

# Generations

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*The Official Publication of the National Ataxia Foundation*

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*Fall 2012*

## The National Ataxia Foundation's Annual Ataxia Research Drive Begins October 15

Michael J. Fox once said, "Medical science has proven time and again that when the resources are provided, great progress in the treatment, cure, and prevention of disease can occur." The National Ataxia Foundation's Annual Ataxia Research Drive begins on October 15 and we need your help to further our efforts in ending ataxia.

The research funds raised during this drive will significantly help in supporting promising ataxia research for fiscal year 2013. In this issue of *Generations* you will see research summaries of studies that were funded for fiscal year 2011. Many of these important studies would not have been funded without the help of our generous donors who supported the annual ataxia research

drive. Your support is crucial in continuing NAF's efforts in supporting promising world-wide ataxia research.

With this year's annual ataxia research drive the National Ataxia Foundation is pleased to announce that the Gordon and Marilyn Macklin Foundation is again offering a matching research challenge. As with last year's matching gift, the match challenge will run from October 15 through December 15. This year, however, the "2012 Macklin Foundation Research Matching Grant Challenge" has raised the dollars matched and will match each research dollar received from October 15 through December 15, after the first \$50,000 is raised during that time period, up to a maximum of \$150,000.

Last year, you and others responded generously to meet the challenge of the Macklin Foundation Matching Grant which in turn enabled NAF to support additional promising ataxia research studies, important studies which would not have been funded without the generous support of you and the Gordon and Marilyn Macklin Foundation. This year the Macklin Foundation has increased its matching grant from \$100,000 to \$150,000.

The National Ataxia Foundation is currently reviewing more than 50 quality ataxia research studies from around the world. With your help,

### Inside This Issue

- **Research summaries** are included on pages 5-13
- The **2013 AMM in Detroit** is previewed beginning on page 14
- Wondering if you should **get a flu shot?** Read what the experts say on page 18.
- Learn about **eye health and safety** in Caregiver's Corner on pages 31-32
- Plan ahead using the **Calendar of Events** that begins on page 43

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***The deadline for the Winter issue of Generations is November 2.***

*NAF Annual Ataxia Research Drive*  
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the most promising of the ataxia studies will be funded in late December 2012 for fiscal year 2013.

The “2012 Macklin Foundation Research Matching Grant Challenge” will begin on October 15 and we encourage you to help support this exciting opportunity to have your research donation matched dollar for dollar beginning October 15. With this opportunity to have your research donation matched, there has never been a better time to consider doubling

your last year’s research gift.

Please watch for your annual ataxia research drive letter in the mail in October 2012 or support the ataxia research drive on-line at [www.ataxia.org](http://www.ataxia.org) from October 15 through December 15 to have your gift doubled.

The National Ataxia Foundation is truly grateful to the Gordon and Marilyn Macklin Foundation for their continued and most generous support of the NAF’s important research efforts as we are truly thankful to you for your continued generosity. Together, we are moving forward to end ataxia. Thank you. ❖

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# Charitable Giving: A Primer

*By David A. Schwandt, JD, CFP*

Someone once said, “Money is a means for making our time and energy portable.” Some are called to become integrally involved in the work of various charitable organizations while others choose to give cash or other property to charities whose work they value and appreciate. Many do both. There’s no right or better way to support a charitable organization. Whether one gives his or her time, energy, or money, the charity and its constituents benefit.

Having served as a financial adviser and wealth manager to clients for nearly 30 years, some of whom are wonderfully generous donors, I can safely say the charitable tax deduction alone is not sufficient to motivate consistent, meaningful giving. Clients need to have a genuine desire to help others and a willingness to part with assets they’ve accumulated in order to do so. In some cases, clients may feel more inclined to give generously when they’re reasonably confident they can remain financially healthy even after making a sizeable gift. A good financial adviser can help the client reach this level of confidence by providing meaningful analysis and projections that are periodically adjusted to reflect changing

conditions and needs.

Generous, charitably-inclined people who wish to make a gift of money or property to a charity need to consider carefully how best to do so. The goal, of course, is to enhance the work of the organization by donating useful, needed resources. But, the treatment of a gift for federal tax purposes will vary depending upon the type of asset donated, the type of organization receiving the gift, and the donor’s tax status.

Different types of assets are subject to different restrictions on deductibility. The Internal Revenue Code (IRC) generally classifies property as follows:

- 1) Ordinary income property
- 2) Short-term capital gain property
- 3) Long-term capital gain property
- 4) Tax-free property

Property is also classified as intangible property or tangible personal property.

Limitations on the deductibility of a charitable gift are also imposed depending upon the type of organization receiving the gift. Donations to

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## *Charitable Giving: A Primer*

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public charities are less restricted than are donations to private foundations.

Donors must take into account the above classifications to determine the value of their gift for charitable deduction purposes:

- Gifts of cash (e.g., check): The value is equal to the amount of the gift
- Gifts of tangible personal property: If the property can be used to advance the charity's tax-exempt purpose, the donor can claim a deduction based upon the asset's fair market value (FMV)
- Gifts of tangible personal property that are not usable for the charity's tax-exempt purpose provide a deduction based on the original cost (minus depreciation) or the FMV of the donated asset, whichever is less
- Any single contribution exceeding \$5,000 (except a contribution of cash or publicly-traded stock) requires a qualified appraisal within 60 days of the date of the gift, and the appraisal must be submitted when the donor files his or her tax return

Finally, a donor's ability to claim a charitable deduction may be limited by his or her adjusted gross income (AGI). Gifts of cash to a public charity may not exceed 50% of AGI in any one

year. A deduction of cash to a private foundation may not exceed 30% of AGI. For gifts of long and short-term appreciated property the deduction is limited to 30% of AGI (gifts to public charity) or 20% (gifts to private foundations). The deductibility in any single year of gifts of cash together with gifts of appreciated property is limited to 50% of AGI overall. Unused deductions may be carried forward for up to five more years. High income earners also need to be aware of restrictions on itemized deductions which are phased out above certain levels of AGI.

Of course, anyone considering making a significant charitable contribution should seek the counsel of a qualified tax professional before moving ahead.

There seems to be no lack of excellent charitable organizations doing marvelous work and using donor contributions wisely and with integrity. But, there always seems to be a lack of sufficient funds to allow these organizations to realize their full potential and to reach all those they could serve with the support and expertise they have to offer. Indeed, the recipients of these vital services benefit immeasurably; but, my personal experience and my work with charitably-minded clients confirm a time-honored adage: It is more blessed to give than to receive. May readers of this article experience the blessings that flow from generous, cheerful giving. ❖

## **Thank You NAF Members!**

Thank you to all who generously responded to this year's NAF Annual Membership Drive: new, renewing, and pledge members as well as those who became NAF Lifetime Members. Thank you all!

If you have not yet become a member, please join today on-line at [www.ataxia.org](http://www.ataxia.org) or use the membership form on the back page of this issue. Thank you!

## **Ask About Matching Gifts**

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

Please ask your employer if they have a matching gifts program. If they do, your gift and the gifts of your co-workers will double in value. Thank you for your support.

## Research Grant Award

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

*Giorgio Casari, PhD, San Raffaele University, Milan, Italy submitted this summary of his NAF funded research award for fiscal year 2011.*

Spinocerebellar ataxia type 28 (SCA28) is a novel form of juvenile-onset, slowly progressive cerebellar ataxia inherited as a dominant trait. Together with the characteristic unbalanced standing and gait incoordination, ocular symptoms are present. Several disease causing mutations have been identified in the AFG3L2 gene. The encoded protein, AFG3L2, resides in the mitochondrion and is crucial for energy production and cellular function.

We developed and characterized a mouse model of SCA28 that recapitulates very well the features of patients. In fact, it shows progressive ataxia due to degeneration and loss of Purkinje cells (PCs), the typical pathological hallmark of SCAs. We found that SCA28 PCs degenerate by cell shrinkage, cytoplasm darkening and atrophy (dark degeneration). Peculiarly, in the SCA28 mouse this type of degeneration originates for the first time from mitochondrial dysfunction.

During this year, we demonstrate that SCA28 PCs are more susceptible to degeneration when stimulated by the neurotransmitter glutamate and this is owing to the mitochondrial inability to handle high calcium concentration within the cell. In fact, we reported results on murine embryonic fibroblasts (MEFs), indicating that AFG3L2 depletion result in reduced mitochondrial  $Ca^{2+}$  buffering capacity.

In addition, we designed a rescue strategy on the mouse model for SCA28. We addressed this aim by a binary approach that is by genetic crossing and by pharmacological approach. We

crossed SCA28 mice with another mouse that displays cerebellar signs due to reduced glutamate stimulation, the opposite of what encountered in our SCA28 mouse. The evaluation of the motor capabilities of the double mutant mouse shows an almost complete rescue of motor function. In addition, we designed a rescue strategy on the mouse model for SCA28. We addressed this aim by genetic crossing and by pharmacological approach with preliminary promising results.

These data open new perspectives for the non-symptomatic treatment of this disease and of other SCA characterized by dark degeneration of PCs. ❖



**Dr. Giorgio Casari**

## Deadline

The deadline for submitting materials for the upcoming Winter issue of *Generations* is November 2.

Please send stories, events and reports by e-mail to [naf@ataxia.org](mailto:naf@ataxia.org) or by mail to the NAF office address listed on page 2.

## Research Grant Award

# Generation of an improved humanized mouse model of Friedreich ataxia containing a long GAA trinucleotide repeat expansion

*The following is a research summary by Dr. Joseph Sarsero, PhD, Murdoch Children's Research Institute, Australia. In responding to why he chose to become a researcher, Dr. Sarsero said, "First learning about the genetic code in high school was fascinating and made me realise that there was an underlying order to the natural world. Wanting to know what made things tick at the molecular level led to a career in science. In pursuing medical research I hope that I can do work that benefits those in need." When he is not working, he is dedicated to spending time with his wife caring for their two young daughters.*

Friedreich ataxia is an inherited disorder of the nervous system and heart. Symptoms include difficulty with balance, impaired coordination of the legs or arms (ataxia), slurred speech and diabetes. Enlargement of the heart, irregular heartbeat and other symptoms of heart disease occur in many individuals with Friedreich ataxia. The genetic defect (mutation) that causes



**Dr. Joseph Sarsero**

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 models of disease are designed to contain an entire human gene of

Friedreich ataxia is a "stutter" in the genetic code of the Friedreich ataxia gene (FXN) termed a 'GAA trinucleotide repeat expansion.' The alteration results in reduced levels of an essential protein termed frataxin in all cells of the body.

interest and harbor the specific disease-causing mutation as found in patients. Such mice should not only manifest the main symptoms of a disorder, but also provide the correct underlying molecular cause of the disease.

We have utilized our expertise in handling the full length gene responsible for Friedreich ataxia, and our current preliminary mouse models of Friedreich ataxia, in an effort to generate an improved humanized Friedreich ataxia mouse model that more accurately reflects disease symptoms and the underlying molecular cause of the disorder.

We previously generated a transgenic mouse model that contains the entire human FXN gene. Mice that were lacking the mouse version of the gene were able to survive using the human gene and frataxin protein. We developed two independent strategies using these mice to insert a long GAA expansion mutation into the human version of the gene. In the first method, a piece of DNA containing a long GAA expansion is introduced into the correct location in the human FXN gene in embryonic stem cells derived from the mouse line. The modified cells can then be used to produce a new mouse line. In the second method, DNA containing a GAA expansion is injected into fertilized mouse eggs using a very fine needle. The DNA inserts into the appropriate location and the eggs are used to produce a new mouse line. ►►

An accurate humanized mouse model of Friedreich ataxia will be an important resource for the study of the pathophysiology of Friedreich ataxia and for the evaluation of novel

therapeutic interventions.

We would like to thank the National Ataxia Foundation for the continued generous support of our research program. ❖

## Research Grant Award

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

*The following is a research summary by Roberto Testi, MD, University of Rome "Tor Vergata," Rome, Italy. When asked why he chose to become a researcher, Dr. Testi stated, "I went into research since I realized that research was the most interesting, challenging, fun and perhaps useful thing to do with my MD degree." In his spare time he enjoys playing his guitar.*

Friedreich ataxia (FRDA) is caused by defective levels of the protein frataxin. In principle, any therapeutic approach should aim at elevating frataxin levels in patients. Like most proteins, frataxin is constantly produced and degraded. Slowing down the physiologic degradation of frataxin might represent a strategy for increasing frataxin levels in FRDA patients.

We are developing potentially therapeutic molecules that act by preventing the degradation of frataxin. These molecules are in fact effective

in elevating cellular frataxin in isolated living cells derived from FRDA patients. Before assessing the efficacy of these novel compounds directly in FRDA patients, we need to test them in an animal model of the disease. This step is necessary for selecting only those molecules that appear better tolerated by a complex organism and that appear more effective in elevating frataxin levels and ameliorate symptoms.

We have now completed the toxicity evaluation in normal mice, injected with the compounds under study, and concluded that the compounds tested are not toxic. We are also establishing a colony of mice that mimic the pathology and clinical features of FRDA that will be utilized to test several compounds, for their ability to increase cellular frataxin and have an impact on functional aspects of the disease. ❖



**Dr. Roberto Testi**

## Film Festival

The American Brain Foundation, of the American Academy of Neurology, is accepting video entries to its 2013 Neuro Film Festival, a contest to raise awareness about why more money is needed for research to find cures for brain diseases. Winners could receive up to \$1,000 and a trip to San Diego to see their film shown at the Neuro Film Festival event. The deadline to enter is January 31, 2013, at [www.NeuroFilmFestival.com](http://www.NeuroFilmFestival.com).

