

# Generations

**SPECIAL EXPANDED EDITION**

*The Official Publication of the National Ataxia Foundation*

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## National Ataxia Foundation Annual Research Drive Begins October 15

Nobel Prize winner Albert Szent-Gyorgyi once said “Research is to see what everybody has seen and think what nobody has thought.” In this issue of *Generations* you will see the promising results of important and innovative ataxia research studies that were conducted in fiscal year 2012 by many of the world’s leading and cutting-edge ataxia scientists.

Much of the funds to support these important ataxia research studies were made possible by you: our generous donors who contributed to the 2011 NAF Annual Ataxia Research Drive.

Through your support, 19 important research studies were funded. The 2012 NAF Annual Ataxia Research Drive saw additional support which enabled NAF to fund \$1 million of promising ataxia research studies around the world.

We ask for your continued support of this year’s National Ataxia Foundation Annual Ataxia Research Drive, “Research ... Finding Answers.” NAF is currently reviewing 81 ataxia research applications from 14 countries and five continents. The research focus of these applications include many forms of SCAs, Friedreich’s ataxia, Sporadic ataxia, AOA, Episodic ataxia, A-T, new gene discoveries, and others. With your help, the most promising of these studies will be funded in late December for fiscal year 2014.

Albert Szent-Gyorgyi also said, “Research is four things: brains with which to think, eyes with which to see, machines with which to measure, and fourth, money.” Three of these parts we have at various leading institutions around the world. The fourth part, money, is what we need now. Funds raised through the 2013 NAF Annual Ataxia Research Drive will tremendously help in our efforts to support the best science in the world. Each research dollar brings us closer

### Inside This Issue

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**The deadline for the Winter issue of Generations is November 1.**

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to finding answers to end ataxia.

Your 2013 NAF Annual Ataxia Research Drive letter will be in the mail in mid-October or you may support the ataxia research drive on-line at [www.ataxia.org](http://www.ataxia.org) from October 15 – December 15.

The National Ataxia Foundation is truly

thankful to you for your continued generosity.

In this issue of *Generations* you will see research summaries of studies that were funded for fiscal year 2012. It goes without saying that many of these important ataxia research studies would not have been funded without the help and generosity of our donors who supported the annual ataxia research drive. Your support is far reaching in continuing NAF's efforts to support promising world-wide ataxia research. ❖

## Meet Ataxia Investigators at the 2014 AMM

The Fifth Ataxia Investigators Meeting, "AIM 2014: Advancing Toward Therapeutics," will assemble an international roster of ataxia investigators to focus on the most recent scientific advances and emerging translational approaches toward therapy. This meeting will take place just prior to the Annual Membership Meeting of the National Ataxia Foundation.

One of the objectives of the AIM 2014 is to promote junior investigators by giving them an opportunity to present their work and to meet persons with ataxia so they can see firsthand the impact of their ataxia research.

Dr. Harry Orr, NAF's Research Director and Director of AIM 2014, stated "Many young investigators have not met patients with ataxia. It can be galvanizing to one's career to participate in question and answer sessions with patients and to hear from them how the disease impacts them and how much they appreciate their research efforts."

To accomplish that objective, a Junior Investigator/Patient Poster Session has been scheduled within the investigator meeting. Annual meeting attendees can meet investigators from around the world on Thursday, March 20, 2014 from 5:15 p.m. – 6:15 p.m. to view their scientific research posters. We welcome persons with ataxia and family members to engage in this opportunity to interact with ataxia researchers.

We encourage you to make your travel



**Learning more about ataxia can be fun!**

arrangements so that you can arrive in Las Vegas early enough on Thursday, March 20, 2014 to have the opportunity to view the scientific posters and meet these researchers who are earnestly seeking to better understand the disease mechanism and translate that knowledge into therapies and treatments for ataxia. ❖

## 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, motorcycle or motor home, please call 1-800-240-0160 or go online at [donateacar.com](http://donateacar.com). 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.



# Join the CoRDS Registry for the National Ataxia Foundation

The Coordination of Rare Diseases at Sanford (CoRDS) national rare disease registry is hosting a patient registry for individuals diagnosed with Ataxia. Individuals who are undiagnosed but at risk for ataxia are also eligible to enroll.

