Behind Ataxia

By Sydney Yocum

Sydney is a Senior at Rosewood High School in Goldsboro, NC. Her plans after high school are to go to college. This is a speech that she gave to the students at her high school on Rare Disease Day, recognized every year on the last day of February.

Spinocerebellar ataxia is a degenerative condition that affects the cerebellum. The main job of the cerebellum is to coordinate the body's ability to move. Ataxia is a Greek word that means "lack of order," and medically it indicates lack of coordination. Ataxia leads to a progressive atrophy of the cerebellum and because of the loss of this quintessential function, there can be wasting away of muscles.

Sydney Yocum (front, center) with students from Rosewood High School.

Spinocerebellar ataxia is a rare disease and there is no cure. It is also a genetic disease which means it was not caused by injury or illness. When I was 13 I was diagnosed with Spinocerebellar ataxia, and when I was 14 and 15 I would always worry about dying soon.

Today I don't worry about death because I have made it this far and I know I can go the rest of the way. I am also encouraged by the amount of research taking place in this disease that might bring a cure or treatments. I have had many obstacles in my life that have been difficult but I have fought through them. People ask me all the time "How do you live every day with ataxia?" or I hear "if I had ataxia I would have given up a long time ago, how do you do it?"

I have had a lot of days where I have had enough and I wanted to give up and kill myself. Something inside of me told me to never give up and keep fighting. On Nov. 12, 2010 my high school show choir hosted a Talent Show/Ataxia Fundraiser for me; we had a silent auction and a bake sale. All of the proceeds were donated to the National Ataxia Foundation, to help researchers find a cure. The choir raised $1,484 for the National Ataxia Foundation.

I found out that my friends call me a best friend and a big sister. I feel honored hearing them call me that. A video was made for the talent show; the video was of me, my mom, and some members of my choir family. The video taught me a lot about myself and members of my choir family. In the video I talk about my struggles, my mom talked about me and my strive to do things, my choir family talked about how much I mean to them and what it's like to have a friend who has ataxia.

We made the video a week before the talent show and I was not allowed to watch it until the night of the talent show. When it was time to watch the video I didn't know what I was in for. One of my friends came to sit with me and I'm glad she did. In that 15 minutes I cried so much; but they weren't sad tears, they were happy tears because what everyone said touched me so much.

I know I struggle through life with this disease but I try to make the best of it. I inspire my friends, family, and other community members. I was recently asked "When they have found a ⏩

cure for ataxia will you get the treatment?" I answered "I'm not sure because ataxia made me who I am today and I would miss my old self." People who don't know me or anything about me judge me by what's on the outside and not what's on the inside.

I don't let it get me down when people talk about me but when someone who doesn't know me or my story talks about me or judges me, that hurts. I try to be strong for the ones I love by not showing when I'm in pain, holding in my anger, not letting the names I get called bother me. But the truth is the names I get called do bother me, it's not good to hold in my anger and any other emotions.

Everybody has a hero; they could either be fictional or a real person. My hero is not fictional but a real person. That person is me. I am my own hero because the obstacles I face every day are a challenge and I strive to be strong for everyone and to never give up no matter what happens. That sounds like a hero to me.

I get called people's hero or inspiration. That means a lot to me because if I didn't have the best support group behind me I would have no one to inspire. One of the most important things in my life is friendship. My friends mean the world to me and I would be nothing without them. I know I can be moody and I say the wrong things to my friends but I would do anything for them. In the past I have made bad choices in friends but I finally have the best group of friends.

> **"I know that life is difficult, but if we choose to fight through these difficulties instead of giving up it makes life worthwhile."**

Three of my friends have made my senior year an unforgettable one and they have changed my life for the best. Jessica, Ariana and Diana are my BFFer's (Best Friends Forever) and my little sisters. It would be difficult to continue living life without them.

I know that life is difficult, but if we choose to fight through these difficulties instead of giving up it makes life worthwhile. I don't know what the future has in store for me and my disease but I do know this: I am going to keep on fighting. Ataxia will not win this battle because I am the strength behind ataxia. ❖

Remembering NAF in Your Will

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

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

Over the years these individuals, who have chosen NAF as a beneficiary, have given anywhere from a few thousand dollars to nearly one million dollars. Their forethought and benevolence has enabled the Foundation to support promising ataxia research and provide meaningful programs and services to ataxia families. It is because of these quiet heroes that many research studies and programs have been funded. Their kindness impacts ataxia families today and will be felt for years to come.

We are truly thankful for their humanitarian and compassionate acts and we will be eternally grateful for the impact they have made in helping ataxia families. Their legacy lives on in the hope they have given ataxia families.

Perhaps this is the time to consider adding the National Ataxia Foundation in your will.

The NAF Board of Directors along with the Central Texas, Houston, and North Texas Ataxia Support Groups would like to invite you to attend the

National Ataxia Foundation
55th Annual Membership Meeting
March 15–18, 2012

Join us in San Antonio where we'll be "Roundin' Up a Cure to Give Ataxia the Boot"

Early Registration opens at the end of December 2011 and runs until mid-February. To take advantage of the discounted room rate of $139 per night at the Grand Hyatt San Antonio, visit *https://resweb.passkey.com/go/NationalAtaxia* or call 1-888-421-1442.

For all ADA room reservations you must contact the National Ataxia Foundation at (763) 553-0020 and ask for Lori, or e-mail her at *lori@ataxia.org*.

For the latest information on conference registration, schedules, and area information, keep checking NAF's website, *www.ataxia.org*.

For more information about San Antonio, visit *www.visitsanantonio.com/meeting*.

We look forward to seeing you in San Antonio!

Quotes from the 2011 NAF 54th Annual Membership Meeting

On "Birds of a Feather" Sessions

"It was great! There was lot of interaction, good question and answer time. One of the largest groups, we had three doctors who had a lot of good information. I would like to thank the doctors we had. My favorite part of the meeting – got to hear good, updated news."

"They're the part I like best about the meetings. The doctors are knowledgeable, the questions are useful."

"The PT and OT were great, just needed more time with them. All who attended had something to say in participation. They all touched my heart."

On General Sessions

"Very excellent – did not miss anything ... Great job."

"Special thanks to Dr. Subramony and the work he is doing. Such a sweet and friendly man – he has become family."

"All were excellent!"

General Comments

"Beautiful lights everywhere ... especially in the ballroom and lobby. They made us all look and feel great!"

Comments About What Attendees Enjoyed Most About The Meeting

1. Networking
2. Research update in layman's terms
3. Information as to how to improve your symptoms

---

1. I enjoyed the interaction in several of the sessions
2. I thought the speakers were very good and highly approachable
3. The support staff was very good and had a great attitude

---

1. First time I met people with same disease
2. Learned about medications that are available
3. Learned about ongoing research

---

1. Parent's meeting
2. Meeting my FA daughter's friends
3. Tour of LA

---

1. Speech and swallowing presentation
2. Internet group
3. Banquet and reception

---

1. Research on therapy
2. Applied research
3. New possibilities to reach a cure

First-Timer Experiences

"It was a good experience for me. I saw people with ataxia like me and very good speakers."

"Excellent, we will plan on going to the one in San Antonio."

"It was a great experience. I have attended several national conferences and meetings for other conditions and thought the NAF's overall meeting was one of the best!"

Travel Grant Experiences

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

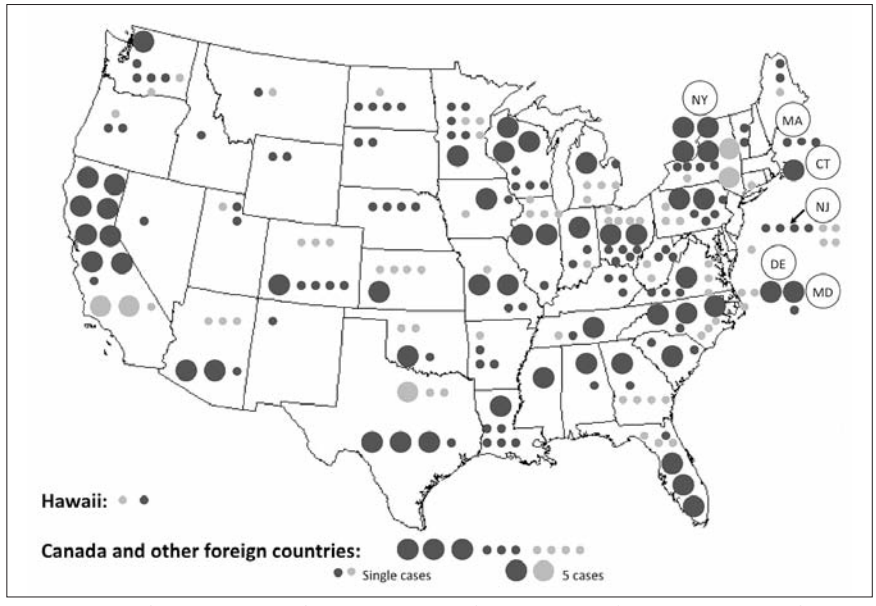
"Thank you for providing me the opportunity to attend this year's AMM. I am grateful."