## Research Grant Award

# Nuclear events affected by ataxin-1

*The following summary of research funded by NAF for fiscal year 2011 was submitted by Chih-Cheng Tsai, PhD at UMDNJ-Robert Wood Johnson Medical School in Piscataway, NJ. He had this to say about why he became a researcher, "I decided to become a life science researcher after I took a genetics course in college. Genetics, developmental biology, and neuroscience are the research topics that interest me the most. I am still doing a lot of fly experiments in my lab. Knowing that my work will make changes to people's lives is a driving force behind my research. Dr. Tsai enjoys gardening, hiking, and walking with his family and two dogs.*

Notch is an important factor known to govern the development and functioning of the nervous system in species ranging from humans to flies.



**Dr. Chih-Cheng Tsai**

we discovered that ATXN1 acts as a negative regulator of the Notch signaling pathway (EMBO R, 2011). For the past two years, my lab has been using the wealth of information known

Faulty Notch signaling has been implicated in several human diseases, including birth defects, cancers, and neurological disorders. During our recent research on ataxin-1 (ATXN1), whose glutamine-repeat expanded form causes SCA1,

about the Notch pathway to study the relationship between this important signaling pathway and ATXN1 in both mammalian cells and *Drosophila*. Our recent studies performed in mammalian cells revealed that ATXN1 interacts with multiple components in the Notch pathway. Therefore, the negative influence of ATXN1 on the Notch pathway is achieved at multiple levels. Consistently, our studies performed in *Drosophila* also reveal that mutant forms of ATXN1 profoundly compromise the activity of Notch during the development the nervous system. Based on these recent findings, we propose that Notch signaling is impaired by mutant ATXN1 in SCA1 individuals. We hope that our current and future studies of the relationship between ATXN1 and Notch pathway will yield important information for finding more effective therapeutic approaches or compounds for treating SCA1. ❖

## CFC Number

The National Ataxia Foundation's Combined Federal Campaign (CFC) number is 10752. This program, the world's largest and most successful annual workplace charity campaign, provides a convenient way to donate to the Foundation, and provides great benefit to those with ataxia.

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

## IAAD Coverage

The 13th Annual International Ataxia Awareness Day was held on September 25. Send us your articles, photos, and proclamations so the entire NAF community can relive this historic day in a future issue of *Generations*.

Please email information to [naf@ataxia.org](mailto:naf@ataxia.org), or mail to NAF, Attn: *Generations* Editor, 2600 Fernbrook Lane, Suite 119, Minneapolis, MN 55447-4752. Thank you.

Research Fellowship Award

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

*The following research summary was submitted by Maria do Carmo Costa, PhD of the Department of Neurology, University of Michigan, Ann Arbor, MI for her Post-Doctorate Fellowship award which was funded for fiscal year 2011. Dr. Costa was fascinated by science as a kid. She made the definitive decision to become a researcher in 10th grade in her first class of biochemistry. Dr. Costa said, "I wanted to be a biochemist and understand how biomolecules work and interact in different ways in the cells determining their function and fate, and then how cells interact with each other in order to form systems with higher complexity responsible for the generation of a life being." When she is not in the lab, her favorite thing to do is spend time with friends and family. She also likes to travel, listen to music, run, explore the outdoors, read, paint, and make jewelry.*

Spinocerebellar ataxia type 3 (SCA3) or Machado-Joseph disease (MJD) may be the most common form of dominantly inherited ataxia and is one of at least six ataxias caused by repeat expansions that encode abnormally long stretches of the amino acid glutamine in the disease proteins. No disease-preventing treatment is yet available for any of the "polyglutamine" ataxias. The shared features of polyglutamine ataxias suggest that common biological pathways might be targeted in an effort to develop class-wide therapeutics, but the mechanisms by which the various disease proteins impair brain cells remain uncertain. Targeting the toxic disease proteins themselves, however, represents a potential therapeutic strategy that does not require a detailed understanding of such mechanisms.

Accordingly, we sought to identify small molecules that reduce levels of the SCA3 disease protein, ataxin-3. We screened 2,880 FDA-approved drugs and natural compounds to identify molecules that reduce levels of ataxin-3, and are testing the efficacy of 10 promising, identified molecules in brain slice cultures derived from a transgenic SCA3 mouse model. We have already confirmed that one identified compound reduces levels of mutant ataxin-3

in cerebellum and brainstem slices. Upon completion of this secondary screen, the best molecule will be tested in vivo in the same SCA3 mouse model. If the promising molecule reduces levels of mutant ataxin-3 in SCA3 mice and/or improves motor impairment, it will present a good candidate for clinical trials in patients with SCA3, and potentially in patients with other polyQ diseases. ❖



**Dr. Maria do Carmo Costa**

## ShopNAF

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

Research Fellowship Award

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

*This research summary is by Sara Lagalwar, PhD, University of Minnesota, Minneapolis, MN who received a Fellowship Award from NAF for fiscal year 2011. She chose to follow a research path versus a clinical path while working as a research assistant in an Alzheimer's lab after graduating from college. Dr. Lagalwar said, "Seeing the gross neuronal loss and shrinkage of the autopsy tissue made me want to learn more about what was going on at a molecular level." In her spare time she tries to spend as much time as she can sailing.*

Spinocerebellar ataxia type 1 (SCA1) is a lethal, progressive neurodegenerative disease which currently has no effective treatment. Previously, we identified an amino acid residue (termed serine 776) found in both normal and mutant ataxin-1 which undergoes a chemical modification termed phosphorylation. Research suggests that



**Dr. Sara Lagalwar**

phosphorylation of serine 776 may be more crucial to initial SCA1 disease progression than the polyglutamine mutation. Therefore, molecules that inhibit phosphorylation at serine 776 may have therapeutic potential for SCA1.

To begin the search for potential SCA1 therapeutics, we began by undertaking a large-scale screen of +200,000 small molecule inhibitor compounds gathered from several commercially available sources. After initial testing and validation, 37 molecules from the large-scale screen have been identified as positive hits for inhibition of ataxin-1 S776 phosphorylation. Furthermore, our team of researchers have gathered and developed several other series of chemical inhibitors that may be of interest for further testing.

We will eventually screen potential inhibitors in mice, but before doing so we would like to filter the list of compounds by examining their efficacy and viability in a series of progressively more complex model systems, as described in the proposal. We now report that we have successfully developed three biological screening systems. The first system will test the inhibitors against human ataxin-1 protein in the context of the cerebellar environment by utilizing mouse cerebellar extract. This system allows us to test several inhibitors at one time, and to test inhibitors against both normal and mutant ataxin-1 protein. We will use this screen to select a subset of inhibitors for further testing.

Our second screen tests the inhibitors against human cells expressing ataxin-1 protein. This screen allows us to verify if the inhibitors will be able to penetrate cell membranes. Our final screen tests the inhibitors against cerebellar slices from mice. This screen will allow us to examine tissue toxicity due to the inhibitor.

All three systems have been developed and calibrated using commercially available inhibitors. We are now beginning to screen inhibitors generated from the large-scale screen and inhibitor development work. We would ultimately like to test three to four inhibitors in mice and are hopeful that our biological screening systems will help us discern inhibitors that are safe and efficacious. ❖

Young Investigator Research Grant Award

## Magnetic resonance imaging and spectroscopy in ataxia with oculomotor apraxia type 2: searching for non-invasive biomarkers

*The following research summary is by Isabelle Iltis, PhD, University of Minnesota, Minneapolis, MN for a Young Investigator Award that was funded by NAF for fiscal year 2011. When asked why she chose research, Dr. Iltis said, "I 'tried' research. I had an opportunity to go to grad school, I took it thinking it wasn't for me but that I had nothing to lose. And I fell in love with the teamwork, the fact that the progress depends on people with very different backgrounds and knowledge coming together to make something work. Plus the intellectual challenge of understanding complex biological questions, and the minute of joy when one of these questions finds a hint of an answer." When she is not doing MRIs or in the lab, she enjoys spending an evening with friends around a bonfire, practicing yoga, petting her old cat and learning how to grow her garden.*

My research focuses on recessive ataxias, in particular Ataxia with Oculomotor Apraxia type 2 (AOA2) and Friedreich's Ataxia. Knowledge of the genes involved in both diseases and the molecular mechanisms causing them is growing, but objective, non-invasive measures of disease progression are still lacking. Such measures, which would ideally reflect directly the biological processes underlying the disease, are called biomarkers.

Recently, the National Ataxia Foundation gave us the opportunity and necessary funding to investigate non-invasive biomarkers in the brain of patients with AOA2. Our goal with this project was to identify biomarkers that will ultimately allow the monitoring not only of disease progression, but also of the efficacy of future therapies. We use Proton Magnetic Resonance Spectroscopy (1H MRS), a technique derived from MRI, that allows non-invasive measurements of concentrations of chemicals in the brain. Measuring these chemicals provide insights into the composition and function of brain cells. This past year, we scanned 20 volunteers at a 3T magnet (an MRI system increasingly available in

hospitals and clinical centers in the USA and in Europe). Ten were patients with AOA2, and 10 were control volunteers. By comparing the levels of the brain chemicals between both groups of participants, we could identify that some of them (involved in the function and viability of the neurons) were affected in the cerebellum. In addition, five patients and five controls agreed to undergo a second MRI exam at 7T, a higher field dedicated to research that allows measuring more neurochemicals in the brain, with a higher sensitivity. The data resulting from the sessions at 7T are still being processed, but we hope to find additional potential biomarkers.

Finally, this pilot study conducted with the



**Dr. Isabelle Iltis**

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*Magnetic Resonance Imaging...*  
Continued from page 11

participation of relatively few volunteers will allow us to hopefully obtain more funding to conduct longitudinal studies (i.e. a study in which

volunteers would be scanned every one to two year over a period of five to 10 years) with more participants. Such a study would allow the identification of biomarkers that would provide a tool for monitoring the efficacy of future therapies. ❖

## Young Investigator Research Grant Award

# Determination of secondary structure of ataxia-3 by X-ray crystallography



**Dr. Meewhi Kim**

*The following is a research summary by Meewhi Kim, PhD, University of Texas Southwestern Medical Center, Dallas, TX of the Young Investigator award that was funded by NAF for fiscal year 2011. Dr. Kim says that she chose to become a researcher because, "Research is one good way to understand and solve problems around us and I love to do it." When she is not in the lab, she enjoys being mom to her son.*

The main aim of the proposed research to determine crystal structure of carboxy-terminal region of ataxin-3 protein containing polyglutamine expansion regions of different length. We were able to solve crystal structure of ATX3 containing 13Q region. Obtained results will help to understand structural behavior of the polyQ region and to investigate possible mechanism of mutant ataxin-3 toxicity. This information can also be useful for developing novel therapeutic agents targeting the polyQ region of ATX3 for SCA3 treatment. ❖

## NAF's Travel Grant Program Needs Your Support

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

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

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

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

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

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

## Young Investigator Research Grant Award

# Assessment of Riluzole treatment as a therapy for SCA3

*The following is a research summary of research funded by NAF for fiscal year 2011 from Jana Schmidt, PhD, University of Tuebingen, Tuebingen, Germany. When Dr. Schmidt is not doing research, she sings in a choir, does some ball room dancing and enjoys doing handicrafts and reading.*

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 wheel-chair bound in later disease stages. Up to now, no curative therapy is available for this disease.

In a study carried out by a group of neurologist at the University Hospital of Rome (Italy) patients with different types of ataxias were treated with Rilutek and compared with untreated patients. Rilutek is a drug already approved and successfully used in the treatment of patients suffering from 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, but no SCA3 patients, and the treatment was only carried out for two months.

The goal of this study therefore was to analyse whether Rilutek may also be suitable for patients suffering from SCA3 and may be beneficial in a long term treatment.

In order to answer these questions we used 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. Once mice showed symptoms of the SCA3 disease we

treated them with Rilutek and performed repeated behavioural tests over a period of approximately six months. In comparison to control mice, treated symptomatic mice showed poor performances in the applied tests and the treatment was not able to improve it even not after six months of treatment. Our results therefore indicate that treatment with Rilutek has no beneficial effect in the SCA3 mouse model we used. Although additional analyses will be required we could not confirm that Rilutek is suitable as a drug against SCA3. ❖



**Dr. Jana Schmidt**

## Share Your Story

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

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

## The National Ataxia Foundation 56th Annual Membership Meeting

### *“Driving Together Towards a Cure”*

**Detroit, MI – March 15-17, 2013**

The National Ataxia Foundation Board of Directors and the NAF Northeast United States Ataxia Support Groups invite you to “save the date” to attend the 56th Annual Membership Meeting at the Detroit Marriott at the Renaissance Center Hotel. A detailed schedule, registration forms and information will be available in the Winter 2012-13 issue of *Generations* which will be mailed in mid-December and on NAF’s website in January 2013.

When registration opens, you are encouraged to register before February 15, 2013 to receive the early registration rate. In addition, members of the National Ataxia Foundation pay a lower registration fee to attend the annual meeting. If you are not currently a member of the Foundation, if your membership renewal is coming soon or if you are uncertain of your membership status, use this opportunity to go online at [www.ataxia.org](http://www.ataxia.org) or call the NAF office at (763) 553-0020 to become a member or renew your membership. Take time now to confirm your membership status and save money when you register for the 2013 Annual Membership Meeting.