A registry is a database of information about individuals with a specific condition. The CoRDS registry provides a secure way for participants to make their basic medical history known to researchers without sacrificing their privacy.

Participation is expected to help accelerate research focused on all forms of ataxia by providing a resource through which researchers can identify people who may be interested in participating in research studies. If participants choose to share their de-identified information with researchers, they may be contacted about opportunities to participate in research. These could include natural history studies, clinical trials or other research projects.

Participation is voluntary and those who enroll may withdraw at any time. Participants can update their information at any time, but CoRDS will contact participants annually to update their information.

**Who can participate:** Anyone diagnosed with any type of Ataxia or those who are undiagnosed but at risk for ataxia.

**How to enroll:** If you want to enroll in

CoRDS, first fill out the CoRDS Registry form at [www.sanfordresearch.org/cordsregistryform](http://www.sanfordresearch.org/cordsregistryform) and indicate whether you prefer to complete enrollment online or by mail. You can also indicate who you were referred by (name of organization/provider) and that you would like to join the disease-specific registry for the National Ataxia Foundation (NAF).

If you choose to enroll online, CoRDS will send you an email that includes a username and password to log-in to the secure site and complete the necessary forms. For those who prefer not to enroll online, CoRDS will send the enrollment forms in the mail. Completing the forms take approximately 20 minutes and you will not be enrolled in the registry until you have completed the forms.

**For more information on CoRDS and/or enrollment, visit [www.sanfordresearch.org/cords](http://www.sanfordresearch.org/cords) to:**

- view a CoRDS enrollment tutorial;
- view the CoRDS FAQ page (click on “Participants”);

**Questions for CoRDS?** Contact CoRDS at [cords@sanfordhealth.org](mailto:cords@sanfordhealth.org) or (605) 312-6423.

**Questions for NAF?** Contact the National Ataxia Foundation at [naf@ataxia.org](mailto:naf@ataxia.org) or (763) 553-0020. ❖

Pioneer SCA Translational Grant Award

# Development of Ataxin-7 ASO Knock-Down Therapy to Treat SCA7

By **Albert La Spada, MD, PhD**  
University of California, San Diego

*The following is a research summary of a grant funded by NAF for fiscal year 2012.*

The purpose of this project is to develop a treatment for SCA7 patients who are going blind due to the retinal degeneration that occurs in this disease. In this study, we are taking advantage of a powerful approach that was recently developed to treat neurodegenerative diseases due to the production of a toxic protein. Years of research have established that if we can reduce the amount of the toxic protein being produced, then we can stem progression of a neurodegenerative disease, or even reverse it. One successful approach has been to generate an “antisense oligonucleotide” or ASO that is perfectly complementary to the disease gene RNA, and will hybridize with the single-stranded RNA to create a duplex molecule that is recognized by RNase H and destroyed. In this way, the disease gene RNA is reduced, resulting in less RNA translation, and therefore less protein. SCA7 retinal degeneration offers a unique opportunity to develop ataxin-7 ASOs and then inject them into the eyes of patients to potentially treat the visual loss that these patients suffer. Importantly, ISIS Pharmaceuticals, our industrial collaborator, has experience creating ASO therapy for ocular disease, with one drug approved by the FDA and is currently in use in patients with CMV retinitis. In this project, we are creating ataxin-7 ASOs, validating them for use in mice, and performing preclinical trials in SCA7 mice to determine if we can prevent blindness, or retard its progression.

When we began this project, we had identified lead ASOs that successfully knock-down ataxin-7 in the brains of mice. We have taken these leads

and attempted to inject them into the retinas of mice to confirm that they can knock-down ataxin-7 in the mouse eye. While the technique for delivery is difficult in the mouse (because the eye is small), we have performed it successfully numerous times now without complications. However, despite successful delivery, our initial leads did not possess sufficient potency to achieve a robust knock-down of ataxin-7 upon ocular injection in validation trials performed in mice. After further consultation with ISIS, we have turned to a more potent ASO formulation, based upon the latest chemistry, known as “cET chemistry.” Without explaining the chemical approach in detail, this strategy yields an ASO with increased binding affinity, resulting in greater potency. The issue here is to achieve a potent, non-toxic ASO drug compound, as delivery to the eye allows for only small quantities of material to be injected. To further improve potency, we are now creating 16-mer ASOs with a 3-10-3 structure, another modification that yields greater potency.