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

Tissue Donations Support Ataxia Research

By Arnulf H.Koeppen, MD, Albany, NY

Many older physicians recall from their medical school years that the "practice of medicine is based on anatomy and pathology." Anatomy, literally derived from the combined Greek words for "separate" (ana) and "cut" (temnein), is the science of dissection to learn more about the normal structures of the human body. Pathology, derived from the Greek for "suffering" (pathos) and "word" (logo), is the study of abnormal (pathological) tissues. Despite advances in clinical chemistry, genetic diagnosis, computed tomography, and magnetic resonance imaging, our understanding of a disease is still based on directly visible changes in the affected organs.



Inquiries about tissue donations to the National Ataxia Foundation (dark dots) and completed tissue donations (light dots) from 1993 to 2011.

The hereditary ataxias affect the brain, spinal cord, nerves, and eyes in various combinations. The spinocerebellar ataxias (SCA) often hurt only the nervous system. In contrast, Friedreich's ataxia (FRDA) involves the spinal cord, spinal ganglia, sensory nerves, eyes, heart, and the insulin-producing cells of the pancreas. To look at the diseased tissues with a microscope allows a pathologist to reach important conclusions about the course of the disease. A key question is: How does the destruction of an organ come about? This process is known under the term "pathogenesis." Understanding the pathogenesis simply cannot be done without detailed analysis under a microscope.

Tissues for pathological study are harvested during an autopsy, also known under the terms "necropsy" and "post-mortem examination." Though the thought of cutting into a dead human body may cause fright and anxiety, the examination is conducted with dignity and respect. It is also invaluable for the teaching of young physicians. Samples are collected for gross and microscopic examination, and frozen tissues allow for the extraction of deoxyribonucleic acid (DNA), the genetic material that harbors the underlying mutations in SCA and FRDA.

The National Ataxia Foundation (NAF) has supported a tissue donation program for many years. The repository of the samples is located at the VA Medical Center in Albany, New York. Patients with SCA, FRDA, or sporadic ataxia, and their kin, are welcome to inquire about tissue donation and the steps that are needed to advance the important goal: cure ataxia by ⏩

understanding the disease. The map at left shows the number of inquiries, by state, over the last 18 years (dark dots). Actual donations since 1993 are shown as light dots. Small dots represent one inquiry; large dots represent five inquiries.

The tissue examinations confirmed what is also known from the practice of clinical neurology: Friedreich's ataxia is the most common form of hereditary ataxia. Among the SCA, SCA-3 (Machado-Joseph disease), SCA-2, SCA-6, and SCA-1 lead the dominant ataxias. In about 25 percent of the dominant SCA, the mutation has not yet been identified. DNA in the stored frozen tissues of these patients is available for future genetic examination. In several donors who had no firm genetic diagnosis during life, DNA extracted from frozen samples proved that they had suffered from late-onset FRDA. This disease is no longer an illness of children and teenagers but may begin at a much later age (30-50 years).

Dr. Arnulf H. Koeppen

Over many years, autopsies were common procedures in most hospitals. Gradually, their numbers declined, and researchers now struggle to obtain correctly harvested samples for their investigations. The value of the autopsy in the diagnosis and therapy of a disease cannot be overstated. It has become more difficult to secure an autopsy near a patient's home, and most hospitals and pathologists now require payment for the procedure. These hindrances are not insurmountable and actually stress the autopsy as an important contribution to public health.

In this NAF program, the families of the deceased ataxia patients receive a letter with the detailed findings disclosed by the autopsy. In this way, the program differs from tissue banks at other medical centers that provide little or no feedback to the donor's next-of-kin. Family members who authorize the autopsy often gain comfort from the realization that the prolonged struggle and death of a loved one were not in vain. The feeling of closure adds to the satisfaction that the donor will help others with ataxia.

If you would like to learn more about tissue donation, contact Dr. Koeppen at the following address:

Arnulf H. Koeppen, MD
Research Service (151)
VA Medical Center, 113 Holland Ave.
Albany, NY 12208
Phone: (518) 626-6377 FAX: (518) 626-6369
E-mail: arnulf.koeppen@va.gov

Acknowledgment: Dr. Koeppen's research laboratory receives support from National Ataxia Foundation, Friedreich's Ataxia Research Alliance, National Institutes of Health, and the Department of Veterans Affairs. Dr. Koeppen is a lifetime member of NAF and has served on the Medical Research Advisory Board for the last 26 years. ❖

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.

ShopNAF.org

Looking for that perfect gift or items for your everyday needs? Shop online through MarketAmerica's NAF shopping website, *www.ShopNAF.org*.

Each purchase you make through this website will help support the National Ataxia Foundation. Thank you.

All California Ataxia Research Meeting Review

By Joanne Loveland

The 8th All California Ataxia Research Meeting (ACARM) was held on Dec. 12 in Sacramento. Seven leading researchers spoke to the audience of ataxians and their families. Three of the speakers addressed on-going studies at their universities using stem cells. Much of the research is being directed toward Huntington's disease (HD) because funding is actively available for that research. Dr. Perlman and other researchers commented that progress with regenerative cures or delaying the progression of HD will also be a breakthrough for ataxia as well.

NAF support group leader Mike Fernandez and NAF medical director Dr. Susan Perlman pose for a photo during the ACARM

Much of the funding for stem cell research in California is coming through the California Institute for Regenerative Medicine (CIRM). Check out their website and all the institutions they have funded at *www.cirm.ca.gov*.

We heard about research being done with adult stem cells, embryonic stem cells, umbilical blood cord stem cells, mesenchymal stem cells, and pluripotent stem cells.

The three speakers represented UC Davis, (Dr. Jan A. Nolta), UC Berkeley (Dr. David Schaffer), and UC Irvine (Dr. Leslie Thompson). These universities all have stem cell research programs.

Dr. Jan Nolta has published over 100 manuscripts in the stem cell field and is editor of the book, "Genetic Engineering of Mesenchymal Stem Cells." Dr. Nolta has more than 20 years experience with human stem cells.

Dr. David Schaffer is co-director of the UC Berkeley Stem Cell Center. Dr. Schaffer applies engineering principles to enhance stem cells and gene therapy approaches for regeneration.

Dr. Leslie Thompson helped identify the gene that causes Huntington's disease. She stated that stem cells have offered us a new way to study the disease by allowing us to examine human neurons carrying the mutation.

Dr. Thompson left our event to fly to Washington D.C. for meetings with the National Institutes of Health and pharmaceutical companies who would like to partner with stem cell research programs. She has reported back that the meetings went exceptionally well.

Also from UC Davis, Dr. Heike Wulff shared her research which is focused on potassium channel activators as potential therapeutics for the treatment of ataxia and other neurological diseases characterized by hyperexcitability.

The ever popular and respected, Dr. Susan Perlman gave an informative talk about research and treatments for non-genetic ataxia (40 percent of the ataxia population have a genetic form of ataxia, 60 percent have a non-genetic form).

Dr. Lisa Ellerby is actively doing research at the distinguished Buck Institute for Research on ⏩

Aging in Novato, CA. Her team is researching the mechanism of neuro-degeneration and therapeutic treatments for Huntington's disease and other polyglutamine expansion diseases.

Dr. Theresa Zesiewicz was our special out of state speaker from the University of Southern Florida (USF) who spearheaded the clinical trials using the FDA approved drug, Chantix. Her report was, "Chantix Up Until Now." Chantix has shown to help gait and balance in some individuals with ataxia. It seems to be the most helpful to those who have Spinocerebellar ataxia. A meeting attendee shared that his daughter, who has Friedreich's ataxia, has clearer speech and better coordination when she takes Chantix. Dr. Zesiewicz did share information about negative side effects.

A big thank you to Mike Fernandez who lined up these very accomplished speakers.

Also, thank you to the event MC from the Aging and Memory Center at UCSF, Dr. Gail Kang. ❖

Book Adaptation

Living with Ataxia

Adapted from the book "Our Trials are a Blessing: A Life Shaped by a Genetic Disease" by Allen G. Smith. Available from Amazon.com.