The meeting registration fee includes attendance at all the sessions, light appetizers at the Welcome Reception and a delicious plated meal at the Banquet.

Because of the generosity of several donors, the National Ataxia Foundation is able to offer Travel Grants to help with a portion of the travel costs associated with attending the meeting. Adults or children with ataxia are eligible to

apply for a travel grant. Visit the NAF website [www.ataxia.org](http://www.ataxia.org) to download the application or contact Lori Shogren at (763) 553-0020 to request one by mail. The deadline to submit an application is January 26, 2013.

The complete meeting schedule and events will be listed in the Winter 2012-13 issue of *Generations*, however, a brief program overview is provided below:

#### **Thursday, March 14**

- Registration Room: 9 a.m. – 8 p.m.
- Silent Auction Drop-off: 9 a.m. – 8 p.m.
- Leadership Meeting: 1 – 3 p.m.
- Fundraising Meeting: 4 – 5 p.m.

#### **Friday, March 15**

- Registration Room: 8 a.m. – 5:30 p.m.
- Silent Auction Drop-off: 8 a.m. – 4 p.m.
- General Sessions: 8:30 a.m. – noon
- Birds of a Feather: 2 – 5 p.m.
- Welcome Reception: 7 p.m.

#### **Saturday, March 16**

- Registration Room: 8 a.m. – 5 p.m.
- Silent Auction Bidding: 8 a.m. – 1:30 p.m.
- General Sessions : 8:30 a.m. – 12:15 p.m.
- NAF Business Meeting: 1:45 p.m. – 2 p.m.
- General Sessions : 2 – 5:30 p.m.
- Silent Auction Pick-up: 4 – 7 p.m.
- Banquet: 7 p.m.

#### **Sunday, March 17**

- Registration Room: 8 – 11 a.m.
- General Sessions: 9 a.m. – 1 p.m.
- Meeting adjourns – See you next year! ▶▶

## About Detroit

Detroit is the largest city in the state of Michigan and the seat of Wayne County. It is the major city among the primary cultural, financial, and transportation centers in the Metro Detroit area, a region of 5.2 million people, and serves as a major port on the Detroit River connecting the Great Lakes system to the Saint Lawrence Seaway. Known as the world's traditional automotive center, "Detroit" is a metonym for the American automobile industry and an important source of popular music legacies celebrated by the city's two familiar nicknames, the Motor City and Motown.

Downtown Detroit has seen an increased role as an entertainment hub with the opening of three casino resort hotels, new stadiums, the city's Greektown and a revitalized riverfront. Many prominent museums are located in the historic cultural center neighborhood around Wayne State University and the College for Creative Studies. These museums include the Detroit Institute of Arts, the Detroit Historical Museum, Charles H. Wright Museum of African American History, the Detroit Science Center, as well as the main branch of the Detroit Public Library.

Other cultural highlights include Motown Historical Museum, the Pewabic Pottery studio and school, the Tuskegee Airmen Museum, Fort Wayne, the Dossin Great Lakes Museum, the Museum of Contemporary Art Detroit, the Contemporary Art Institute of Detroit, and the Belle Isle Conservatory. The Detroit Historical Society provides information about tours of area churches, skyscrapers, and mansions.

For more information about Detroit visit the Detroit Convention and Visitors website at [www.visitdetroit.com](http://www.visitdetroit.com).

## About the Detroit Marriott

The Detroit Marriot Hotel is the official conference hotel of the 2013 NAF Annual Membership Meeting. Located 21 miles from the Detroit-Wayne County Airport (DTW)

on the Detroit Riverwalk at the Renaissance Center, the Detroit Marriott boasts stunning views of the Detroit River and Canada.

Guest room reservations are available for a special group rate of \$139 per night plus tax. Make your reservations early in order to secure the special group rate. To book your stay online go to [https://resweb.passkey.com/Resweb.do?mode=welcome\\_ei\\_new&eventID=9525602](https://resweb.passkey.com/Resweb.do?mode=welcome_ei_new&eventID=9525602) or call 1-877-901-6632 or (313) 568-8300 and request the National Ataxia Foundation group rate. The width of the bathroom door in the standard guestrooms is 26 inches. Please reserve an ADA room if you require a wider bathroom door.



**Detroit will host the 2013 National Ataxia Foundation Annual Membership Meeting.**

ADA rooms are available on a first-come, first-serve basis. Information about the availability of an ADA room at the Detroit Marriott Hotel can be learned only by contacting the National Ataxia Foundation at (763) 553-0020 or [naf@ataxia.org](mailto:naf@ataxia.org). The Detroit Marriott provides a service dog relief area.

The Renaissance Center is a large facility. There is a free one-hour tour available of the Renaissance Center offered Monday through Friday at noon and 2 p.m. For information on touring, shops, and dining in the Renaissance Center visit [www.gmrency.com/home.axis](http://www.gmrency.com/home.axis).

## Transportation and Getting There

The Detroit Marriott does not provide transportation from the airport. Available options

*2013 Annual Membership Meeting Preview*  
Continued from page 15

will be listed in the Winter 2012-13 issue of *Generations* and posted on the website.

**Accessible Equipment, Wheelchair, and Scooter Rentals**

The following may be a helpful guide as you consider equipment rentals in Detroit.

Medical Town LLC – (480) 659-6765 or 1-877-701-6765 <https://medicaltowne.com/rentals>

Volusia Medical Supply – 1-866-956-2025 or (386) 756-2025 [www.volusiamedicalsupply.com](http://www.volusiamedicalsupply.com)

Scotaround – 1-888-441-7575 [www.scotaround.com](http://www.scotaround.com)

**Personal Care Attendants (PCA)**

Because of liabilities and health concerns, NAF staff or volunteers and hotel employees are not able to provide personal care attendant services. If you plan to attend the meeting, please make arrangements for an attendant if you need one.

The following may be used as a helpful guide for attendant services.

HomeCare Network of Michigan – (248) 254-3711 <http://personalcareassistant.near.me/local/6nh6FZq?aid=115696&v=2.3.0.0> ❖

## Highlights of the General Sessions of the Annual Membership Meeting in Detroit

Highlights of the General Sessions of the Annual Membership Meeting in Detroit will include:

“**The Michigan Experience**” – You won’t want to miss the opening session of the 2013 meeting on Friday morning which will provide an overview of the important work taking place in ataxia in Michigan. Each speaker is very involved in the field of ataxia as a researcher and/or clinician.

**Henry Paulson**, MD, PhD, will be our MC for the morning’s General Sessions. His laboratory explores the reasons why the aging brain degenerates in various neurodegenerative diseases. He will briefly present his work on the polyglutamine expansion diseases, including several inherited ataxias, and then introduce us to some of his colleagues who are doing renowned work in the field of ataxia.

We can look forward to hearing from **Vikram Shakkottai**, MD, PhD, who is interested in what happens to the functional properties of cerebellar neurons in disease. As his lab’s website states, “Defining early physiologic changes in the ataxias is important because such changes

represent outstanding therapeutic targets for symptomatic and preventive treatment of neurodegenerative disorders.”

**Sid Gilman**, MD, Director of the Balance Disorders Clinic at University of Michigan which provides diagnostic evaluation, management and treatment for patients with disorders of balance and coordination will be presenting his most current research in MSA.

**Margit Burmeister**, PhD, who is interested in finding new genes involved in ataxia, **Peter Todd**, MD, PhD, who looks at the neurodegenerative disorders, most notably Fragile X Tremor Ataxia Syndrome, **Kevin Kerber**, MD, who directs the Department of Neurology Dizziness Clinic, and **Sokol Todi**, PhD, whose new laboratory at Wayne State is involved in projects to identify enzymes important for neuronal homeostasis and neurodegeneration will all present their research findings. Hear how leading universities in Michigan are doing cutting edge research and clinical work in ataxia.

The popular “**Birds of a Feather**” sessions will take place after the lunch break. These small group break-out sessions, divided by the type ►

of ataxia or the role a person has (i.e., parent, spouse, sibling, etc.) have been a tradition at NAF annual meetings and are often the highlight for meeting attendees.

On Saturday morning the General Sessions continue with speakers providing practical information on living well with ataxia. This is another session you will not want to miss that begins with **Laura Rice-Oeschger**, Licensed Social Worker discussing emotional balance. The morning continues with presentations on physical balance using biomechanical devices by **Kathleen Sienko**, PhD, and balanced-based torso weighting by **Cynthia Gibson Horn**, PT. An Annual Meeting would not be complete without an expert in speech and swallowing issues for ataxia patients. **Karen Kluin**, MS, whose clinical interest is in cognitive-communicative functioning in neurodegenerative disorders, will share some strategies with us. **Polly Swingle**, PT, from The Recovery Project was recommended by the Detroit Support Group. She has extensive clinical experience, specializing in rehabilitative therapy in neurological diseases. And as in past years, **Dr. Jeremy Schmahmann** will bring his latest research discoveries on the non-motor problems that a person with ataxia may experience.

Saturday afternoon will include the important aspect of Financial Planning as it relates to a

family member with a disability. The popular participatory Wheel Chair Yoga session is back led by **Ralph Miller** with our own members demonstrating the poses. We will hear from members of NAF's Medical Research Advisory Board; **Dr. George Wilmot** from Emory University will describe the importance of rating scales to measure ataxia so that treatments can be proven effective and **Dr. Harry Orr**, Research Director, will give the State of Ataxia Research Update. **Dr. Guangbin Xia**, from University of Florida, will provide important information on stem cells as models for the SCAs to enhance research.

Sunday morning will begin with **Dr. Susan Perlman**, NAF's Medical Director, sharing any late-breaking news on ataxia treatments and medications available for treating symptoms of ataxia. **Dr. David Lynch** will present an update on Friedreich ataxia research and **Dr. Laura Ranum** will provide new insights into two of the SCAs. **Armin Alaedini**, PhD, who is researching ataxia caused by wheat allergies, will provide new insight into that form of ataxia. **Michael Parent**, Executive Director of the National Ataxia Foundation will give a report on the Foundation's activities in the past year and **Dr. Sarah Ying** will give the popular wrap-up talk of the meeting "What we have learned." ❖

## Silent Auction Scheduled for New Time

The Silent Auction held during each Annual Membership Meeting is a fun way to support NAF and for you to bid on quality items from various states and countries. This long-standing NAF tradition begins on Saturday, March 16 at a NEW TIME – 8:00 a.m. – with the final bidding ending at a NEW TIME – 1:30 p.m. – that day.

Auction items should range from something that represents your state or country, art work, sports memorabilia, theme baskets, hand-crafted items, hotel stays and weekend

getaways. Items being donated for the Silent Auction should be delivered to the Silent Auction room at the hotel. If you are not able to attend the meeting, but have a quality item that you would like to donate for the auction, please contact the National Ataxia Foundation at (763) 553-0020 or [naf@ataxia.org](mailto:naf@ataxia.org) for details on where to ship your item. Donate an item and then have fun bidding on the items of your choice!

Thank you for supporting this event and sharing items from your local area. Good luck!

# Annual Meeting Exhibitors Wanted

Companies or individuals who have products or services that would be helpful for those with ataxia are invited to exhibit during the National Ataxia Foundation Annual Membership Meeting (AMM) to be held in Detroit, MI on March 15-17, 2013.

If you are affected by ataxia or are a caregiver and know of a product or service that has been

helpful for you, please recommend they be an exhibitor by calling (763) 553-0020 or e-mailing [naf@ataxia.org](mailto:naf@ataxia.org).

Ataxia researchers, who have an IRB-approved study, may have exhibitor fees waived.

For more information on exhibiting at the AMM, please call (763) 553-0020 or e-mail [naf@ataxia.org](mailto:naf@ataxia.org). ❖

# Help for Travelers with Disabilities

Traveling can be a stressful time for someone with a disability. The Transportation Security Administration (TSA) has a webpage – [www.tsa.gov/travelers/airtravel/disabilityandmedicalneeds/index.shtml](http://www.tsa.gov/travelers/airtravel/disabilityandmedicalneeds/index.shtml) – and a travel helpline number – 1-855-787-2227 – to provide information for passengers with disabilities and medical conditions and their families before they fly.

They recommend calling 72 hours in advance to learn what to expect at airport security checkpoints. They will also be able to coordinate your security screening ahead of time when they know about your disability.

This valuable service allows you to plan in advance, and to know exactly what to expect at specific airports. ❖

# Flu Shot Recommendations

This year the Center for Disease Control is recommending that everyone get the flu shot, however, for those affected with ataxia, the scenarios below take priority.

If an ataxan meets any of these criteria, he/she **should** be vaccinated for seasonal flu:

- Children aged six months up to age 19
- Pregnant women
- People 50 years of age and older
- People of any age with certain chronic medical conditions (heart disease, lung disease)
- People who live in nursing homes and other long-term care facilities
- People who live with or care for those at high risk for complications from flu, including:
  - Health care workers
  - Household contacts of persons at high risk for complications from the flu

- Household contacts and out of home caregivers of children less than six months of age (these children are too young to be vaccinated).