We recently completed a large screen of



**Dr. Albert La Spada**

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*La Spada Research Summary**Continued from page 5*

ataxin-7 cET – 3-10-3 ASOs, and we have a satisfactory number of promising leads (~12). These leads are being re-screened in the mouse brain to identify the best ASOs to move forward into the mouse eye. After we achieve successful knock-down of ataxin-7 in the mouse eye, then we can move forward with our final aim to test if the ataxin-7 ASO is effective in treating SCA7 retinal degeneration. As ASOs have been approved for clinical trials in human patients with ALS and Huntington's disease, we are confident that FDA approval for use in SCA7 patients will be straightforward, if we are successful. Indeed, a very recent publication in the journal *Neuron* has just shown how effective ASO therapy was in a mouse model of Huntington's disease; hence, we are confident that we are on the right track with this approach. Furthermore, we have just completed a study in SCA7 mice where we "turned off" the expression of the mutant gene, and found that uncoordinated mice with motor problems fully regained their motor function, underscoring that reduced expression of disease protein should prevent disease progression, and that recovery of function may even be possible in these diseases.

The other strategy that we are taking utilizes single-stranded short-interfering RNAs (ss-siRNAs), and in collaboration with ISIS Pharmaceuticals, Inc. and Dr. David Corey, we have screened and identified a set of CAG targeting ss-siRNAs for use in the SCA7 knock-in mouse model, that develops a rapidly progressive retinal degeneration phenotype with mice going blind by ~12 weeks of age. One key advantage to the CAG ss-siRNA approach is that this strategy has been shown to preferentially target the mutant allele, since the CAG repeat is much longer on the mutant allele than it is on a normal allele. (Recall that SCA7 is a dominant disease; hence, patients carry one mutant allele and one normal allele.) With this approach, knock-down of the

normal allele is minimal, as we have validated in fibroblast cell lines taken from patients where we have used Western blot analysis to quantify the protein expression levels of ataxin-7. As CAG ss-siRNAs promote reduced translation of their targets without promoting substantial RNA degradation, measurement of protein expression is necessary to gauge the response to the different oligonucleotide ss-siRNA "drugs" that we are testing. At this point, we are confident that CAG ss-siRNAs are capable of preferentially knocking down mutant ataxin-7 protein expression, and we are now gearing up to do a preclinical trial in SCA7 knock-in mice to test if we can prevent blindness by intravitreal injection of either ataxin-7 ASO or CAG ss-siRNA.

We will soon commence this preclinical trial and will for now test a single drug. If we can obtain additional funding, possibly through this Pioneer Award mechanism, we will expand the number of oligonucleotide drugs to be tested in preclinical trials in mice in the future. If we achieve successful results in SCA7 mice, we will be in a position to approach the FDA for planning an IND to initiate a clinical trial in SCA7 patients.

As we are optimistic that this therapeutic strategy has a good chance of preclinical success, we have already partnered with the National Eye Institute (NEI) of the NIH to organize a clinical study of SCA7. This five year study, which will be led by Dr. Brian Brooks at the NEI, will evaluate progression of SCA7 retinal disease to establish the best examination tools for following SCA7 vision loss in patients. These examination tools will then be selected for use in subsequent clinical trials that will test oligonucleotide drugs, coming out of our preclinical testing pipeline, in human SCA7 patients.

We appreciate the support provided last year for this critical therapy development project, and we remain hopeful that additional support will be possible in the near future to keep this bench-to-bedside research on track. ❖

## Pioneer SCA Translational Grant Award

# Exploring the Therapeutic Potential of VEGF in SCA1

By **Puneet Opal, MD, PhD**

Northwestern University, Chicago, IL

*The following is a research summary of a grant funded by NAF for fiscal year 2012.*

SCA1 is a dominantly inherited neurodegenerative disorder characterized by progressive motor incoordination. A CAG trinucleotide repeat expansion in the SCA1 gene results in a glutamine repeat expansion in the encoded protein, ataxin-1 (the normal length of repeats ranges from 6-40). In SCA1, cerebellar Purkinje cells are the first neurons to succumb, accounting for motor incoordination (ataxia) as the presenting symptom. Eventually, other neuronal groups are affected, leading to mild cognitive and dysexecutive symptoms. Patients eventually die from brainstem dysfunction with ensuing aspiration and respiratory complications.