I was close to 40 when I recognized the first symptoms of what turned out to be late onset Friedreich's Ataxia. It happened on one of my regular nighttime runs on an unlit fire road in the Santa Monica mountains of California. I liked to run at night when it was cooler and quieter on the fire roads; the moon and stars provided all the light I needed. I had the beginning of a cold, but in those days my response to impending illness was to run harder – I didn't have time to be sick, so I burned the demons out of my system with exercise. As always, I drove that night to the trailhead. There wasn't much of a moon, so I would have to rely on feel, muscle memory, and the faint glow of ambient light on the fire road for navigation during my run. Tricky, perhaps, but nothing I hadn't done a hundred times before. After a few brief strides from my car I had to negotiate an S-shaped maze constructed by the park service to admit horses to the trail while barring vehicles. I couldn't do it. At least, I couldn't do it without difficulty. I banged into the rails trying to negotiate the tight turns, scratching my shins.

Over the next few years more symptoms emerged. I couldn't walk with a glass of water without sloshing; I could't play hopscotch with my young daughter; I lost my balance and fell more often; I had trouble running or even walking in a straight line. Most debilitating, though, was a growing fatigue when I traveled for my job. Eventually, my wife had seen enough and scheduled a neurology appointment at the UCLA Medical School. After a series of genetic tests, my doctors diagnosed late onset Friedreich's ataxia.

That was 25 years ago. Since then my condition has continued to progress. I retired on disability in 2000 and my wife and I moved to the San Juan Islands in Washington. I walk haltingly with a cane or walker, relying on wheelchairs in airports. I try to take a nap every day.

By any objective measure my condition has deteriorated. But I am happier than I have ever been. Sure, part of that are the naps, but there is more. For me, and I don't claim that everyone is

Continued on page 20

Living with Ataxia
Continued from page 19

the same, there are a few rules that help make it possible not only to live but to thrive with ataxia. Here they are, in no particular order:

Recognize that, "I am not my body."

Our culture makes a big deal of bodies. Young people are taught that their self-worth is based on how their bodies look and on what those bodies can do. It's little wonder that most people have trouble distinguishing themselves from their bodies. It wasn't always that way. St. Francis, for example, referred to his body as "Brother Donkey," a fleshy vehicle that had to be fed and watered so it could carry his spirit about. The Buddha and centuries of yogis prescribed disciplines to still the body so that the mind could soar. Ataxia forces us to remember that truth; our bodies may be deteriorating but that has nothing to do with what goes on in our heads. If anything, my mind has grown sharper over the last 25 years. I'm always amused at airport security checkpoints when TSA agents, assuming that physical handicaps equate to mental handicaps, speak louder to me using small words that they struggle to pronounce slowly. My kids think this is a riot; to this day when I accomplish some trivial task they say "Good job!" in the special-education-teacher voice they once heard an agent use.

"I know there are stages of grief and that anger is one of them. My advice is to get through it as fast as possible and to be grateful instead for all the good that remains in life."

Keep fit.

I may not be my body, but I do have to rely on that body to carry me around. Especially as my balance worsens, I find that I must rely on muscles to do what most people take for granted, such as standing erect without falling over. My old forms of exercise, such as running and biking, may not be feasible any more, but there are plenty of alternatives. I invested in a recumbent tricycle that I ride all over the island. Because it has three wheels (two in front and one in back) balance isn't an issue. I like to call it The World's Fastest Lawn Chair. For rainy days I have a stationary bicycle inside. I do yoga daily.

Everyone is handicapped; some handicaps are just more visible than others.

I have a friend, now in his forties, who comes from a family in which no male has lived more than 50 years because of heart conditions. I have another friend whose sister, mother, and grandmother all died young from ovarian cancer. A former colleague is tied to his easy chair by chronic back pain. There are physical conditions or time bombs in every family tree. And that's just looking at the body. Many more are paralyzed or bent by dysfunctional or traumatic family backgrounds. Others are so depressed that each day is an ordeal. Everyone has physical, mental, or spiritual challenges that must be faced. At least my challenge comes with a good parking spot!

Go beyond the intellect, nurture the spiritual side.

This one is very personal, and harks back to the first tip. If one believes that one's skin defines the limits of existence, life with ataxia can be depressing. Ataxia is an opportunity to examine one's life, to rethink priorities, and to move past the I-am-immortal day to day concerns to the big questions of life. Some may find solace in faith and prayer. For me, it was the practice of meditation and study of Eastern religions. Everyone must find their own path, but by all means look.

Keep a sense of humor.

I don't know if laughter is the best medicine, ▸▸

but it certainly makes a life with ataxia (for that matter, any life) more fun. Humor puts those around us at ease with our condition, and it puts us at ease with others. Without it, there always is a certain awkwardness in new people: "Do I try to ignore the handicap or not?" If we don't allow ourselves to see the humor in the situation, no one in these politically correct times will. My friends used to joke that I could play second base at company softball games. That is, I could literally *be* the second base. I thought then it was funny, and still do. Life is too short for thin skin.

Don't expect or demand special treatment and you will be amazed by the kindness of others.

I don't do buffets well, but they are now common in America. I have a silly little personal rule: I will never ask anyone to bring me food. If someone offers, I smile gratefully and accept. If no one offers, I don't eat. Cheerfully. In twenty-some years I think I have gone hungry twice. People all over the world are remarkably kind and remarkably helpful without being asked. Let that kindness come out on its own. Demanding special treatment just makes people uncomfortable, makes one sound whiney, and sets up disappointment. Just take what is offered with cheerful gratitude. It's more than enough.

Don't waste time and psychic energy being angry. It will do no good and fosters self pity.

Getting angry at God or at fate is a bit like throwing hot embers with bare hands: it hurts the thrower more than it hurts the target. I know there are stages of grief and that anger is one of them. My advice is to get through it as fast as possible and to be grateful instead for all the good that remains in life. If the mind is clear and if one is surrounded by those one loves, none of the rest matters. As a very wise person once said: "The things that happen to us do not matter; what we become through them does." ❖

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.

Arnulf Koeppen, MD
Professor of Neurology
VA Medical Center
113 Holland Ave., Albany, NY 12208
Phone: 518.626.6377 Fax:518.626.6369
E-mail: Arnulf.Koeppen@va.gov

Have You Remembered NAF In Your Estate Planning?

When you make or revise your will or trust, or review your life insurance contracts or retirement funds, please consider naming the National Ataxia Foundation among the charities included as beneficiaries.

The use of the following language ensures that your gift is directed appropriately: "I bequeath ___% of my estate (or fund) to the National Ataxia Foundation, a non-profit organization located at 2600 Fernbrook Lane, Suite 119, Minneapolis, MN 55447-4752."

For further information about naming the National Ataxia Foundation as a beneficiary, contact Mike Parent at *mike@ataxia.org* or (763) 553-0020. Thank you for your support of the important work of the Foundation.

National Ataxia Foundation
54th Annual Membership Meeting
"Bringing the Ataxia World Together"
Los Angeles, California – March 17-20, 2011

By Lori Shogren, NAF Special Projects Coordinator

The 2011 NAF Annual Membership Meeting was hosted by NAF's Los Angeles, Orange County, and San Diego Ataxia Support Groups. NAF would like to congratulate the support groups on organizing a highly successful meeting and would like to thank them for their team effort in coordinating the event. This 54th NAF Annual Membership Meeting was attended by 507 registrants, 25 speakers, and 12 exhibitors. Attendees travelled from more than 35 U.S. states and 10 international countries including Argentina, Australia, Belgium, Canada, France, Germany, Hong Kong, India, Netherlands, and the United Kingdom.

Thursday, March 17 was the day when most attendees arrived at the conference. The day was kicked off with registration activities which included packet pick-up and exhibitor displays. On Thursday evening, registrants attended the St. Patrick's Day Welcome Reception – many donning their favorite shade of green for the occasion. Festive décor, music, delicious food and great company were enjoyed by all. At the reception, Certificates of Appreciation were presented to the organizers of various NAF fundraising events and activities held throughout the past year. Funds raised from these events supported NAF funded research and other important support programs. The Foundation would like to thank all the supporters and organizers of these events for their dedication and hard work.

On Friday, March 18 the general session program began with a welcome given by Michael Parent, executive director of the National Ataxia Foundation. As part of the welcome, he formally introduced the audience to the President of the NAF Board of Directors, Charlene Danielson. Los Angeles Ataxia Support Group Leader, Cherilyn McLaughlin served as the MC for the days' presentations. NAF would like to thank UCLA and other Los Angeles area medical professionals for their participation and support of this conference.

Friday afternoon gave attendees the opportunity to meet others who share their type of ataxia or role in the life of someone with ataxia through the popular "Birds of a Feather" session. These small group sessions provided a comfortable setting for registrants to discuss and share personal experiences. Physicians, ataxia investigators and other helpful professionals visited with each group to provide information and answer questions.

On Friday and Saturday attendees had the chance to observe and try the Nintendo Wii game system. Thank you to Cherilyn McLaughlin for sharing her Nintendo Wii game system with conference attendees. A special thank you to Heather Evans for demonstrating the Nintendo Wii system.