If an ataxan meets any of these criteria, he/she **should not** be vaccinated:

- People who have a severe allergy to chicken eggs.
  - People who have had a severe reaction to an influenza vaccination.
  - People who developed Guillain-Barré syndrome (GBS) within six weeks of getting an influenza vaccine in the past.
  - Children less than six months of age (influenza vaccine is not approved for this age group)
  - People who have a moderate-to-severe illness with a fever (they should wait until they recover to get vaccinated.) ❖

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

**National Ataxia Foundation  
56th Annual Membership Meeting  
March 15-17, 2013**



***Join us in Detroit for the Annual Membership Meeting!***

**Renaissance Center, 400 Renaissance Drive, Detroit, MI 48243**

The Detroit Marriott at the Renaissance Center is pleased to provide the facilities for the 2013 National Ataxia Foundation Annual Membership Meeting. The Detroit Marriott is situated on the River Walk in downtown Detroit, overlooking the Detroit River and Canada, with easy access to shopping, restaurants, entertainment, and the People Mover.

**— The NAF Group Rate at the Detroit Marriott is \$139 + tax —**

**For accessible rooms:** You MUST contact the NAF office at (763) 553-0020 or [lori@ataxia.org](mailto:lori@ataxia.org).

**For standard rooms:** Please visit the NAF group reservation website: [https://resweb.passkey.com/Resweb.do?mode=welcome\\_ei\\_new&eventID=9525602](https://resweb.passkey.com/Resweb.do?mode=welcome_ei_new&eventID=9525602) or call 1-877-901-6632 and request the National Ataxia Foundation group rate.

For more information on Detroit visit [www.visitdetroit.com](http://www.visitdetroit.com).

For the latest information on reservations, conference registration, schedules, and area information, keep checking the National Ataxia Foundation website, [www.ataxia.org](http://www.ataxia.org).

# Ataxia Clinics Across the U.S.

There has been an increase in the number of neurologists who have established ataxia clinics in their institutions. The following is a listing of those clinics with the neurologists' names. Links to these clinics can be found at the National Ataxia Foundation website, [www.ataxia.org](http://www.ataxia.org).

## Arizona

- University of Arizona Medical Center – Vertigo and Ataxia Clinic – Dr. Terry Fife

## California

- UCLA Ataxia Clinic – Dr. Susan Perlman and Dr. Brent Fogel
- Stanford Movement Disorders Center – Dr. Rosalind Chuang
- UCSF Neurogenetics Cognitive & Movement Disorder Clinic / UCSF Memory and Aging Center – Dr. Sharon Sha

## Colorado

- University of Colorado – Dr. Abigail Collins

## Florida

- USF Ataxia Research Center – Dr. Theresa Zesiewicz
- University of Florida Ataxia Center of Excellence, Gainesville, FL – Dr. SH Subramony or Dr. Tetsuo Ashizawa

## Illinois

- Northwestern Memorial Hospital, Chicago – Dr. Puneet Opal
- University of Chicago Ataxia Center – Dr. Christopher Gomez

## Maryland

- Johns Hopkins University Ataxia Center – Dr. Ray Dorsey

## Massachusetts

- Massachusetts General Hospital Department of Neurology Ataxia Unit – Dr. Jeremy Schmahmann

## Michigan

- Balance Disorders (Ataxia) Clinic at the University of Michigan – Dr. Vikram Shakkottai or Dr. Sid Gilman

## Minnesota

- University of Minnesota Ataxia Center – Dr. Khalaf Bushara

## New York

- Columbia University Division of Parkinson's Disease and Other Movement Disorders – Dr. Sheng Han Kuo
- University of Rochester Medical Clinic-Periodic Paralysis, Myotonia and Episodic Ataxia Clinic – Dr. Robert Griggs

## Pennsylvania

- The Friedreich's Ataxia Program at the Children's Hospital of Philadelphia, PA – Dr. David Lynch

## Texas

- Clinical Program for Movement Disorders at UT Southwestern – Dr. Pravin Khemani

## Utah

- University of Utah Healthcare Movement Disorders Clinic – Dr. Stefan Pulst ❖

## Vehicle Donation

The donation of your vehicle to the National Ataxia Foundation will help support the important work that is being done on behalf of all who are affected by ataxia.

To donate your car, truck or motor home, call the NAF office at (763) 553-0020. Your vehicle will be picked up at your home, office or other place that you designate. Be sure to have the certificate of title with the vehicle.

# Barriers to Treatments

By George Wilmot, MD, PhD

*This is an edited excerpt of the presentation given by Dr. Wilmot at the 2012 annual membership meeting in San Antonio.*

*Dr. Wilmot received his MD, PhD from the University of Michigan, did a neurology residency at Emory University, and then remained at Emory as faculty in the Department of Neurology. Although trained in basic science and initially focusing his research on mechanisms of axonal stability and regeneration, Dr. Wilmot is currently most active in clinical research in ataxia.*

## **Why don't we have a treatment for ataxia yet?**

We hear this often and it is a reasonable question, because we want to have a treatment for ataxia. This talk will explain globally the issues with treatment development as well as treatment implementation of what we already have. We will discuss what the barriers are and why we don't have something more at this point. First some definitions:

**Treatment** – the care and management of a patient to combat, ameliorate, or prevent a disease, disorder, or injury.

Treatment is a little different than cure. We would love to cure ataxia.

**Cure** – a method or course of medical treatment used to restore to normal health.

Cure is a much, much larger problem that we might not be able to tackle as easily. As we define "cure," I am going to use this opportunity to talk about prevention; when cure is removal of a disease totally, that is a long way off, but another way to remove some diseases is through genetic and family planning and not passing on the disease through your families. That is a personal decision that everyone has to make, but sometimes we don't consider that option as a cure and in some ways it is.

Treatment has two things: it can be symptomatic or it can be disease modifying. Disease modifying is where we are actually making the pathology in the brain (the problem with the brain) better. You can use the analogy of treating

a person with pneumonia by giving someone cough medicine vs. an antibiotic. Both can be important to the treatment of the individual. One treats the symptom, one is disease modifying. Disease modifying in ataxia is making the pathology in the brain better.

We focus on disease modifying treatments because ultimately we think it will be more effective. In ataxia, we have always felt that symptomatic treatment of the movement problem, in other words giving someone medicine to make someone more coordinated, even though it is not improving the health of the brain, is not very possible. That has shifted over the past few years so we are now looking at symptomatic treatments for ataxia. It is nice to see that we are beginning to address the symptomatic in addition to the disease modifying. Finding disease modifying treatments is ultimately our goal, but it is more difficult to do.

Developing a treatment is HARD. That message needs to get across. It is a very difficult thing to go from a disease to a treatment. And it is complicated because people's expectations can be a little unrealistic. You may hear something about stem cells and then suddenly you think, "Oh, we can just do that." However, there are many difficulties with implementing treatments and proving that a treatment will actually work.

However, we are doing a good job. If you look at the field of ataxia, the research, the organiza-

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*Barriers to Treatment*  
Continued from page 21

tions that support it, the patient involvement, we should be proud of the job we are doing, but there are certainly ways to improve things to facilitate treating ataxia. I give us a passing grade but I think that, hopefully, it will even be a higher grade in the future.

So this is the basic paradigm. You take a clinical disease. You want to treat human disease. How do you do it? There are steps along the way.

First, you establish the etiology (cause) of the ataxia. We want to know what is causing the ataxia. And in order to develop a treatment that is an important first step.

After that, you try to model the disease, because it is hard to go from a disease directly to humans. You need to understand more and the models can give you more understanding of the cause. Also the models give you something to treat. Once you treat the models and you see some benefit, then it might (but not necessarily) make sense to try it in humans.

Some symptomatic treatment doesn't have to go through all the steps, sometimes you can jump to symptomatic treatment right away.

**What do we need to develop effective treatments?**

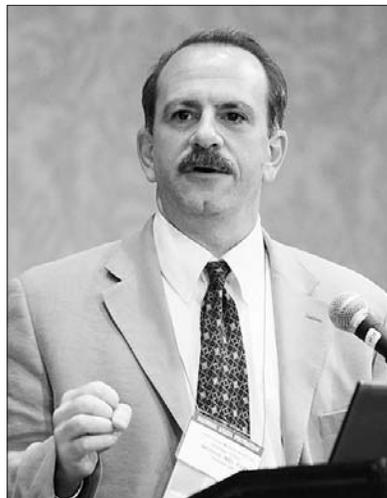
*Knowledge of the disease pathophysiology* – it could be a gene defect, but you need to understand why does that mutation cause disease, what gets sick about particular neurons? Then that can lead to finding out more about what you can do to prevent it.

*A way to measure disease* – when you move into human trials, you need to measure the disease. And that is not a simple task. What is the disease? Is the disease the cognitive stuff; is the disease the movement? If you just measure movement are

you really measuring the disease? That is really important. We want to treat the disease, but it is a very hard target. It is a moving target and a hard thing to measure.

*An understanding of the natural history of the disease* – If someone gets sick and progresses very rapidly that is going to be applicable for certain kinds of treatment trials, if the progression is long and drawn out, it may be applicable to other types of trials.

*Research infrastructure* – you need to be able to do the research, you have to have researchers and funding.



**Dr. George Wilmot**

**What do we know about the cause? How have we done in the ataxia field?**

- We've discovered ataxia genes galore – we are up to SCA36, for about half of those we have genes, the rest of them we know where they are on the chromosomes. We know about the downstream consequences of these gene mutations. For instance the mitochondrial involvement in Friedreich's – how don't they work? We need to try to understand more about

the disease. We understand the circuitry of the cerebellum. We understand more of the physiology of the cerebellum which we use to discuss the firing patterns. How do certain cells fire and how does that create and control movement? We are beginning to get insights which might get us to symptomatically treat the movement abnormalities in ataxia.

- We also have relevant models, mice, fruit flies, worms. They are very exciting, but no model is perfect.

- We have candidate treatments, so we are doing well. We have ideas about what to try and a lot of that is informed by our understanding of the pathophysiology of the disease. We understand the disease mechanisms and ultimately they will prove to be more helpful. ▶▶

- We use clinical scales, instrumented measures such as peg boards, also biomarkers. We are looking at Magnetic Resonance Spectroscopy as a way to measure chemicals in the brain which is a way to follow the disease in a way that is a little different but complimentary to the actual clinical measures. The clinical measures are just one facet of the actual underlying disease. We really need biological ways of looking at the disease, as well. That is really early, that is where we are spending a lot of effort right now. We need an understanding of how fast these diseases progress and the variability of these diseases.

We need the National Ataxia Foundation, the National Institutes of Health, we need you as research subjects, we need researchers. The more of all those things we have, the faster treatments will come ... to a degree. But there are issues that we have to deal with as researchers, as clinicians planning clinical trials. There are still limitations; there are inherent problems with clinical research that cannot be overcome simply by more funding, that cannot be overcome by researchers staying up more hours. They are just part of the clinical research enterprise and that is why it takes long to develop treatments.

### **There is the need for appropriate clinical trial design. How can the likelihood of a positive clinical trial be improved?**

- Reduce variability (Enroll more patients; study a homogeneous population; develop better measures)
- Increase the trial timeline (In a longer study you can be more certain however a long study requires more funding)
- Use a more effective treatment (We'd like to do that, but ultimately, we might not have one that is more effective)

### **What can be done to facilitate treatment development?**

Learn from other diseases. In ALS, they have done clinical trials with over 30 agents. Only one has proven to work. That is what diseases face. It's hard to find treatments.

### **Are the animal models valid ways for looking at clinical trials?**

There is literature on this. There are a lot of reasons that limit the utility of animal models for clinical drug development, beyond the fact that mice are mice and men are men. In animal results there are probably a lot of negative trials that are never reported.

There is research ongoing that is looking at treatments not to prolong life but to improve quality of life. There are things that can be done, for instance in ataxia: movement. For instance, exercise. We don't have to spend a lot of money in drug development to know that there are exercise opportunities out there. A recent study in the SCA 1 mouse showed that low level cardiovascular exercise actually changed the pathophysiology of the disease in the mice. They had some changes in the biochemistry in those mice, and when you looked at the life span of the mice, they lived longer when they had low level exercise. Translating these into human treatment is a good idea and we ought to be focusing on that.

Never underestimate the value of dedicated action. The advances that we have made in ataxia are largely due to this. People who have dedicated a large part of their life in trying to make the world a little bit better for people with ataxia. It is due to all of you, it is due to patients who do the little things that make treatment of ataxia more likely to come forward; people who participate in trials, patients who get up every day and kick us clinicians a little bit and ask what are we doing now. That is important. So keep doing what you are doing. Find a way that you can help in whatever way you can. And we will all move forward to a treatment as fast as we can.

Thanks to my patients and families who I see in clinic. They keep everything in perspective for me. Also thank you to the coordinators who I work with in the Ataxia Center at Emory; to my colleagues who have taught me so much. We all learn from each other. And thank you to the funding agencies. ❖

## BOOKS

### — ATAXIA RESOURCES —

#### **Evaluation and Management of Ataxic Disorders for Physicians**

by Susan Perlman, M.D.

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

#### **Healing Wounded Doctor-Patient Relationships**

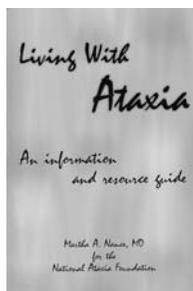
by Linda Hanner with contributions by John J. Witek, M.D. and doctors and patients around the nation

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

#### **Living with Ataxia: An Information and Resource Guide**

by Martha Nance, M.D.

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



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

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

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

### — FICTION & PERSONAL STORIES —

#### **Ten Years to Live**

by Henry J. Schut

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

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

by Dave Lewis

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

### — COOKBOOKS —

#### **Recipes and Recollections** by Kathryn Hoefler Smith

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

#### **Cooking for a Cause**

by Julie Karjalahti for FRDA research

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

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



# Slower Is Faster

By Peter Meyerhoff

All my life I have tried to be efficient. It was instinctive. Don't waste time. Multi-task. Don't dawdle. Make a decision. Get on with it. I arranged my chores in a sequence that minimized time and distance. Life is short.