Our grant focused on exploring the potential of using VEGF as a therapeutic agent in SCA1. There were two aims of the grant, and we have described progress for both the aims:

**Aim 1: Explore the possibility of infusing vascular endothelial growth factor (VEGF) as a treatment option in SCA1.**

We have made important progress in this aim. In our last progress report, we reported that we had published a manuscript describing these findings and acknowledged the support of the National Ataxia Foundation (Cvetanovic et al., *Nature Medicine* 2011). We are now comprehensively exploring the therapeutic role of VEGF in the mouse SCA1 knock-in focusing on non-cerebellar symptoms. Specifically, we have performed Morris Water Maze assays. For these assays, we have performed studies on genetic VEGF delivery, since we were concerned that water may be a source of infection from the ICV

pump. We are also delivering VEGF later in the disease to see whether VEGF continues to improve the cerebellar phenotype of the SCA1 mice. We hope to publish this work in the coming year. In addition, we are performing mechanistic experiments to determine how VEGF is exerting its beneficial effects in SCA1.



**Dr. Puneet Opal**

**Aim 2: Explore of the possibility of using VEGF as a biomarker for SCA1 toxicity.**

A major shortcoming in SCA clinical trials is the lack of biomarkers to follow disease progression. Given that we have discovered that VEGF, which is a secreted protein, is decreased in the cerebella of SCA1 mice, we will test whether there is a detectable decrease in VEGF in cerebrospinal fluid of these mice. We have had difficulty in making progress in this aim, because it has been difficult to obtain CSF samples in a relatively non-traumatic manner for mice. Instead, we have redirected this aim to begin to explore novel ways by which VEGF can be delivered. Specifically, we are collaborating with Dr. Sam Stupp, a nano-engineer to develop a

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*Opal Research Summary*  
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novel reagent: VEGF-PA (VEGF-Peptide Amphiphile). The molecular design of VEGF-PA involves covalent attachment of a previously described fifteen-amino acid VEGF mimetic sequence (KLTWQELYQLKYKGI) to a peptide amphiphile (PA) (D'Andrea et al., 2005; Webber et al., 2011). In the aqueous tissue environment, the PA induces hydrophobic collapse, while the peptide backbone of the PA promotes intermolecular-sheet hydrogen bonding. Together these effects promote the self-assembly of the VEGF-PA molecules into cylindrical nanostructures (~10 nm in diameter) that present the VEGF mimetic sequences on the surface at a high van der Waal density (~1015/cm<sup>2</sup>) (Silva et al., 2004; Webber et al., 2011).

A therapeutic strategy using VEGF-PA offers several potential advantages over both the VEGF mimetic peptide and native recombinant VEGF protein: First, VEGF-PA has a better pharmacokinetic profile for long-term delivery. This is because of (a) *a long half-life*: VEGF-PA are retained in tissues even four weeks after delivery, eventually being biodegradable by design (recombinant VEGF itself only lasts a few hours in vivo, and the 15 residue peptide itself is even less stable); (b) *slow release*: VEGF-PA form small filamentous structures that break apart slowly; (c) *polyvalent nature*: each nanoparticle presents

VEGF mimetic peptides at a high valency; this promotes receptor dimerization and sustained activation; (d) *hydration and spread in vivo*: VEGF-PA are highly hydrated, a feature that also promotes efficient and potent receptor binding and signaling. Overall these properties allow for continuous and sustained signaling. VEGF-PA also has other important qualities: they do not cause an immune response, and they are a relatively inexpensive reagent, an important feature given the high cost of using recombinant VEGF for a slowly debilitating disease like SCA1. Finally, this nanoreagent is already in an advanced stage of development (Webber et al., 2011). Specifically, VEGF-PA has been shown to enhance the proliferation, survival, and migration of endothelial cells by activating VEGF receptors, it has strong in vivo activity, inducing angiogenesis in the well-established chicken chorioallantoic membrane assay; moreover when tested in a mouse hind-limb ischemia model, VEGF-PA, given as a single bolus, enhanced tissue perfusion, resulting in limb salvage and functional recovery in gait and treadmill endurance – with beneficial effects lasting 28 days after delivery (the longest time tested) (Webber et al., 2011). It is important to point out that in this model, VEGF-PA outperformed recombinant VEGF in its sustained biological efficacy as evidenced by significant increase of angiogenesis, and a reduction in limb necrosis.