On Saturday, March 19 the conference continued the general session program – with both new and familiar medical professionals and researchers presenting throughout the day. Jane Jaffe and Alfredo Moran served as the MCs for these sessions.

Saturday's banquet was a fun-filled Hollywood-themed experience for all who attended. Many registrants got their picture taken with a Marilyn Monroe cut-out and strolled along the NAF Walk of Fame outside the banquet hall. Adorned with personalized, decorative stars, the NAF Walk of Fame was a popular area for attendee visits and photos. Sales of the stars raised more than $750, and meeting attendees found them to be a ⏩

great and touching way to honor friends and loved ones.

Meeting attendees as well as members of the NAF Board of Directors and staff paid tribute to former NAF President, DeNiece Roach, who passed away in December 2010. Purple was DeNiece's favorite color, so to honor her memory, the color purple was incorporated into many of the weekend's events. A purple star was printed on event name badges, and many attendees wore purple attire to the banquet on Saturday. A plaque for the Roach Family in recognition of DeNiece was accepted by NAF President, Charlene Danielson.

At the banquet, NAF recognized Arnie Gruetzmacher for his 40 years of service on the NAF Board of Directors. The Foundation also recognized Charlene Danielson for her 25 years of service on the NAF Board of Directors.

Fundraising activities from the weekend included the 50/50 raffle and silent auction. The raffle raised more than $3,000 for NAF and sales from the silent auction raised more than $4,000. Thank you to everyone who donated items for this year's silent auction and to those who participated in these events. Congratulations to the raffle and silent auction bid winners. NAF would like to thank DJ Frank Fiorito, who provided such wonderful dancing music and entertainment at the banquet.

On Sunday March, 20 NAF Executive Director, Michael Parent discussed highlights from 2010. His remarks were preceded by the NAF business meeting led by NAF President, Charlene Danielson. The general session program continued throughout the morning with Jane Jaffe serving as the MC for these presentations. George Wilmot, MD, PhD (Emory University) gave the closing presentation of the conference with his review of what was learned throughout the weekend.

Each day's general sessions were followed by a question and answer session which included the presenters of the day. The transcriptions of selected presentations will be published in future issues of *Generations*. Also, you can access the slides from these presentations on our website *www.ataxia.org*. Audio presentations synched with the PowerPoint presentation slides can be purchased through Digital Conference Providers at *www.dcprovidersonline.com/naf/*.

A Special Thank You

The National Ataxia Foundation would like to extend a special thank you to all the attendees, speakers, facilitators, exhibitors, and volunteers of the 2011 NAF Annual Membership Meeting. This was an excellent and exciting meeting! We appreciate your participation in making this conference so successful. The wealth of information and knowledge brought to the conference by all the speakers, facilitators and exhibitors was exceptional. Conference attendees returned to their local communities with valuable resources and information, as well as new and renewed friendships.

A special thank you is extended to the Los Angeles, Orange County, and San Diego Ataxia Support Groups for the outstanding job they did in organizing and coordinating the weekend's events and activities. Our staff enjoyed working with Chad Beecher, Cindy DeMint, Jeff Furton, Cherilyn McLaughlin, Earl McLaughlin, Ana Moran, Daniel Navar, and all of the other individuals who volunteered their time throughout the weekend. NAF would also like to thank our on-site nurse, Lora Morn for volunteering her time and talents at the meeting. A big thank you is extended to David Garcia for taking such memorable photos at the meeting.

NAF would also like to thank this year's sponsors, Athena Diagnostics and Santhera Pharmaceuticals. Thank you to Chad Beecher, Jeff Furton, Cherilyn McLaughlin and the DeMint family, who gathered and donated items for the welcome bags at the conference. Bags and water bottles were donated by California Analytical Instruments, Inc. (CAI). Contents of the welcome bags were donated by CAI, Recellular.com, Sue Procko Public Relations, and the DeMint family. A special thank you is extended to Church Offset Printing for printing the 2011 NAF AMM Program and for their continued support of NAF projects.

NAF would also like to thank the Hilton Los Angeles Airport Hotel and Marriott Los Angeles Airport Hotel for their service and hospitality throughout this event. ❖

THE NATIONAL AT

54th Annual Men

"Bringing the Ataxi

Los Angeles, California

Dr. Larry Schut (left), Louise Chalcraft-Frank (center), and Loretta Schut pose for a photo during the Saturday evening banquet.

Meeting volunteers Jane Jaffe (left), Lisa Jaffe (center), and Larry Jaffe enjoy the Saturday evening entertainment.

Meeting attendees enjoy music and entertainment at the Saturday banquet.

Mary Romero (left), Rita Garcia (center), and official event photographer David Garcia

Meeting attendees enjoy the Saturday evening banquet.

NAF Executive Director Michael Parent presents a Certificate of Appreciation to the Los Angeles Ataxia Support Group for the 2010 Walk n' Roll.

NAF Board President Charlene Danielson accepts a plaque during the Saturday evening banquet.

Regis

TAXIA FOUNDATION

nbership Meeting

ia World Together"

— March 17-20, 2011 ———

Meeting attendees mingle near the registration room.

NAF volunteer, Polly Fanchin (left), NAF Support Group Leader Greg Rooks (center), and NAF Board Member and Support Group Leader Camille Daglio pose during the Saturday banquet.

Banquet centerpieces

Meeting attendees enjoy the music and entertainment at the Saturday evening banquet.

strants participate in wheelchair yoga, led by Ralph Miller.

Meeting attendees Topher Marsh, Daniel Navar, Amy Champlin, and Todd Hartsfield pose for a photo during the St. Patrick's Day reception.

NAF Executive Director Michael Parent presents Lynda Howell with a Certificate of Appreciation for her work with the NAF Virtual Walk n' Roll.

NAF Medical Director, Susan Perlman, MD, answers a question from the audience.

Speakers from the Friday morning presentations (left to right): Melinda Guttry, PT; Jacquelyn Glenn, OTR; Susan Perlman, MD; Anne Lefton, MA-CCC-SLP; and Al LaSpada, MD, PhD, FACMG.

Sid Gilman, MD

Speakers from the Saturday morning presentations (left to right): Vikram Shakkottai, MD, PhD; Richard Ivry, PhD; Henry Paulson, MD, PhD; Clive Svendsen, PhD, Theresa Zesiewicz, MD, FAAN; and Joel Gottesfeld, PhD.

Joanna Jen, MD, (left) answers a question from the audience.

Speakers from the Saturday afternoon presentations (left to right): Christopher Gomez, MD, PhD; Mary Anne Ehlert, CFP; and S.H. Subramony, MD.

Special thanks to photographer David Garcia for taking all the photographs you see on these pages

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"Bringing the Ataxia World Together"

Los Angeles, CA – March 17-20, 2011

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	FRIDAY: March 18, 2011	
	Friday General Sessions	
NAF 1100	LA Experience & Ataxia Medical Update	❒ MP3 / MP4
NAF 1101	OT/PT for Ataxia	❒ MP3 / MP4
NAF 1102	Speech & Swallowing	❒ MP3 / MP4
NAF 1103	Poly Q SCAs/SCA7	❒ MP3 / MP4
	SATURDAY: March 19, 2011	
	Saturday General Sessions (A.M.)	
NAF 1104	Adaptive Recreation, What You CAN DO!	❒ MP3 / MP4
NAF 1105	How Cerebellar Dysfunction Affects Motor Control	❒ MP3 / MP4
NAF 1106	HDAC Inhibitors in FRDA	❒ MP3 / MP4
NAF 1107	Clinical Trials and Natural History Study	❒ MP3 / MP4
NAF 1108	Analysis of Chantix Clinical Trial	❒ MP3 / MP4
NAF 1109	Stem Cell Research for Ataxia	❒ MP3 / MP4
NAF 1110	Research Update	❒ MP3 / MP4
	Saturday General Sessions (P.M.)	
NAF 1111	Medication for Ataxia Symptoms	❒ MP3 / MP4
NAF 1112	National Ataxia Registry	❒ MP3 / MP4
NAF 1113	Wheelchair Yoga	❒ MP3 / MP4
NAF 1114	Financial Planning	❒ MP3 / MP4
	SUNDAY: March 20, 2011	
	Sunday General Sessions	
NAF 1115	Sporadic Ataxia and MSA Research	❒ MP3 / MP4
NAF 1116	Management of Neurogenic Bladder	❒ MP3 / MP4
NAF 1117	Management of Dizziness in Ataxia	❒ MP3 / MP4
NAF 1118	Applying for Social Security Disability	❒ MP3 / MP4
NAF 1119	Recessive & Paraneoplastic Ataxia	❒ MP3 / MP4
NAF 1120	What We Have Learned	❒ MP3 / MP4

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Don't Forget About the End

By Martha A. Nance, MD
Hennepin County Medical Center HDSA Center of Excellence

The following article was printed in the Spring 2011 issue of "HDSA Minnesota Highlights" newsletter. Huntington's disease is a genetic, progressive neurogenerative movement disorder. It is one of several CAG Triplet Repeat Disorders which includes the spinocerebellar ataxias (SCAs) types 1, 2, 3, 6, 7 and 17. Although this article was written for those affected with Huntington's Disease, it provides excellent advice for those with ataxia. Martha Nance is a member of NAF's Medical Research Advisory Board. Published with permission.