This strategy served me well until I got ataxia. That changed everything.

Gradually, as the symptoms worsened, I learned that slower is faster. Fast can land me on the floor with injuries that could really slow me down. So here are some examples of how I have learned to cope:

- I have a walker that I pick up with each step. When I have to change direction, I stop completely with both feet firmly on the ground, turn the walker to the new direction, and then walk on. It's slower but can avoid a fall.
- I am at a restaurant. The waitress brings a glass of water. Even though I am tempted to drink right away, I delay and ask for a straw.

Drinking from a straw and a chin tuck tends to keep me from choking.

- I am about to go outside. It's drizzling. I need to "quickly" put on a jacket. I am tempted to stand up to do this. But it is much safer if I take the extra time to find a chair and sit down. In general, I always dress and undress sitting down.

- If walking with a funny gait, using a cane, a walker or a wheelchair makes me look decrepit and unattractive, so be it. All of these obviously slow me down but as an ataxian I cannot afford vanity.

- Vanity does not stop me from putting on a bib (I bring it with me) at a restaurant. It beats washing clothing which is more time consuming.

- Although I am tempted sometimes to take a few steps (two to three feet) across an open space without my walker, I'd rather grope along the wall for 15 feet to reach my destination. This is slower but is better than falling,

- In my pre-ataxian life, if I accidentally dropped something on the floor, I would pick it up immediately in an attempt to minimize the embarrassment, fix the error. Now I wait until I get my grabber and pick up from a sitting position.

- I used to always figure out how to save a few steps. If I had to do something in the bed room and the bath room and the kitchen and the living room, I would get the sequence right to minimize the total travel. Now I pay more attention to safety.

- One of the hardest decisions I made in my life was to give up driving. I had trouble coordinating the foot movement from the gas pedal to the brake pedal. After a near accident, I surrendered my driver's license voluntarily. Life was much slower after that; but better slow and safe than fast and sorry.

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Thank you for your donation or payment by check. If you have questions about this process, contact Julie at [julie@ataxia.org](mailto:julie@ataxia.org).



# Research Funds: The Financial Planning for the Removal of Barriers to Treatments

By Harry Orr, PhD, National Ataxia Foundation Research Director

*This article is an excerpted version of Dr. Orr's presentation at the 2012 Annual Membership Meeting in San Antonio, TX.*

Thank you for inviting me to speak. It is always a pleasure to be here. I am going to title my talk today "The Financial Planning for the Removal of Barriers to Treatments." I will talk about how ataxia research is funded and to what extent NAF plays a role. I am here not as an individual ataxia researcher but rather as Chair of the Medical Research Advisory Board for the NAF and I am basically giving you a financial report on how well we have done over the past few years and how well we project ourselves to do financially in terms of research over the next year.

But first I want to say congratulations and thank you to Dr. Paulson and Dr. Gomez for the success in the Ataxia Investigators Meeting that took place prior to this meeting. They deserve an enormous round of applause for organizing this meeting but particularly for setting an important format on how future AIM meetings will be organized with one of the goals to develop strategies by which the scientists can interact with you: the patients and the families. I cannot emphasize enough how important your interaction with the investigators is, particularly with the younger investigators, so I encourage you as we move forward to the meeting in 2014 to look for these efforts to engage with the scientists at future meetings. When they see and meet you that really commits them to ataxia research.

Now, talking in broad strokes, research for ataxia, or for most any disease, can be categorized in two general areas:

**Basic science** where we are trying to understand the science of the disease. We call this pathogenesis – how does the disease develop.

**Translational research** where we are trying to get a treatment or ideally a cure for the disease.

In many cases in biomedical research how to connect these two areas of investigation is extremely difficult and not as straight forward as we originally thought it was. One analogy that I have come up with Dr. Huda Zoghbi is when we cloned the SCA1 gene, we thought that getting to a treatment would be like getting on an escalator. You get on the bottom step and then you just let the thing take you to the top. And you don't really have to do a whole lot. But that is not the case. Rather than a straight automatic path, from basic science to clinical research, we investigators are confronted with many difficult challenges on the way.

The concept of translational research is an effort for basic scientists to be particularly aware that the goal is to get a treatment and to be attentive to the aspect of their research that may be directly linked to getting a treatment. This is not a one-way street. We have to be talking with the clinicians and the patients. We have to understand clinically what are the important aspects of the disease.

**In this broad picture of research, how has NAF positioned itself in terms of funding these various things?**

We use research grants, the Young Investigator awards, the trainee fellowships and the tissue donation program to support both pathogenesis and to develop strategies to move some of this basic science towards the clinic and treatment.

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*Continued on page 28*

*Research Funds...**Continued from page 29*

More recently, because of new financial dollars, we have additional strategies such as the Pioneer SCA Translational awards which were implemented for the first time and are being funded for 2012. We've used in the past and continue to use research funds to support the patient registry and ataxia data base. These latter two are particularly important in terms of positioning ourselves so that as we get things from basic science we can quickly move them through the patient population and begin to hone in on those that show the greatest promise for a treatment or a cure.

### **Dollars are the critical aspect in biomedical research.**

Let's talk about how research is funded. The federal government provides the largest supply of funding for biomedical research. Federal research and the dollars to support it come from taxpayers. That's the reality. Federal support of biomedical research is extremely important and an appropriate use of taxpayer dollars. One of the things that you can do is be an effective communicator to your legislators at the federal level that indeed federal support of biomedical research is important.

In addition to the research dollars from the federal government, researchers also receive dollars from private foundations and the National Ataxia Foundation being particularly important for ataxia research.

**Young Investigators:** One of NIH's priorities in biomedical research is the training and career development of the next generation of researchers. I can't highlight the importance of that enough because really it will be the next generation who will find a cure for ataxia. It is incredibly uplifting to me to realize that the next generation is smarter than most of the members of the current generation that I am aware of, and I am speaking personally for myself. It is always great to see the people coming behind you being

smarter than you are.

**Translational Research for Rare and Neglected Diseases:** NIH understands and appreciates that there is a group of disorders that in their total affect a large number but each individually affects a relatively small number of people. And so the best way to move this research forward is to spread the cost across the society and not on any one area or group of individuals. That is what the federal government's research budget does, it spreads the cost of doing research across the resources of the total society and not restricting it to one type. And clearly ataxia fits into this strategic plan.

**NAF Research Budget:** This year, 2012, is a banner year in supporting research and it is projected that 2013 will be an equally exciting year. NAF's research commitment for FY 2012 was \$875,000. So where did that \$875,000 come from? Here is the financial breakdown:

- \$500,000 from an Anonymous Donor to support research in the SCAs
- \$100,000 was the Macklin Foundation Matching grant
- \$50,000 from the Bob Allison Ataxia Research Center (BAARC)
- \$225,000 provided by NAF donors and friends.

As we review these numbers, the first key word is partnership. NAF will partner with others who are equally interested in seeing that we get to the goal that we want to reach. And key in this partnership are the donations from NAF members and friends.

These are the core dollars that we take to other entities and tell them that we have this very dedicated group of donors who are here to see ataxia research move forward. They see how well we do with this money and say, "Okay we are going to put our money into this organization." So even though the \$225,000 is around one-fourth of what was awarded for FY 2012, if those research donations had not been made, the other dollars would not be there. ▶▶

**What is the review process?** The review process is to link these dollars to the brightest ideas. We received 90 applications. The way the scientific review process works, at NAF or at any of the private foundations or at NIH is a process called *peer review*. The investigator submits their research application. The application is evaluated by their scientific peers and then applications are funded, based in the case of NAF, on two scores. One score is the scientific merit, so first of all the application has to have outstanding science and the second score, is relevance to ataxia. So it has to be both outstanding science and exceedingly relevant to ataxia. To do this we typically have two to three investigators from around the world review each application. This year that required 196 reviews be generated from 40 reviewers and all done pro bono. And from this process we were able to fund 16 grants.

### Five Types of Grants

- Research Grant, four were funded between \$15,000-\$30,000.
- Young Investigator Award, one funded at \$50,000
- Trainee Fellowship, two funded at \$35,000
- Young Investigator Award for SCA, five funded between \$30,000-\$50,000
- Pioneer Award for SCA research, four funded between \$70,000-\$100,000

Because of the partnership with BAARC, we were able to fund more of these grants than we had initially anticipated.

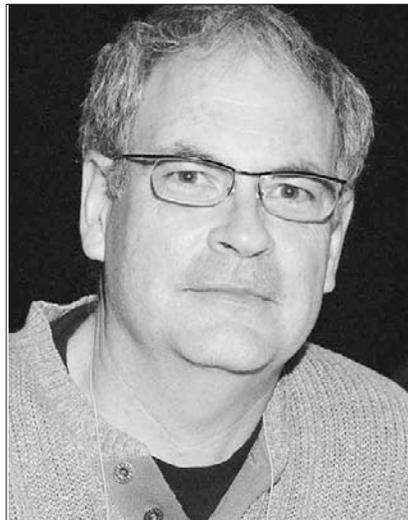
Although we are the National Ataxia Foundation, when it comes to funding outstanding ataxia research, we fund investigators from all over the world.

### Approaches

- Gene discovery
- Stem cells (Induced Pluripotent Stem Cells)
- Drug development

- Gene-based therapeutics
- Neuroprotective agents
- New mouse models
- Translational research – taking basic science to treatments
- Genomics – genetics that is being done as a result of having sequenced the human genome a few years ago.

We continued to provide funds to the Tissue Donation Program in Albany, NY, the Ataxia Data Base housed at UCLA and the National Ataxia Registry that was developed at the University of Florida.



**Dr. Harry Orr**

Research in ataxia enhances research in other neurodegenerative diseases and research in other neurodegenerative diseases enhances research in ataxia. This is the power of working together.

One example in closing: yes, I work on the genetic form of ataxia; yes, most of the investigators at this meeting work on a genetic form of ataxia; no, most of you have to deal with a sporadic form of ataxia and there is a bit of a disconnect here. Trying to develop meaningful strategies on the sporadic ataxias has been particularly difficult and I am encouraged by a recent paper that was published on Alzheimer's disease where the investigators took these iPS cell. This is done by getting skin from individuals. We take it back to the lab and we work with genetic strategies where we end up with these pluripotent stem cells that we can subsequently induce to become neurons, which in reality becomes "disease in a dish." The exciting thing about this Alzheimer's study is they are finding similarities in neurons generated from individuals with genetic forms of Alzheimer's compared to those with sporadic forms of Alzheimer's, so now we are beginning

*Research Funds...**Continued from page 29*

to develop a research mechanism by which we can link gains made in the genetic form of ataxia with the sporadic forms of ataxia. So the reality is we ataxia investigators are going to come back and literally ask you to put some skin in the

game. So be forewarned that the next time you visit your ataxia doctor or researcher that they may ask you to stick your arm out, after having you sign a consent form.

In closing, as I do every year, I thank you. I cannot tell you how important your support and courage is to us as researchers. Thank you very much. ❖

## Third Annual KMLHS Soccer Tournament Raises Funds for Ataxia Research

*By Matthew Moeller, teacher and varsity coach at KMLHS*

On Thursday, July 19, friends and family of the Kettle Moraine Lutheran High School (KMLHS) soccer program worked to raise funds for ataxia research in the third annual KML 3 v. 3 Soccer Tournament and Ataxia Fund Raiser. KMLHS is a Wisconsin Evangelical Lutheran Synod high school located in Jackson, WI, which is located about 30 miles northwest of Milwaukee.

Barry Washburn, long-time supporter of the KML soccer program and an assistant varsity boys and girls coach for the past nine years,

suffers from ataxia.

A 3 v. 3 soccer tournament was hosted that included current and former KMLHS players, current KML varsity coach Matt Moeller, and players from the KML elementary school soccer camp that wrapped up on that same day.

The tournament was won by a trio of sophomores: Griffin Hoerchner (who won the tournament last year with his two sisters), Ryan Olsen, and Noah Semmann.

Cash and check donations from friends of the KMLHS soccer family totaled \$310. ❖

### Tissue Donation

Donating tissue for medical research is an important and deeply personal decision. Proper planning can help ensure that wishes are honored at the time of your or a loved one's passing. For more details or to make arrangements for tissue donation please follow-up with Dr. Koeppen directly at his contact information listed below.

Dr. Arnulf Koeppen  
Professor of Neurology & Pathology  
VA Medical Center  
113 Holland Ave., Albany, NY 12208  
(518) 626-6377 Fax: (518) 626-6369  
E-mail: [Arnulf.Koeppen@va.gov](mailto:Arnulf.Koeppen@va.gov) or  
[akooppen@nycap.rr.com](mailto:akooppen@nycap.rr.com)

### Ataxia Study Patients Needed

Patients with SCA1, SCA2, SCA3, SCA6 and MSA-C are needed for an MRI study to evaluate the chemistry of the brain in ataxias at the Center for Magnetic Resonance Research at University of Minnesota, Minneapolis, MN.

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

If you are interested or have questions, please call Diane Hutter at (612) 625-2350 or e-mail [hutte019@umn.edu](mailto:hutte019@umn.edu).

# Caregiver's Corner

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

## Eye Safety, Eye Health

### Home Can Be a Dangerous Place for Eyes

Prevent Blindness America has named October "Home Eye Safety Awareness Month." It's easy to forget how easily, quickly and tragically an accident can happen, robbing us of our most precious sense – sight.