Patients, families, and doctors are all hesitant to talk about the late stages of HD, the end stages, or death and dying. Children don't want to upset their parents, spouses don't want to upset their affected loved one, patients don't want to think about death, and doctors may be equally uncomfortable talking about death. Research, rightly so, is focusing on finding treatments that stabilize or reverse the disease early in the course, possible even before the current time of typical diagnosis.

But the elephant in the room grows ever larger as the disease progresses, and until we find a cure for HD, it is true that people who are symptomatic with the disease will die of HD unless they die prematurely from some other cause. By not talking about it, by harboring fears of dying the way Grandma did, by hoping that if we don't think about it, it won't happen, we all make it more likely that the days and weeks leading up to death will be uncomfortable for the person who is dying and for those who care about him (or her).

Conversely, by talking about death and planning for it, by understanding when it is likely to occur and what it looks like when it comes, we will be better able to make the dying process comfortable, dignified – and sometimes even beautiful, is always bittersweet.

Here are some tips about how to make the dying process better:

• Everyone with HD should assign a health care agent - someone who can speak for them in the event that they are no longer able to speak for themselves. This can and should be done early, before it is "needed."

• The health care agent and the person with HD should discuss what the person's wishes are as they move to the late stages of the disease. Is there a point at which they would not want to be hospitalized? Would they want a feeding tube if they were no longer able to swallow well enough to keep up their weight? What if they were bedbound or unable to communicate? Would they ever want doctors to limit the aggressiveness of care (such as resuscitation, use of antibiotics, hospitalization, IV fluids, diagnostic tests, etc.)?

• The person with HD should also attend to his or her financial and estate concerns. Completing a will and designating someone to serve as the power of attorney for financial affairs is important.

• Everyone who has HD should know what stage of the disease they are in. Are you expected to live 10 or more years? Five years? No more than one to two years? Or is death coming within the next few weeks or month? Talk to the doctor! You should understand this aspect of the disease just as much as you should understand what a CAG repeat number is!

• I have learned over the years to embrace the use of hospice services. Hospice can be provided in the home, the nursing home, or the hospital, and includes services provided by a team of experts, focusing on comfort, dignity, respect, freedom from pain, and family involvement (as ⏩

opposed to diagnosis and aggressive treatment of diseases, hospitalization, invasive intravenous or gastrointestinal tubes). The longer the hospice team is able to work with a patient and family, the more able they are to ease the path from life to death.

I received a wonderful card recently from a longtime friend whose adopted son had struggled terribly with HD. "We lost Jimmy [not his real name] this year," his mother wrote ... "we decided to bring in hospice so he would not have to keep going back and forth to the hospital [not his favorite place] ... we celebrated his Home-Going a few days later in a way that we think would have made him very happy ..."

I wish for such comfort, peace, and acceptance for everyone who has to complete his or her course of HD before science has found the cure we all dream of. ❖

Everybody Needs a Plan

Reprinted with permission from The Minnesota State Council on Disability (www.disability.state.mn.us).

Be Prepared for Disasters

According to the National Organization on Disability (NOD), "To be better prepared as a nation, we all must do our part to plan for disasters. Individuals with or without disabilities can decrease the impact of a disaster by taking steps to prepare BEFORE an event occurs."

"You are in the best position to know your abilities and needs before, during, and after a disaster."

According to the National Fire Protection Association (NFPA) Emergency Evacuation Planning Guide for People with Disabilities, "All people, regardless of circumstances, have some obligation to be prepared to take action during an emergency and to assume responsibility for their own safety."

Practice and planning **do make a difference**. During the 1993 bombing of the World Trade Center, a man with a mobility disability was working on the 69th floor. With no plan or device in place, it took over six hours for him to evacuate.

In the 2001 attack on the World Trade, the same man had prepared himself to leave the building using assistance from others and an evacuation chair he had acquired and had under his desk. It took less than 90 minutes for him to get out of the building the second time.

Create a Home Plan

- You may be on your own for a few minutes, a few hours or in the worst case scenario, a few days ... you need to plan for this possibility.
- Meet with household members, neighbors or personal care assistants to discuss what would happen in an emergency.
- Remember, when creating a plan for an emergency, networking with those that are in close proximity is important.
- Discuss different types of emergencies:
  - Tornado
  - Pandemic
  - Flood
  - Chemical spill
- Determine what you will need to do to respond to each type of emergency:
  - Will you shelter in place or will you evacuate?
  - Shelter in place – do you have enough water, food, medical supplies, PCA support?

Continued on page 30

Everybody Needs a Plan
Continued from page 29

– Evacuation: do you have a transportation source; is the evacuation site accessible, do you have enough medical supplies, PCA support?

Checklist

❑ Post emergency telephone numbers where you can find them, near the telephone or programmed into your cell phone.

❑ Teach children and others in the household what to do, who to call and when.

❑ Listen to a battery or crank-operated radio for emergency information.

❑ Know where the flashlights are located.

❑ Know where the First-Aid kit is located.

❑ Arrange for a relative, friend or neighbor to check on you in an emergency.

❑ Teach those who may need to assist you in an emergency on what to do:

• the best way to notify you of an emergency if you are deaf or hard of hearing

• the best way to communicate

• how to assist with a transfer

• how to do a blood pressure check

• how to assist with an insulin injection

• how to operate necessary lift or medical equipment, etc.

❑ Keep family records, medical records or other important documents in watertight, fireproof containers.

❑ Consider getting a medical alert system that will allow you to call for help if you are immobilized in an emergency.

❑ Consider getting a medical ID bracelet or medical dog tags that state your medical condition.

❑ Try to identify a second exit, in case the primary exit is blocked. At a minimum, have some ideas on how you would evacuate in this situation.

❑ Consider your transportation options; do you have access to a vehicle?

❑ Do you have a network of friends, family or neighbors that would be able to provide transportation in an emergency?

❑ Does your transportation provider have resources available during an emergency?

❑ Pick one out-of-state and one local friend or relative for family members to call if separated by disaster.

❑ Pick two meeting places:

• A place near your home in case of a fire.

• A place outside your neighborhood in case you cannot return home after a disaster.

❑ Learn how to turn off the water, gas and electricity at main valves or switches.

❑ Know how to connect or start a back-up power supply if needed.

❑ PLAN AND PRACTICE HOW TO ESCAPE FROM YOUR HOME IN AN EMERGENCY.

❑ If you live in an apartment, ask the management to identify and mark accessible exits.

❑ Plan & Practice

Prepare a Disaster Supplies Kit

Assemble supplies you might need in an evacuation. Store them in an easy-to-carry container such as a backpack or duffel bag.

Include:

❑ A battery or crank-operated radio, flashlight and plenty of extra batteries for them.

❑ A first aid kit, extra pair of glasses.

❑ If you take medication or use supplies, make sure you have a week's worth, if not more, available and travel ready.

❑ A supply of water – store water in a sealed, unbreakable container. Identify the storage date and replace every six months.

❑ A supply of non-perishable food and a non-electric can opener, plus any special food you require.

❑ A sturdy whistle.

❑ Cash or travelers checks.

❑ Soap and sanitation products. ▸▸

❑ A change of clothing, rain gear, and sturdy shoes.

❑ Blanket or sleeping bag.

❑ Important family and medical documents that include:

• A list of family physicians and the relative or friend who should be notified if you are injured.

• A list of the style and serial numbers of medical devices such as pacemaker.

• Keep family records, medical records or other important documents in your disaster supply kit in watertight containers.

❑ An extra set of car keys.

❑ If you have a baby, include extra diapers and other infant care items.

❑ Extra wheelchair batteries, oxygen, medication, catheters, food for guide or service animal, or other special equipment you might need.

❑ Plastic garbage bags.

Also…

❑ Store back-up equipment, such as a manual wheelchair, at a neighbor's home, school or workplace.

Learn your community's evacuation plan

• Will your community have transportation options available?

• Are the shelters accessible?

• How will you secure a sign language interpreter?

• Will guides or assistants be available?

To learn more or if you have questions, contact the emergency planner for your area.

Resources

- *www.codeready.org*
- *www.disability.state.mn.us*
- *www.DisasterHelp.gov*
- *www.fema.org*
- *www.hsem.state.mn.us*
- *www.noaa.gov*
- *www.nod.org*
- *www.PrepareNow.org*
- *www.ready.gov*
- *www.redcross.org*

Contact information

For additional information, contact the Minnesota State Council on Disability (MSCOD), 121 East 7th Place, Suite 107, St. Paul, MN 55101; (651) 361-7800 (v/tty); 1-800-945-8913 (v/tty); *www.disability.state.mn.us.* ❖

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. The I Do Foundation's Charity Registry service also makes it easy for guests to make donations in lieu of gifts.

All of these services are available free of cost at *www.IDoFoundation.org*. Check it out today, and be sure to select NAF as the beneficiary of your charitable wedding.

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.

NAF Mer

BOOKS

— ATAXIA RESOURCES —

Evaluation and Management of Ataxic Disorders for Physicians

by Susan Perlman, M.D.

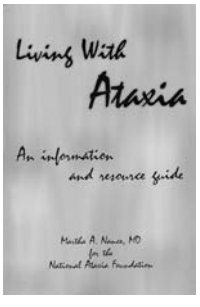
This resource is intended to inform and guide physicians who may be caring for patients with ataxic symptoms or who have been diagnosed with ataxia. It will provide health care practitioners with a vocabulary to aid in the understanding of what is and is not ataxia, diagnostic protocols for use in defining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

Healing Wounded Doctor-Patient Relationships

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

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

Living with Ataxia: An Information and Resource Guide



by Martha Nance, M.D.

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

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

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

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

— FICTION & PERSONAL STORIES —

Summer Born: A Life with Cerebellar Ataxia

By Cheryl Wedesweiler

Although the characters are fictional, the story is based on the author's real life experiences with having cerebellar ataxia. $15.95

Ten Years to Live

by Henry J. Schut

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

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

by Dave Lewis

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

— COOKBOOKS —

Recipes and Recollections

by Kathryn Hoefer Smith

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

Cooking for a Cause

by Julie Karjalahti for FRDA research

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

Recordings of presentations from the 2011 Annual Membership Meeting are now available to order.
See page 27 of this issue of *Generations*.

chandise

SHIRTS/MISCELLANEOUS

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

2011 Annual Membership Meeting T-Shirt
Gray, short-sleeved with the "Bringing the Ataxia World Together" logo. Sizes medium to XX-large. $10

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

NAF Polo Shirts
Mens – Royal blue w/white embroidered NAF logo. Sizes medium to XXX-large. Womens – Light blue w/ navy embroidered NAF logo. Sizes small to XX-large. $25

NAF Denim Shirt
Denim with white embroidered NAF logo. $27.50

"Ataxia is Not a Foreign Cab" T-Shirt
White. New design. Sizes small to XXX-large. $10

"Ataxia is Not a Foreign Cab" 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
$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
A discussion of ataxia. 50 minutes. VHS $20 or DVD $25

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

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Eye Movement Abnormalities in Ataxia

By Sarah H. Ying, MD

Dr. Sarah Ying received her BA from Harvard-Radcliffe College in Cambridge, and her MD from The Johns Hopkins University School of Medicine in Baltimore. Following internship training at The Johns Hopkins Hospital, she completed residency training in Neurology at Barnes Hospital in St. Louis. She pursued additional training with Dr. Robert Baloh and Dr. Arthur Toga at the University of California, Los Angeles, then returned to Johns Hopkins for a clinical and research fellowship in neuro-otology and neurophthalmology with Dr. David Zee. Now an Assistant Professor of Neurology with a secondary appointment in Ophthalmology, Dr. Ying specializes in dizziness, imbalance (including ataxia), and eye movement abnormalities.

The following article is from a portion of Dr. Ying's presentation at the 2007 NAF Annual Membership Meeting in Memphis, TN. It was edited for publication in Generations.

Difficulty with reading is one of the most common complaints associated with abnormalities of *saccade* – abrupt rapid small movements of both eyes, such as when the eyes scan a line of print – control and alignment. Clinical management should begin with careful ophthalmologic evaluation to rule out any treatable causes of loss of your static visual acuity. Make sure your eyes are okay themselves, much less looking at the control of the eyes. For example, ensuring an up-to-date prescription for your glasses is a critical first step.

Dr. Sarah H. Ying

But realize that it may be necessary to have multiple pairs of glasses because of this difficulty of convergence and for viewing at different distances. For example, people may need a special pair of glasses for looking at a computer which is actually a medium distance that is farther than the prescription that you would get for a bifocal reading up close. You can get a pair of glasses cheaply at the drug store and have them right next to your computer.

Another group of people who have had trouble like this is music teachers, where they can't see music on a stand that is a little bit farther away. Prisms can be used to correct for these alignment issues but it may be necessary to tailor the glasses prescription to the expected distance. Another thing is making sure that your prescription has actually been filled correctly. This can be checked during a follow-up visit to the ophthalmologist where they can actually look and see whether the prescription that is in your glasses is what they actually ordered. So don't be afraid to go back if you feel you still can't see properly. Check and make sure your glasses are actually correct.

Also associated with ataxia is retinal disease, particularly in some forms of hereditary ataxia. Actually there are many on-going clinical trials testing vitamin and micronutrient therapies and so it is important to see a retinal specialist. Other treatable causes of impaired vision include cataracts which are very common and very treatable. Glaucoma is much less common but it is treatable also. Progression can be halted with the treatment. ⏩

As an historical note, acetazolamide, a treatment for downbeat nystagmus, was originally introduced as a treatment for glaucoma.

There are also many strategies to optimize reading conditions for anyone with low vision and a visit to a low vision specialist may help. Proper lighting is critical. A good reading lamp or an architect's or artist's lamp may be useful. Sunlight is actually the best lighting available. Setting up a place to sit with the early morning sunlight on your back, shining directly on the page is ideal. Another thing to do is ensure that your text is of excellent high contrast. For example a lot of people complain that they can't read the newspaper anymore. That is because newsprint is actually very, very low contrast. It is made of all those little dots so just switching to a weekly periodical can increase the amount of contrast by about five times. Note that this applies to publications that are on glossy paper, not newsprint.

Reading online is another excellent alternative, particularly with the use of a very high quality digital LCD screen to maximize the sharpness of the print. Of course, use of the computer also enables customization of your font size. Other types of magnification, for example of hard copies of books and documents, can be facilitated with many devices, anywhere from a simple stand magnifier to more elaborate assisted reading systems such as a video magnifier which actually projects the image onto a screen. Another simple technique is actually to isolate words such that only a few words or only a single line is visible at a time so you don't have a crowding effect from the other words on the page.

Then from the eye movement stand point, it is also critical to dampen *nystagmus* – constant, involuntary, cyclical movement in any direction of the eyeball – or other movements of the eyes. Other than the pharmacologic interventions that we mentioned, there are some physical maneuvers that may also be helpful. For example, many patients may have a null point where their eyes actually are stable in space, that's not necessarily directly ahead or where you are holding your book or your computer screen. An individual may find that by holding their reading material off to the side just a little bit, keeping their head straight, but keeping their eyes moved a little bit to the side, or perhaps just below center may help to stabilize vision. If such is the case you may also find that it might be necessary to tilt a computer screen appropriately. Finding the appropriate position to avoid double vision is also important and may require adjustments in reading distance. With very little accommodative reserve in the system, it is possible that even with glasses that are specifically designed just for use with the computer or the music stand, they only work within a range or have a depth of field of about an inch so you might need to find exactly where that is.

"There are many strategies to optimize reading conditions for anyone with low vision ... Proper lighting is critical."

Another thing that is a simple maneuver is just planning your heavy reading for times of day that are better for you. Patients often report that vision is more stable when they are well rested in the morning or maybe perhaps it is several hours after getting up. And finally, there are many strategies out there to limit the amount of reading that is required. Lots of books are available on tape, or can be uploaded to an iPod. And even getting something like an automatic bill paying service can be helpful.

In conclusion, these orders of eye movement control underlie important symptoms of poor vision in cerebellar ataxia. Observations of these signs can help us to understand ataxia better. While some treatment is available for some of these symptoms, more research is necessary. ❖

Chapter and Support Group News from Around the Country

DE/PA Ataxia Support Group Update

By Chris Rakshys and Joe DeCrescenzo

The DE/PA Ataxia Support and Information Group had our third meeting on March 12 at the Penn State Milton S. Hershey Medical Center University in Hershey, PA. The meeting was very informative and warmly appreciated by those who were there.

Our first presentation on Elder Law and Estate Planning was very well-received. Everyone had positive comments about Ms. Jackie Kelly's subject matter, and more importantly, how she presented it to us. (She is an attorney with a local office, Jan L. Brown and Associates.) We felt we were being advised by a friend instead of someone we had just met.

Our second presentation on Genealogy in Ataxia Families was also very well-received. Bill Lee, one of our elder members, shared his personal knowledge and had members of the group, complete their own family pedigree. He gave us very helpful handouts on hereditary ataxia.