To protect your eyes –

- Never mix cleaning agents or other chemicals. Read and follow all manufacturer instructions and warning labels.

- Wear safety glasses with side protection or dust goggles to protect against flying particles. Wear chemical goggles to guard against exposure to fumes and splashes. Many safety glasses or goggles will fit over your regular prescription glasses. Regular eyeglasses do not always provide enough protection, and may even cause further injury upon impact.

- Remove debris from lawns before mowing. Keep others away or make sure they are wearing eye protection – bystanders can be hit by flying debris.

- Keep paints, pesticides and fertilizers securely stored, especially if the person in your care has dementia. Read and follow all product instructions.

- Keep tools in good condition; repair or replace damaged tools.

- Limit exposure to fluorescent lights, computer screens, smoke and excessive sunlight.

- Get enough sleep; sleep allows the eyes to rest and repair.

- Stay hydrated to prevent dry, irritated eyes.

- Quit smoking! Lighting up more than 20 cigarettes a day doubles the risk of macular degeneration.

### Eat Well To Boost Eye Health

- Vitamins A, C, E and minerals like copper and zinc are essential to eyesight, as are antioxidants like beta-carotene, lutein and zeaxanthin. Find them in eggs and yellow and green veggies.

- Garlic and onions are rich in sulfur, cysteine and lecithin that protect the lens from cataracts.

- Blueberries and grapes contain anthocyanin, an antioxidant that improves vision.

- Sardines, mackerel, cod and salmon have DHA, an important fatty acid.

Source: [www.preventblindness.org](http://www.preventblindness.org)

### Causes of Vision Loss

Most seniors notice changes in eyesight, usually because it becomes more difficult to read small print, get around in dim lighting, or tell the difference between dark blue and black. These changes are a normal part of aging. But other vision changes can be much more serious, caused by stroke, traumatic brain injury or a brain tumor. This type of loss may be temporary or permanent.

### Common Eye Conditions in People over 50

*Macular Degeneration (MD)* – Characterized by vision loss in the center of eye, blurred vision, straight lines looking wavy, and needing more light to see. MD can affect either one or both eyes. Over 9 million Americans over 40 have MD. Although there is no cure yet, treatments can slow its progress.

*Glaucoma* – This leading cause of blindness in the U.S. is characterized by gradual loss of peripheral (side) vision, difficulty driving at night, and loss of contrast. It is important to

*Continued on page 32*

### Caregiver's Corner

Continued from page 31

get treatment for early symptoms to prevent total blindness.

**Cataracts** – Cause clouding of the normally clear lens of the eye. Symptoms are hazy vision, difficulty driving at night, double vision, trouble distinguishing colors, and sensitivity to glare. It typically develops gradually. Cataract surgery removes the diseased lens and replaces it with a plastic one.

**Diabetic Retinopathy** – Typically occurs in people with advanced diabetes and high blood sugar levels. It is caused by leaking blood vessels. Its symptoms are blurred or changing vision, difficulty reading, and floaters that affect either central or peripheral vision. About 25 percent of people with diabetes have some diabetic retinopathy, but few develop severe vision problems. Usually there are no symptoms in the early stages, so people with advanced diabetes should have regular vision exams. The best prevention is maintaining stable blood sugar levels.

See a doctor immediately if the person has blurred vision, flashes of light or blind spots.

### Eye Specialists

- Ophthalmologist – MD for care and surgery of the eyes
- Optometrist – Specialist for basic eye care
- Optician – Fitting and making of eyeglasses and contact lenses

### The Eyes – A Window into Health

Your eye doctor can learn a lot about your overall health by looking deep into your eyes, at the blood vessels and nerves in the back of the eye. This painless exam may catch the first signs of high blood pressure, diabetic complications or autoimmune disease.

### When to Get a Vision Screening

Forty-Plus: Age-related changes in vision and the earliest signs of glaucoma, cataracts and diabetic retinopathy caught early can help minimize

vision loss. Frequency of follow-up screenings depends on your test results, medical conditions and your eye-health history.

Seniors over 60: Seniors should have their eyes examined once a year to screen for cataracts, glaucoma, diabetic retinopathy, and age-related macular degeneration.

If you have risk factors for eye problems like high blood pressure or diabetes, your doctor may check you more frequently.

Source: *American Academy of Ophthalmology*

### Quick Quiz

Those with vision impairment are more likely to experience falls and injuries. Visual impairment makes a person more likely to trip over objects they are unable to see in their walking path. Read this article and answer True or False to the questions below about eye health.

- 1) Smoking more than 20 cigarettes a day doubles the risk of macular degeneration. *T F*
- 2) Our eyes can never be injured in the safety of our own home. *T F*
- 3) People over 65 no longer need to get eye exams. *T F*
- 4) Glaucoma is the leading cause of blindness in the U.S. *T F*
- 5) It is important to see the doctor immediately if the person has blurred vision, flashes of light or blind spots. *T F*
- 6) Good nutrition affects many things, but not eyesight. *T F*
- 7) Excessive exposure to fluorescent lights, computer screens, smoke and sunlight can damage eyesight. *T F*
- 8) An eye exam can alert you to the first signs of high blood pressure. *T F*
- 9) Fire kills and injures more people every year than any other force of nature. Senior and disabled persons are especially vulnerable. *T F*
- 10) There is no cure for Macular Degeneration, but treatments can slow its progress. *T F*

Answers: 1. T; 2. F; 3. F; 4. T; 5. T; 6. F; 7. T; 8. T; 9. T; 10. T

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# My Abilities

By Adam Payne

Doctor: Hello Adam, How are you today?

Me: Well, I've been having trouble keeping my balance lately. It may be time to consider a chair.

Doctor: That makes sense. If you feel you can't walk anymore then it's time for a chair.

Me: It's not that I can't walk! When I walk I fall and that hurts, so I don't walk anymore.

There's a big difference between saying "I can't do something" and saying "I don't do something." When you say "I can't" you are releasing yourself from the choice. You are, in effect, saying that "I used to be able to do this but because of this disease. I can't do it anymore." You are taking yourself out of the argument and giving the power to your disease.

By saying "I don't" you keep the choice with you. People may ask, "But why 'don't' you do this anymore?"

"Because when I try, the consequences are bad."

"O.K."

Do you see a difference? The discussion is no longer about your disease. It's about you. The fact that you have ataxia doesn't enter into your conversation. You are also not giving a bully anything to bully about.

In social work there is a theory called explanatory legitimacy theory. It's a relatively new theory with direct implications for ataxians. The theory understands that you have a disease but that's a medical diagnosis. That's totally out of

your control. (The fact that it's out of anyone's control is another discussion for another time.) What is in your control is the way you react to your disease. In our cases, how we react to our major incoordination makes a difference.

We have some choices: We can go to the extremes of either reacting like Buddha, where we try to not let anything affect us, or we can get mad at everyone and throw things. Or we can react with a combination of the two. The important thing is that we are making the choice. No one, no matter how well intentioned, can make the choice for us because any consequences have to be borne by us. They can't be borne by anyone else.

Not to say that if you truly can't do something there is any shame in admitting it. You may feel that there is shame, but there really isn't. I don't believe in stupidly setting yourself up for failure by trying to do something you can't. There's a difference between someone who has been using a

wheelchair for years saying that they will run the New York City marathon next year and that same person going kayaking on a Saturday.

I bet the kayaking will be more fun. It's all about the choices you make.

*Editor's Note: Adam Payne was diagnosed with an unknown form of ataxia in 1997. He lives in New York and is a member of the Tri State Ataxia Support Group.* ❖

“  
**No one, no matter how well intentioned, can make the choice for us because any consequences have to be borne by us.**  
 ”

## Attention NAF Chapters and Support Group Leaders

Please submit your 2013 meetings and events by November 2 to [lori@ataxia.org](mailto:lori@ataxia.org).

# Chapter and Support Group News from Around the Country

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## Central New York Ataxia Support Group

The Central New York Ataxia Support Group met on Saturday, June 16. Twelve members were present. We welcomed five new members to our group.

Our topic of discussion was “Items and Techniques to Help Meet the Challenges We Face with Ataxia.” We shared ataxia information with each other while we enjoyed snacks that our members brought to the meeting.

At the end of the meeting we packed approximately 250 used cell phones. These cell phones were sent to a recycler who will send a donation check to the NAF.

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## Los Angeles Ataxia Support Group – “The Thursday Walker/Rollers”

Most people agree that a little exercise is good for us. Combine it with a group of wonderful people and you have a party.

Every Thursday, support group members who live in the Los Angeles valley areas get together to walk and roll, then enjoy a lot of wonderful



“The Thursday Walker Rollers” enjoying time together

conversation over coffee. Rotating the event between Glendale Galleria and Santa Anita Mall, makes it easier for more people to join us.

Meeting in this very casual setting has enabled us to forge real friendships, something that’s hard to do in a meeting. When new members join us for the first time, they are able to get many questions answered and hear from others with the same challenges.

The other benefit is the real partnership that’s grown between the employees of Peets Coffee and our group. These wonderful people have become part of our ataxia family. A big thank you to Stephanie and her crew at Peets for supporting the Los Angeles Ataxia Support Group Thursday Walker/Rollers.

Would you like to join us? E-mail Sherry at [ccherilynmc@yahoo.com](mailto:ccherilynmc@yahoo.com).

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## Tri-State Ataxia Support Group

Here’s hoping everyone is enjoying a safe, happy and healthy summer. Our meeting started at 6:30 p.m. with the usual greetings and introductions. We welcomed our newest member Renee and her brother David to our group for their first (but hopefully not last) meeting.

Our first topic of discussion for the night was to talk about a gluten vs. gluten-free diet. After listening to everyone’s input the consensus was that if you feel better then no problem, but right now, medically, there is no positive connection. ►►

Dr. Kuo did inform the group that he will be starting a study to see the effects gluten has on an ataxia patient. Dr. Kuo will keep the group updated when he is ready. We were also introduced to Siri, who is a second-year fellow working with Dr. Kuo and assisting him in this study.

Everyone then went on to discuss what we do throughout the day. Some activities are reading, exercising and going to the gym. As always, keeping active was stressed as being most important to all of us. Remember to always do all you can – never let ataxia stop you.

The benefits of checking out the National Ataxia Foundation website – [www.ataxia.org](http://www.ataxia.org) – were discussed. The website always has up-to-date information. Some of that info was printed and handed out to everyone including information about the 3rd Annual Virtual IAAD Walk 'n' Roll. You can register and read more about it at the Virtual Walk 'n' Roll website.

As part of your membership in the NAF you are eligible to receive *Generations*, the newsletter provided. Now the NAF is going “green” and *Generations* is also available electronically.

Details are now available for the NAF 56th Annual Membership Meeting which will be held in Detroit, MI on March 15-17, 2013.

**Denver Ataxia Support Group**

*By Charlotte DePew*

At our July 21 quarterly meeting, a progress report was given regarding our planned 2nd Annual Run, Walk n' Roll scheduled for September 9 in Denver's City Park.

Our speaker was Dr. Tom Clouse and his topic was “Walking with Ataxia.” His message was that in responding to our progressive ataxia symptoms, we learn to use numerous maladapt-



**The Tri-State Ataxia Support Group at a recent meeting**

ive movement patterns which actually make our movement problems worse. Since these are learned movement patterns they can also be unlearned. With diligence and a willingness to work, we can change and we can replace them with more normal movements. This undoing of learned adverse habits requires improved fitness and a core-strengthening level, just like any normal person has to do to improve their movement abilities. Using members at the meeting he demonstrated the techniques he teaches and in minutes we also witnessed the positive results in each of those member's stability and movement. The improvements were so very obvious that additional members requested to work with him during his scheduled time in our area, for a total of 11 individuals.

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**Northern CA Ataxia Support Group**

*By Joanne Loveland*

Northern CA Ataxia Support Group held its third meeting this year on July 14. We had 30 attend including six new guests, two who had recently been diagnosed with ataxia, and one with MSA.

We began our meeting with a delicious lunch made and served by loyal members.

After a welcoming round of introductions,

*Chapter and Support Group News*  
*Continued from page 35*

we began our business meeting. Our meeting was led by Joanne Loveland and Shirley Hanks. Committees were formed for this year's Walk n' Roll and our new event, an "Exercise and Mobility Matters Faire." We will be inviting anyone with a "movement disorders" to meet and participate with professionals who will be demonstrating techniques to maintain flexibility, improve balance and gait.

Exercise benefits EVERYBODY. We are delighted to have Dr. Thomas Clouse as a special guest at our event. He will be staying in the Bay Area for several weeks to work individually with those who signed up for time with him. We are even planning some Olympic games and competition.

With additional press releases this year, we hope to really increase ataxia awareness as we all help raise funds to benefit NAF and grant funding for needed research. ❖

# Spud



*By Amy Cantrell*

I have had SCA2 for about 12 years. My older brother has it and my dad did too.

This past month, my youngest son was tested for SCA2. I have two boys and neither one has SCA2. My dad had two kids and we both have it. Anyone that has a disabling disorder knows that on some days you just feel sorry for yourself and question "why me?"

It took a little Jack Russell terrier named Spud to show me how to come to grips with it and teach me a lesson of life. Spud has cerebellar ataxia too. He thinks he is perfect the way he is, and to us, he is perfect. Everyone should feel that way.