We ended the meeting with a brainstorming session about ideas for future meetings and group fundraising.

Johns Hopkins Ataxia Support Group Update

By Jill Detherage

Our January Ataxia Outreach Meeting was a great experience! I want to first thank our speaker, associate professor of neurology, Amy Bastian, PhD. She educated us on several ataxia studies and trials going on at Johns Hopkins. If you are interested in participating in any studies please contact Dr. Bastian at (443) 923-2718.

This meeting was very interesting and informative. It was great to know about the different studies that people can participate in regardless of their type of SCA and physical limitations. I had a wonderful time meeting everyone who was in attendance. To those who could not make it I look forward to meeting you in the future.

If you would like a copy of our e-mail list and/or want to be added, please let me know. Please do not hesitate to e-mail me.

NE Florida Support Group Update

By Mac Kelso

The NE Florida Ataxia Support Group had another great meeting on Feb. 12 at Baptist Hospital South. Our meeting had over 30 in attendance. We were joined by Helen Brown, director of marketing at Home Instead Health Care, and Dr. Julee Miller, acupuncturist at Health Pointe Jacksonville. Members of the Spastic Paraplegia Foundation were also in attendance to support their fellow member and our primary guest speaker, Kathi Geisler.

Our first speaker was Helen Brown. She enlightened our group about the health care services and benefits provided by her company. The in-home services ranged from companionship to skilled nursing care 24/7 without a contractual agreement. She explained that her organization is not an insurance-based company – meaning they do not take insurance payments. Helen had a flyer with the different services and hourly prices. The members – caregivers in particular – were very interested to learn that they could hire a healthcare employee at a moment's notice.

Our second speaker, Dr. Julee Miller, was ▸▸

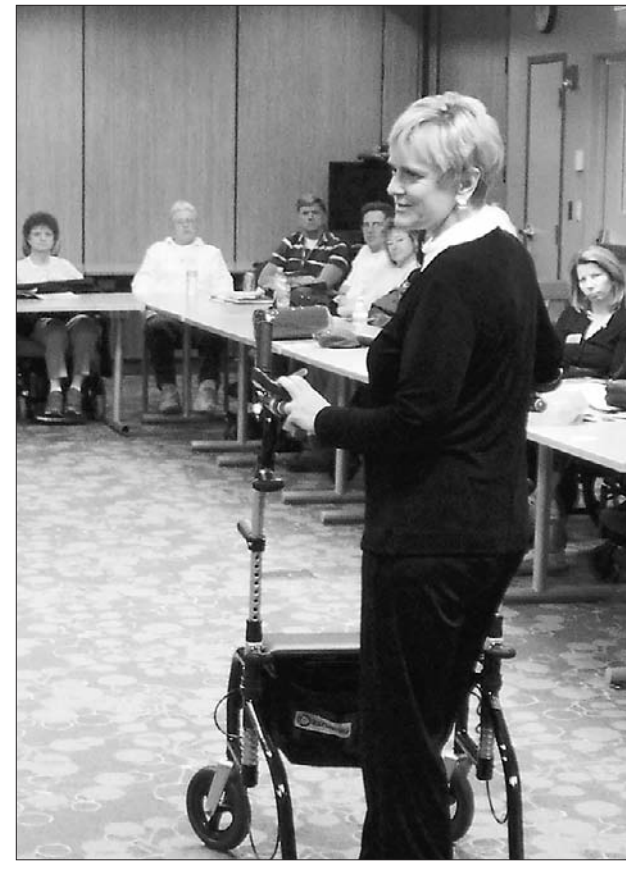
invited by our support group member Sherri Richwine. Dr. Miller is a practicing acupuncturist. She briefly discussed the physiology of acupuncture and how it could be beneficial to our members. Dr. Miller gave out her business card and took questions from the group.

Our primary guest speaker was Kathi Geisler, who gave a presentation and demonstration of the Dashaway Walker. Kathi has Spastic Paraplegia, uses the walker herself and is also a representative for the company. Regarding the Dashaway Walker, Kathi said "I love it and it got me out of the wheelchair."

Kathi said the Dashaway Walker can be used to facilitate balance, rehabilitation and exercise programs, allowing patients to safely perform routine activities while in an upright and neutral position. Additionally, it easily folds for transport, allows for quick-set height adjustment, and has a default safety brake option providing an added level of safety. The brakes stay engaged until you pull one or both hand brakes. For more information visit *www.dashaway.net*.

Kathi assisted several members to walk with the Dashaway Walker. Most were impressed with the support and balance it afforded. Kathi answered questions at the end of her presentation and several members placed orders for the item. If interested in the Dasahaway Walker, you may contact Kathi at (978) 204-7432 or *kathi.geisler@dashaway.net*.

After the meeting, all members of the NE Florida Ataxia Support Group and Spastic Paraplegia Foundation were invited to Applebee's to talk and enjoy the company of new and old friends, family and significant others. Our next meeting will be held Saturday, May 14, at 1:30 at Baptist Hospital South.



Kathi Geisler answers questions from the NE Florida Support Group about the Dashaway Walker.

Greater Denver Ataxia Support Group Update

By Charlotte DePew

Our Jan. 15 meeting was attended by 41 individuals (ataxians, family members, and caregivers). After enjoying the great food everyone brought for our potluck lunch, we had brief introductions.

Our speaker was Dr. Abigail Collins, a pediatric neurologist and movement disorder specialist from the University of Colorado Children's Hospital. Although a pediatric neurologist, she was very knowledgeable about adult ataxias due to her educational and fellowship background. She discussed the ataxia definition, pathophysiologies (functional changes associated with or resulting from disease or injury), causes, types, management, and current research. Her message in summary: currently there are no cures (now or in the very near future); drugs or treatments are often disappointing or have short-lived results; research progress increases each year toward improving lives of ataxians; and more is

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Chapter and Support Group News
Continued from page 37

learned each year about how existing drugs, diet, exercise and more can improve ataxia symptoms. After her talk, she answered many questions and was applauded for her knowledge and honest professional assessments and conclusions regarding ataxia management.

After Dr. Collins' talk, our support group co-leaders, Charlotte DePew and Kathryn Morgan, discussed highlights from the most recent issue of *Generations* and the group's first Run-Walk 'n Roll event which will be held Sept. 24. After the formal meeting, volunteers for the planned Run-Walk 'n Roll met for about 45 minutes. It was a rewarding meeting with enthusiasm that breeds success.

Kansas City Ataxia Support Group Update

By Lois Goodman

The Kansas City Ataxia Support Group met Feb. 12 for our first meeting in 2011. We are going into our 21st year meeting at the same library and time. We are only meeting every other month this year.

We had 18 in attendance, but were missing four regular attendees. We had a good round-robin discussion. The group had a small turnout for our Christmas meeting due to weather and illness, but those who did attend enjoyed a catered dinner and a fun time was had by all.

We hope to have guest speakers at some of our meetings this year – all in all we are here to give and get support from each other. ❖

Remembering DeNiece Roach

DeNiece Roach served on the National Ataxia Foundation's Board of Directors for nearly 32 years. Sadly, DeNiece lost her battle with cancer on December 24, 2010.

Her commitment and dedication to the ataxia community was an inspiration to us all. Even in her last days, DeNiece's thoughts were of NAF and the many friends she had met over the years through the annual membership meetings.

DeNiece Roach

DeNiece was first elected to the National Ataxia Foundation's Board of Directors on February 10, 1979 and became President, a volunteer position, on March 21, 1987, a position she held until late November 2010. Her commitment to NAF and the ataxia community was extraordinary and her impact will be felt for years to come.

DeNiece dedicated thousands of volunteer hours over the years to help ataxia families. Many of you met DeNiece at various NAF Annual Membership Meetings. DeNiece looked forward each year to attending the annual membership meeting to see old friends and to meet new ones. Her smile, grace, and humor will be greatly missed.

On March 19, 2011 at the National Ataxia Foundation Annual Membership Meeting Banquet, the Foundation introduced the "Strength Behind Ataxia Award." This award is a formal recognition of an individual or organization that has made a significant contribution towards NAF's mission.

The first annual "Strength Behind Ataxia Award" was awarded to the family of DeNiece Roach in honoring her tireless efforts as she dedicated nearly 32 years of service to NAF and the ataxia community.

Our deepest condolences go out to the Roach family during this difficult time.

NAF Directory of Chapters, Support Groups and Ambassadors

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

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

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

Social Networks

NAF BULLETIN BOARD
Moderator – Atilla
ww.ataxia.org/forum/toast.asp

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

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

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

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

Chapters, Support Groups and Ambassadors

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SAN DIEGO AREA SUPPORT GROUP LEADER
Earl McLaughlin

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NAF Directory
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Calendar of Events

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

Saturday, April 30, 2011

Alabama Ataxia Support Group Meeting
10 a.m. – 2 p.m. at Covenant Presbyterian Church, Homewood, AL. For more information please contact Becky Donnelly at (205) 987-2883 or *donnelly6132B@aol.com*. *www.ataxia.org/chapters/Birmingham/default.aspx*

Sunday, May 1, 2011

New England Ataxia (North Shore) Support Group Meeting
1 – 3 p.m. in the food court of the North Shore Mall in Peabody, MA. These coffee club meetings are very casual. We just meet and chat over lunch. Everyone is welcome to attend! For more information contact Donna Gorzela at (978) 475-8072. *www.ataxia.org/connect/support-groups.aspx*

Saturday, May 7, 2011

Central Texas Ataxia Support Group Meeting
Meets on the first Saturday of every other month from 11 a.m. – 1:30 p.m. at the Dell Children's Medical Center of Central TX, 4900 Mueller Blvd., Austin, TX. We will meet in Central Conference Room 4E.031 A&B (located between 4N & 4C) on the 4th floor. The medical Center's main number is (512) 324-0000. For more information, please contact Linda Crawley at (512) 635-9478 or *lcrawley57@gmail.com*. *www.ataxia.org/chapters/Linda/default.aspx*

West Central FL Ataxia Support Group Meeting
Noon – 3:00 p.m. at USF Morsani Center, 3000 Medical Park Dr. (MDC 25) Tampa, FL. Presentation by Kathy Kirchner. For more information please contact Cindy Steever-Ziegler at (239) 878-3092 or *csteever@msn.com*. *www.ataxia.org/chapters/TampaBay/default.aspx*

Wednesday, May 11, 2011

Willamette Valley Ataxia Support Group Meeting
11:30 a.m. – 1 p.m. on the second Wednesday of every month at Albany General Hospital, 1046 6th Ave. SW, Albany, OR. For more information please contact Ivy Stilwell at (541) 812-4162 or *istilwell@samhealth.org*. *www.ataxia.org/chapters/Willamette/default.aspx*

Thursday, May 12, 2011

Tri-State Ataxia Support Group Meeting
6 – 8 p.m. at Beth Israel, Phillips Ambulatory Care Center (PACC), second floor conference room #3, 10 Union Square, New York, NY. For more information contact Denise Mitchell at (212) 844-8711 or *markmeghan@aol.com*. *www.ataxia.org/chapters/Tri-State/default.aspx*

Saturday, May 14, 2011

Los Angeles Area Ataxia Support Group Meeting
2 – 4 p.m. on the second Saturday of every other month. For meeting location and general information, contact Sherry McLaughlin at (626) 791-1558 or *ccherilynmc@yahoo.com*. *www.ataxia.org/chapters/LosAngeles/default.aspx*

North Texas Ataxia Support Group Meeting
The group meets the second Saturday of every month from 10 a.m. – 12 p.m. at the Las Colinas Cancer Center Located at 7415 Las Colinas Blvd., Irving, Texas. Parking is free and the building is handicap accessible. We meet in the front lobby. There is a map on their website: *www.LasColinasCancerCenter.com*. Most of the meeting time is for sharing and asking questions about the difficulties and successes we have in our everyday life with ataxia. From time to time we do have an outside speaker address some of our concerns from the caregivers, patients and families. For additional information please contact David Henry Jr. at *cheve11e@sbcglobal.net*. Please check the group's webpage for updates. *www.ataxia.org/chapters/NorthTexas/default.aspx*

Northeast Florida Ataxia Support Group Meeting
1:30 p.m. at Baptist Hospital South. Directions to Baptist South: From I-95, take exit 335 which is Old St. Augustine Rd. Go East. Follow the signs to the hospital. We are less than a 1/2 mile off the interstate. Directions to the conference rooms from the main entrance: Come in the main entrance and make a right. Go past the first hallway on the left and the Azalea, Begonia and Camellia conference rooms will be the next doors. All meetings will be in the Azalea and Begonia rooms. For more information please contact Ann Mayo at *annwaynemayo@bellsouth.net* or (904) 471-4579. *www.ataxia.org/chapters/NortheastFlorida/default.aspx*

Southeast PA Ataxia Support Group Meeting
10 – 11:30 a.m. on the second Saturday at Mercy Suburban Hospital Walkup Room on the second ⏭

floor, followed by lunch at Applebee's across the street. Attendees MUST RSVP to Liz Nussear by Friday before the meeting at (610) 272-1502 or *Lizout@aol.com*. *www.ataxia.org/chapters/SEPennsylvania/default.aspx*

Sunday, May 15, 2011

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 Richard Carr at (847) 253-2920 or *caasg@aol.com*. *www.ataxia.org/chapters/Chicago/default.aspx*

Saturday, May 21, 2011

Greater Atlanta Ataxia Support Group Annual Meeting
1 p.m. at Emory Center for Rehabilitation Medicine, 1441 Clifton Rd., Rm 101, Atlanta, GA. For more information contact Dave Zilles at (770) 399-6710 or *dzilles@earthlink.net*. *www.ataxia.org/chapters/Atlanta/default.aspx*

Nashville Area Support Group Meeting
2 p.m. at Amerigo's Restaurant – Coolsprings, 1656 Westgate Circle, Brentwood, TN. For more information contact Vicki Tyler at (615) 646-3024 or *tylerv2@comcast.net*. *www.ataxia.org/chapters/VickiTyler/default.aspx*

Twin Cities Ataxia Support Group Meeting
10 a.m. every third Saturday of the month at the Presbyterian Homes of Roseville at 1910 West County Rd. D, Roseville, MN. For more information please contact Lenore Healey Schultz at *schultz.lenore@yahoo.com*. *www.ataxia.org/chapters/TwinCities/default.aspx*

Sunday, June 5, 2011

Ortho Foundation Half Marathon – Run for Team Lunzer
With Greg Lunzer as their inspiration, David and Mary Lunzer will run in the Team Ortho Foundation half marathon in Minneapolis, MN. Their goal is to raise awareness and at least $5,000 in pledges to support research for a treatment of not only SCA 2, but all ataxias. Learn more at *https://naf.myetap.org/fundraiser/TeamLunzer/*

Wednesday, June 8, 2011

Willamette Valley Ataxia Support Group Meeting
11:30 a.m. – 1 p.m. on the second Wednesday of every month at Albany General Hospital, 1046 6th Ave. SW, Albany, OR. For more information please contact Ivy Stilwell at (541) 812-4162 or *istilwell@samhealth.org*. *www.ataxia.org/chapters/Willamette/default.aspx*

Saturday, June 11, 2011

Kansas City Area Ataxia Support Group Meeting
2 – 4 p.m. the second Saturday every other month at the Northeast Library, 6000 Wilson Rd., Kansas City, MO. For more information contact Lois Goodman at (816) 257-2428 or Jim Clark at (816) 468-7260 or *clarkstone9348@sbcglobal.net*. *www.ataxia.org/chapters/KansasCity/default.aspx*

North Texas Ataxia Support Group Meeting
The group meets the second Saturday of every month from 10 a.m. – 12 p.m. at the Las Colinas Cancer Center Located at 7415 Las Colinas Blvd., Irving, Texas. Parking is free and the building is handicap accessible. We meet in the front lobby. There is a map on their website: *www.LasColinasCancerCenter.com*. Most of the meeting time is for sharing and asking questions about the difficulties and successes we have in our everyday life with ataxia. From time to time we do have an outside speaker address some of our concerns from the caregivers, patients and families. For additional information please contact David Henry Jr. at *cheve11e@sbcglobal.net*. Please check the group's webpage for updates. *www.ataxia.org/chapters/NorthTexas/default.aspx*

Sunday, June 12, 2011

New England Ataxia (North Shore) Support Group Meeting
1 – 3 p.m. in the food court of the North Shore Mall in Peabody, MA. These coffee club meetings are very casual. We just meet and chat over lunch. Everyone is welcome to attend! For more information contact Donna Gorzela at (978) 475-8072. *www.ataxia.org/connect/support-groups.aspx*

Saturday, June 18, 2011

Orange County Ataxia Support Group Meeting
Meets on the third Saturday of every other month from 1:30 – 4 p.m. at the Orange Coast Memorial Medical Center (Breast Center Blg., Room 1A), 9900 Talbert Ave., Fountain Valley, CA. For more information contact Daniel Navar at *dnavar@ucla.edu*. *www.ataxia.org/chapters/Orange County/default.aspx*

Twin Cities Ataxia Support Group Meeting
10 a.m. every third Saturday of the month at the Presbyterian Homes of Roseville at 1910 West County Rd. D, Roseville, MN. For more information please contact Lenore Healey Schultz at *schultz.lenore@yahoo.com*. *www.ataxia.org/chapters/TwinCities/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 2010 through February 2011. 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.

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