Spud did not show signs of having anything wrong until he was about a year old. Then everyone noticed his front legs and back legs were not synchronizing together. He runs with all legs flailing and has no brakes. We read an article in a dog magazine that this breed can get cerebellar ataxia. I took him to the vet and he agreed he must have a neurological disorder. What are the odds that we would both

have this disorder?!? We don't know what kind of ataxia he has, just that life presents difficulties for him too.

He wrestles all day with our other dog. When he gets going, he can't stop, so he has developed the art of rolling to a "T." He does have the advantage of four legs! He does the "butt balancing" on our family members' feet all the time. If our legs are crossed, he backs up and balances on them. He needs the support. He has evolved the world to fit him!

We had heard that Jack Russell terriers are hyper and jump. We knew something was wrong because he couldn't jump. We lift him on the bed or in the car. He has adjusted to the world just fine and with a happy bark.



**Amy Cantrell and Spud**

When I think this is so unfair, I can consider everyone is fighting some kind of battle, or hug Spud! I believe God brought me Spud for those times!

Spud and I will be walking again in the Walk, Run and Roll this September in Denver. ❖

## From the Desk of the **Executive Director**

There is much excitement around NAF with International Ataxia Awareness Day events just concluding and Walk n' Rolls for ataxia being conducted throughout the country. We are truly thankful to the organizers, sponsors, donors, and volunteers for all their efforts in bringing ataxia awareness to their local communities and in supporting the important work of the National Ataxia Foundation.

NAF is also excited about the quality and number of promising ataxia research applications which are currently being reviewed. The research focus of these studies include many of the SCAs, Friedreich's ataxia, Sporadic ataxia, Episodic ataxia, new gene discoveries, and others. Again this year NAF is seeing scientists from around the world who are applying for NAF research grants. These countries include the United States, Germany, Australia, United Kingdom, Portugal, Belgium, Spain, Italy, and Netherlands.

We are very grateful for The Gordon and Marilyn Macklin Foundation, who recently announced their continued commitment in challenging the NAF membership to support the 2012 annual ataxia research drive. The Macklin Foundation has raised the level of their research match from \$100,000 last year to \$150,000. Once the first \$50,000 is raised starting on October 15, the Macklin Foundation will match each research donation dollar for dollar up to \$150,000. We encourage you to help support this wonderful opportunity to fund more ataxia studies.

We are truly thankful for the continued

generosity of our anonymous donor who last year made a three-year, \$1.5 million dollar commitment to NAF in support of important ataxia research.

We are grateful for the continued commitment of the Michael and Patricia Clementz Family Endowment Fund for SCA3 Research who has donated more than \$1 million dollars for research over the past few years.

The commitment of NAF's chapter presidents, support group leaders, and ambassadors are making a profound impact in bringing the local ataxia community together to share, learn and network. We are indebted to NAF's Medical and Research Advisory Board and to the scientists and clinicians who review research applications so that the most promising of these studies are awarded funding. We are also indebted to those who have been involved with clinical trials, have registered in the patient registry, or have made arrangements for tissue donation for research.



**Michael Parent**

Our members, corporate and foundation friends, those who contribute to various NAF sponsored events and drives, volunteers, and sponsors all play a key role in partnering with NAF to help fulfill our important mission in serving ataxia families. We are truly grateful for their support and commitment. NAF is also fortunate to have an engaged and committed board of directors and dedicated staff to help further the goals of the National Ataxia Foundation.

The proverb, It takes a village ... is certainly true. Together, we are making a difference in providing help and hope to ataxia families. Thank you.

# NAF Directory of Chapters, Support Groups and Ambassadors

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

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

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

## Social Networks

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### NAF CHAT ROOM

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[www.ataxia.org/connect/chat-rooms.aspx](http://www.ataxia.org/connect/chat-rooms.aspx)

### NAF FACEBOOK GROUP

[www.facebook.com/group.php?gid=93226257641](http://www.facebook.com/group.php?gid=93226257641)

### NAF FACEBOOK CAUSES

[www.causes.com/causes/368602?m=71bb3202&recruiter\\_id=52877151](http://www.causes.com/causes/368602?m=71bb3202&recruiter_id=52877151)

### NAF FACEBOOK FANS

[www.facebook.com/lshogren?ref=profile#!/pages/National-Ataxia-Foundation/227766109304](http://www.facebook.com/lshogren?ref=profile#!/pages/National-Ataxia-Foundation/227766109304)

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[www.ataxia.org/chapters/Carolinas/default.aspx](http://www.ataxia.org/chapters/Carolinas/default.aspx)

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

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

**– TEXAS –****CENTRAL TEXAS SUPPORT GROUP**

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

**NORTH TEXAS SUPPORT GROUP LEADER**

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

**AMBASSADORS**

**Angela Cloud**  
 Houston, TX  
 E-mail: angelahcloud@aol.com  
[www.ataxia.org/chapters/Houston/default.aspx](http://www.ataxia.org/chapters/Houston/default.aspx)

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

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

**– UTAH –****UTAH SUPPORT GROUP LEADERS**

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

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

**– VIRGINIA –****CHESAPEAKE CHAPTER PRESIDENT**

**Carolyn Davis**  
 Vienna, VA  
 (703) 759-2008

E-mail: ccnafpres@gmail.com  
[www.ataxia.org/chapters/Chesapeake/default.aspx](http://www.ataxia.org/chapters/Chesapeake/default.aspx)

**AMBASSADORS**

**Donna Ring**  
 St. Stephens Church, VA  
 (804) 769-3983  
 E-mail: ringwh@peoplepc.com  
[www.ataxia.org/chapters/Ring/default.aspx](http://www.ataxia.org/chapters/Ring/default.aspx)

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

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

**AMBASSADOR**

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

## International Support Groups and Ambassadors

**– AUSTRALIA –****AMBASSADOR**

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

**– CANADA –****AMBASSADORS**

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

**Prentis Clairmont**  
 Ottawa, Ontario  
 (613) 864-8545  
 E-mail: prentis.clairmont@qmail.com  
[www.ataxia.org/chapters/PrentisClairmont/default.aspx](http://www.ataxia.org/chapters/PrentisClairmont/default.aspx)

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

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

**Chandu Prasad George, CH,**  
 Secunderabad, India  
 Phone: 0091-040-27961269  
 Mobile: 0091-9949019410 Fax: 091-040-27971043  
 E-mail: sam\_ataxiaindia@yahoo.com  
[www.ataxia.org/chapters/Chandu/default.aspx](http://www.ataxia.org/chapters/Chandu/default.aspx)



# Calendar of Events

The most current event information is available on the NAF website, [www.ataxia.org](http://www.ataxia.org).

## SUPPORT GROUP MEETINGS

– **Saturday, October 6, 2012** –

### West Central FL Ataxia Support Group Meeting

**Time:** Noon – 3 p.m.

**Location:** USF Morsani Center, 13330 USF Laurel Dr., Tampa, FL

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

– **Wednesday, October 10, 2012** –

### Willamette Valley Ataxia Support Group Meeting

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

**Location:** Albany General Hospital, 1046 6th Ave. SW, Albany, OR 97321

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

– **Saturday, October 13, 2012** –

### Central Minnesota

#### Ataxia Support Group Meeting

**Time:** 10 a.m. – noon

**Location:** Liberty Savings Bank, 111 7th Ave. S. #101, St. Cloud, MN 56302

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

### Kansas City Area Ataxia Support Group Meeting

**Time:** 2 – 4 p.m. the second Saturday every other month

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

**Details:** For more information contact Lois Goodman at (816) 257-2428 or Jim Clark at (816) 468-7260 or [clarkstone9348@sbcglobal.net](mailto:clarkstone9348@sbcglobal.net).

### North Texas Ataxia Support Group Meeting

**Time:** 10 a.m. – noon the second Saturday of every month

**Location:** Las Colinas Cancer Center, 7415 Las Colinas Blvd., Irving TX 75039

**Details:** Parking is free and the building is handicapped accessible. We meet in the front lobby of the Las Colinas Cancer Center, a one-story building behind the Regions Bank. There is a map on their web site, [www.LasColinasCancerCenter.com](http://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 concerns from caregivers, patients and families. For more information please contact David Henry Jr. at [cheve11e@sbcglobal.net](mailto:cheve11e@sbcglobal.net).

### Northern CA Ataxia Support Group Meeting

**Time:** 11:30 a.m. – 2 p.m.

**Location:** Our Savior's Lutheran Church (Recreation Hall), 1035 Carol Lane, Lafayette, CA

**Details:** The cost to attend is \$7 per person with lunch or \$4 per person without lunch. RSVP by October 5. For more information please contact Joanne Loveland at [joanneloveland@gmail.com](mailto:joanneloveland@gmail.com).

### Tar-Heel Ataxia Support Group Meeting

**Time:** Noon – 2 p.m.

**Location:** Nature Center at White Deer Park in Garner, NC (same place we had the picnic). The address is 2400 Aversboro Rd. in Garner, NC.

**Details:** When you enter the park, you will come to a fork so take the left-hand fork. The Nature Center is at the end of the parking lot you come to. Take I-40 to Exit 299 (Person St./Hammond Rd.). Take the turn onto Hammond Rd. (you will be going away from Raleigh and toward Garner). Stay on Hammond Rd. (which turns into Timber Dr. later) for a little over five miles. Turn right onto Aversboro Rd. and go one mile. White Deer Park is on your right. Please RSVP via e-mail and mark your calendar for this meeting date. To RSVP or for further information contact Norma Bryant at (919) 526-5539 (home), (513) 417-9289 (cell) or [norma\\_bryant1@gmail.com](mailto:norma_bryant1@gmail.com).

– **Saturday, October 20, 2012** –

### Denver Area Ataxia Support Group Meeting

**Time:** 1 – 4 p.m.

**Location:** Swedish Medical Center, 501 E. Hampden Ave., Englewood, CO 80113

**Details:** We meet in Meeting room Spruce A & B. For more information contact Charlotte DePew at (720) 783-3190 or [cldepew77@comcast.net](mailto:cldepew77@comcast.net).

### Orange County Ataxia Support Group Meeting

**Time:** 4 – 5 p.m.

*Continued on page 44*

*Calendar of Events**Continued from page 43*

**Location:** Orange Coast Memorial Medical Center, Breast Center Building, Classroom 1A (building nearest to Talbert Ave. & Foster St.), 9900 Talbert Ave., Fountain Valley, CA 92708

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

**Twin Cities Ataxia Support Group Meeting**

**Time:** 10 a.m. on the third Saturday of every month

**Location:** Langton Place, which is located on the south side of the road on County Rd. D roughly four-tenths of a mile east of I-35W in Roseville at 1910 W. City Rd. D., Roseville, MN 55112

**Details:** We wanted to provide a central location that it easy to access which is why we picked this place. Please join us, and make new connections! Family and friends of an afflicted individual are always welcome. For more information contact Lenore Healey Schultz at (612) 724-3784 or [cshultz.lenore@yahoo.com](mailto:cshultz.lenore@yahoo.com).

– **Sunday, October 21, 2012** –

**Chicago Metro Ataxia Support Group Meeting**

**Time:** 1 p.m.

**Location:** Ravenwood Chiropractic & Wellness Center, 5215 N. Ravenswood Ave., Suite 105, Chicago, IL

**Details:** For more information contact Christopher Marsh at (312) 662-1127 or [cmars34@ameritech.net](mailto:cmars34@ameritech.net).

– **Saturday, November 3, 2012** –

**Central Texas Ataxia Support Group Meeting**

**Time:** 11:00 a.m. – 1:30 p.m. on the first Saturday of every other month

**Location:** Dell Childrens Medical Center of Central Texas, 4900 Mueller Blvd., Austin, TX 78723

**Details:** We will meet in Central Conference Room 4E.031 A&B (located between 4N & 4C) on the fourth floor. The medical center's main number is (512) 324-0000. For more information contact Linda Crawley at (512) 635-9478 or [calebsnana2@msn.com](mailto:calebsnana2@msn.com).

– **Thursday, November 8, 2012** –

**Tri-State Ataxia Support Group Meeting**

**Time:** 6 – 8 p.m.

**Location:** Beth Israel, Phillips Ambulatory Care Center (PACC), 2nd floor, 10 Union Square, New York, NY

**Details:** For more information contact Denise

Mitchell at (212) 844-8711 or [markmeghan2@gmail.com](mailto:markmeghan2@gmail.com).

– **Saturday, November 10, 2012** –

**Central Minnesota****Ataxia Support Group Meeting**

**Time:** 10 a.m. – noon

**Location:** Liberty Savings Bank, 111 7th Ave. S. #101, St. Cloud, MN 56302

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

**Greater Atlanta Ataxia Support Group Meeting**

**Time:** 1 – 3 p.m.

**Location:** Emory Center for Rehabilitation Medicine, 1441 Clifton Rd., Room 101, Atlanta, GA 30322

**Details:** For more information contact Dave Zilles at (770) 399-6710 or [dzilles@earthlink.net](mailto:dzilles@earthlink.net).

**Los Angeles Area Ataxia Support Group****Pizza Party**

**Time:** 2 – 4 p.m.

**Location:** TBA

**Details:** UCLA Research Update. For more information contact Sherry McLaughlin at (626) 791-1558 or [ccherilynmc@yahoo.com](mailto:ccherilynmc@yahoo.com).

**North Texas Ataxia Support Group Meeting**

**Time:** 10 a.m. – noon the second Saturday of every month

**Location:** Las Colinas Cancer Center, 7415 Las Colinas Blvd., Irving TX 75039

**Details:** Parking is free and the building is handicap accessible. We meet in the front lobby of the Las Colinas Cancer Center, a one-story building behind the Regions Bank. There is a map on their web site, [www.LasColinasCancerCenter.com](http://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 concerns from caregivers, patients and families. For more information please contact David Henry Jr. at [cheve11e@sbcglobal.net](mailto:cheve11e@sbcglobal.net).

– **Wednesday, November 14, 2012** –

**Willamette Valley Ataxia Support Group Meeting**

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

**Location:** Albany General Hospital, 1046 6th Ave. SW, Albany, OR 97321

**Details:** For more information contact Ivy Stilwell ►►

at (541) 812-4162 or [istilwell@samhealth.org](mailto:istilwell@samhealth.org).

– **Saturday, November 17, 2012** –

#### **Baltimore Ataxia Support Group Meeting**

**Time:** Noon – 2 p.m.

**Location:** Johns Hopkins Outpatient Center, Conference Room 2140, 601 N. Caroline St., Baltimore, MD 21287

**Details:** For more information contact Bailey Vernon at (410) 616-2811 or [bvernon1@jhmi.edu](mailto:bvernon1@jhmi.edu).

#### **Detroit Area Ataxia Support Group Meeting**

**Time:** 1 – 4 p.m.

**Location:** Harper Hospital (Wertz Classroom 1237) Near the main entrance off John R (3990 John R)

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

#### **Northeast Florida Ataxia Support Group Meeting**

**Time:** 1 p.m.

**Location:** Baptist Hospital South in Jacksonville, FL off I-95 Exit 333 (Old St. Augustine Rd.). Go East one-half mile and follow signs to the hospital entrance. We will meet in the Azalea and Begonia conference rooms.

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

#### **Twin Cities Ataxia Support Group Meeting**

**Time:** 10 a.m. on the third Saturday of every month

**Location:** Langton Place, which is located on the south side of the road on County Rd. D roughly four-tenths of a mile east of I-35W in Roseville at 1910 W. City Rd. D., Roseville, MN 55112

**Details:** We wanted to provide a central location that it easy to access which is why we picked this place. Please join us, and make new connections! Family and friends of an afflicted individual are always welcome. For more information contact Lenore Healey Schultz at (612) 724-3784 or [cshultz.lenore@yahoo.com](mailto:cshultz.lenore@yahoo.com).

– **Sunday, November 18, 2012** –

#### **Chicago Area Ataxia Support Group Meeting**

**Time:** 1 p.m.

**Location:** Good Samaritan Hospital – White Oak Room, 3815 Highland Ave., Downers Grove, IL

**Details:** For more information contact Richard Carr at (847) 253-2920 or [caasg@aol.com](mailto:caasg@aol.com).

– **Saturday, December 1, 2012** –

#### **South FL Ataxia Support Group Meeting**

**Time:** Noon – 3 p.m.

**Location:** TBA

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

– **Saturday, December 8, 2012** –

#### **Central Minnesota**

#### **Ataxia Support Group Meeting**

**Time:** 10 a.m. – noon

**Location:** Liberty Savings Bank, 111 7th Ave. S. #101, St. Cloud, MN 56302

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

#### **Greater Atlanta Ataxia Support Group**

#### **Holiday Party**

**Time:** 2 – 5 p.m.

**Location:** Emory Center for Rehabilitation Medicine, 1441 Clifton Rd., Room 101, Atlanta, GA 30322

**Details:** For more information contact Dave Zilles at (770) 399-6710 or [dzilles@earthlink.net](mailto:dzilles@earthlink.net).

#### **Kansas City Area Ataxia Support Group Meeting**

**Time:** 2 – 4 p.m. the second Saturday every other month

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

**Details:** For more information contact Lois Goodman at (816) 257-2428 or Jim Clark at (816) 468-7260 or [clarkstone9348@sbcglobal.net](mailto:clarkstone9348@sbcglobal.net).

#### **North Texas Ataxia Support Group Meeting**

**Time:** 10 a.m. – noon the second Saturday of every month

**Location:** Las Colinas Cancer Center located at 7415 Las Colinas Blvd., Irving, TX 75039

**Details:** Parking is free and the building is handicap accessible. We meet in the front lobby of the Las Colinas Cancer Center, a one-story building behind the Regions Bank. There is a map on their web site, [www.LasColinasCancerCenter.com](http://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 concerns from caregivers, patients and families. For more information please contact David Henry Jr. at [cheve11e@sbcglobal.net](mailto:cheve11e@sbcglobal.net).

#### **Orange County Ataxia Support Group**

#### **Holiday Gathering**

**Time:** 4 – 5 p.m.

*Calendar of Events*  
Continued from page 45

**Location:** TBD

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

– **Wednesday, December 12, 2012** –

**Willamette Valley Ataxia Support Group Meeting**

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

**Location:** Albany General Hospital, 1046 6th Ave. SW, Albany, OR 97321

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

– **Saturday, December 15, 2012** –

**Greater Cincinnati Area Ataxia Support Group Meeting**

**Time:** 1 – 3 p.m.

**Location:** Groesbeck Public Library, 2994 W. Galbraith Rd., Cincinnati, OH

**Details:** For more information contact Jennifer Mueller at (513) 834-7002 or [jenmu@yahoo.com](mailto:jenmu@yahoo.com).

**Twin Cities Ataxia Support Group Holiday Party**

**Time:** 10 a.m. the third Saturday of every month

**Location:** Langton Place, which is located on the south side of the road on County Rd. D roughly four-tenths of a mile east of I-35W in Roseville at 1910 W. City Rd. D., Roseville, MN 55112

**Details:** We wanted to provide a central location that it easy to access which is why we picked this place. Please join us, and make new connections! Family and friends of an afflicted individual are always welcome. For more information contact Lenore Healey Schultz at (612) 724-3784 or

[cshultz.lenore@yahoo.com](mailto:cshultz.lenore@yahoo.com).

**INFORMATIONAL AND  
AWARENESS EVENTS**

– **Saturday, October 6, 2012** –

**Central Texas Walk n' Roll for Ataxia**

**Time:** 9 a.m.

**Location:** San Gabriel Park, Georgetown, TX

**Details:** Walk n' Roll registration is \$25 and includes a T-shirt. If you have any questions, comments, or suggestions contact Linda Crawley at [lcrawley57@gmail.com](mailto:lcrawley57@gmail.com) or (512) 635-9478. All proceeds benefit the National Ataxia Foundation. <https://naf.myetap.org/fund-raiser/12TXWnR/>

**Dewayne's Walk, Run n' Roll for Ataxia**

**Time:** 7:30 a.m.

**Location:** First Baptist Church, 441 Lewie St., Gilbert, SC 29054

**Details:** For more information or to volunteer contact Anna Hite at (803) 532-2447 or [doca35@att.net](mailto:doca35@att.net). All proceeds benefit the National Ataxia Foundation.

– **Thursday, November 15, 2012** –

**Cruise for Ataxia Awareness**

**Location:** Tampa, FL

**Details:** Join the West Central FL Ataxia Support Group November 15-19 on Royal Caribbean International's "Jewel of the Seas." Departing Thursday, November 15; embark in Tampa. Returning Monday, November 19; disembark at 9 a.m. in Tampa. Itinerary: Tampa; Day at Sea; Cozumel, Mexico; Day at Sea; Tampa. For booking or for more information, please contact Cindy Steever-Ziegler at (239) 878-3092 or [csteever@msn.com](mailto:csteever@msn.com). ❖

## Coordinative Training Fact Sheet

Ludger Schöls, MD, is full professor at the Department of Neurology, University of Tübingen where he heads a specialty outpatient clinic for neurodegenerative diseases. In 2009 a physiotherapy concept was developed by Doris Brötz, Tübingen, Germany, and then studied with the results published in *Neurology* 2009; 73:1823-1830. The research demonstrated that this type of physical therapy works for ataxia.

With Doris Brötz's permission, the National Ataxia Foundation has created a fact sheet with

diagrams and instructions for these exercises. Dr. Schöls reported that although the exercises do not solve the disease, there is a good chance that movement will improve and it is beneficial.

The fact sheet is available at [www.ataxia.org](http://www.ataxia.org). If you prefer to receive a printed copy, please e-mail [naf@ataxia.org](mailto:naf@ataxia.org) and provide your full name and complete mailing address.

You should consult with your physician or physical therapist before beginning any new exercise program.

# Memorials and In Your Honor

The National Ataxia Foundation is grateful to those who have made contributions in memory or in honor of their friends and families whose names are listed below. This list reflects contributions made in June 2012 through July 2012. We are sorry that we cannot separate the memorial contributions from those made in honor of someone, as sometimes the person making the contribution does not let us know if the contribution is a memorial or in honor of their friend or family member.

Carleen Augustyn	Charles Eustache	Yvonne Johnson	Ellen Moetsch	Cheryl Serge
Sharon Baggett	Daniel Eustache	Keiko Kain	Alfred Moline	James Skok
Jay Bambery	Floyd Eustache	Barry Karas	Carol Mullen	Marian Smith
Jeffery Barberi	Jeanette Eustache-	Jamie Kosieracki	Michael Nagle	Terry Snider
Mary Barton	Thaman	Chester Kulis	Abel & Amabel	Stafford Children
Charles Bearint	Trinity Falk	Madelyn Leake	Navar Wedding	Stafford Family
Ted Benson	Jill Flinn	James Lehr	Gwendolyn	Joseph Stammer
Fred Blasberg	Steve Flinn	Johna Leidholt	Nygaard	Marilyn Stevens
David Brown	Jerry Frey	Howard Levine	Paula Partilla	Dawn Stewart
Bob Burman	Ronald Goossen	Peggy Littlejohn	Steve Perry	Joan Swartz
Edward Burman	Brenda Graner	Irene Littleton	Domonick Pollino	Joe Sweeney
Jim Burman	Duane Graner	Walter Lowry	Kim Poor	Mike Sweeney
Adonis Carey	Lawrence Graner	Caryn Mahaffy	Charity Ranger	Tom Sweeney
Carey Family	Diane Greer	Clarence Marsh	Jimmy Richards	Ernest Talarico
John Caruso	Larsen Gregory	Sister Mary Baker	Sherri Richwine	Tiffinay Talarico-
Grace Case	Richard Gregory	Anthony	Janet Riley	Compiano
Tju-Ko Chuang	Donna	Massanova	Sally Riley	Fayne Thiel
Kevin Cook	Gruetzmacher	Larry Massanova	David Robinson	Patricia Tobias
Larry Cooley	Katie Taylor & Rob	Sandra Massanova	Kenneth	Cecelia Urbanski
Lola Cooley	Guptill Wedding	Vic Masserant	Rosthauser	Jacob Van-Buren
Roger Cooley	Dan Gurtner	Family	Tom Sander	Linda
Mary Danson	Marcella Hansen	Nell McDaniel	Ace Santa Croce	VanValkenburg
Joe DeCrescenzo	Donald Hardy	Charlie McLaughlin	Kenneth Saunders	Barry Washburn
Timothy DeMint	Pennie Haydon	Earl McLaughlin, Jr.	Gavin Schenck	Vernon West
Connie	Johnny Hogan	Mike & Chenoa	George Schenck	David Westrick
DiVincentis	Sidney Howell	McMullin	Mary Schmidt	Elizabeth Wright
Fred Donnelly	Krista Humes	Wedding	John Schooley	Joanne Yeager
Rick Donnelly	Dean Johnson	Linda Meier	Mary Segura	Hitomi Zeller
Andrew Egeressy	Kerry Johnson	Vivian Mestayer	Derek Semler	Jon Zilles



## Remembering NAF in Your Will

Each year we are reminded by the kindness of others who have named the National Ataxia Foundation as a beneficiary in their wills.

These planned gifts have made a profound impact on NAF's ability to fund important research and programs and are felt for years after they are gone.

Many times NAF is unaware of these gifts until after the donor has departed. We are truly grateful to those who have named NAF in their wills

and are honored to follow the last wishes of the donor.

Please know that gifts through wills and estates have enabled NAF to support a number of crucial research studies, along with important programs and operational support.

We are truly grateful to all who have named NAF in their Wills. Your kindness has a lasting impact in giving all of us hope.

Thank you!



# National Ataxia Foundation

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

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Permit No. 32

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

## GIFT – HONOR – MEMORIAL

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

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

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

My contribution is:

- In Memory    In Honor    Gift Membership

Name \_\_\_\_\_

Occasion \_\_\_\_\_

Send Acknowledgment Card to:

Name \_\_\_\_\_

Address \_\_\_\_\_

City/State/Zip \_\_\_\_\_

From:

Name \_\_\_\_\_

Address \_\_\_\_\_

City/State/Zip \_\_\_\_\_

## MEMBERSHIP

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

- Lifetime membership                      \$500

*Annual memberships:*

- Patron membership                      \$100-\$499

- Professional membership              \$55

- Individual                                  \$35

- Household                                  \$55

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

Name \_\_\_\_\_

Address \_\_\_\_\_

City/State/Zip \_\_\_\_\_

Phone \_\_\_\_\_

E-Mail \_\_\_\_\_

- Yes, sign me up for NAF e-mails

## PAYMENT INFORMATION

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

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

Total Amount Enclosed \$ \_\_\_\_\_

Credit Card:  Visa  MasterCard  Discover

Name on Card \_\_\_\_\_

Card # \_\_\_\_\_

Exp. Date \_\_\_\_\_ CVV # \_\_\_\_\_

Signature \_\_\_\_\_

Phone Number \_\_\_\_\_