For all these reasons, we are excited to test its potential in SCA1; indeed this would be the first application of this technology for any neurodegenerative disease. In our preliminary experiments we have found that these nanoparticles spread rapidly in the brain once injected (we have used fluorescently tagged PA to show their spread in the substantia nigra as an example. We hope that in the coming year we will be able to completely validate the efficacy and safety profile of VEGF-PA.

I should also add that I am using preliminary data generated by this grant to prepare an NIH R01 application to continue this work. ❖

## 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.

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

Pioneer SCA Translational Grant Award

# Small Molecule Inhibitors of PKA: A Therapeutic Strategy for SCA1

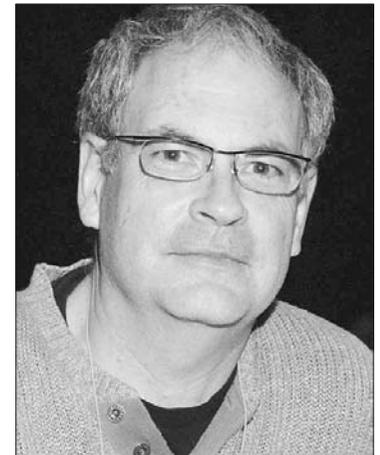
By **Harry Orr, PhD**

University of Minnesota, Minneapolis, MN

*The following is a research summary of a grant funded by NAF for fiscal year 2012. This Pioneer SCA research grant was jointly funded by NAF and the Bob Allison Ataxia Research Center (BAARC).*

Spinocerebellar ataxia-type (SCA1), a progressive lethal neurodegenerative disorder, is due to a CAG trinucleotide expansion in the Ataxin-1 gene. This mutation results in a disease-causing protein (Ataxin-1) with increased number of glutamines, 40 or greater. In addition to an increase in glutamines, evidence indicates that phosphorylation of the amino acid at position 776, a serine, is critical for a mutant Ataxin-1 to cause disease. Phosphorylation is a well-known means by which the function of a protein can be regulated. In the case of Ataxin-1, this modification regulates its clearance as well as its interaction with other cellular proteins. Both of these processes impact disease severity. Thus, the goal of our work supported by the SCA Pioneer Award from the NAF is to find a small molecule that blocks the enzyme that phosphorylates serine 776 of Ataxin-1. Identification of such a molecule would be an important step towards developing a drug for treating SCA1. In the first twelve months of funding we purchased, synthesized, or had donated from industry several potential candidates and tested them using a series of biochemical and cell-based assays for their ability to inhibit Ataxin-1 phosphorylation at serine 776. From this pool of material we selected the 25 best compounds (commercial and synthetic) for further analysis. These compounds are now being tested for the best combination of physicochemical properties that are known to be predictive of having the highest likelihood of being a good drug. Once this analysis is

completed, during the current year of funding the best 1-2 of these compounds will be screened for their ability to modify disease using our SCA1 mouse model. Finding a high-quality small molecule with validated biology



**Dr. Harry Orr**

(i.e. has treatment efficacy in our SCA1 mouse model) will be critical for a successful submission of an application to the National Institutes of Health (NIH) Therapeutics for Rare and Neglected Diseases Program for final development of potent and selective inhibitors of Ataxin-1 serine 776 phosphorylation into a drug that can then be tested in SCA1 patients. ❖

## Research Drive

The National Ataxia Foundation needs your help in supporting promising ataxia research by contributing to the 2013 Annual Ataxia Research Drive.

Please make your online gift today at [www.ataxia.org](http://www.ataxia.org), and help our cause by spreading the word to your friends and family. Thank you.

Pioneer SCA Translational Grant Award

# Novel Cell-Based Screens for Therapeutic Compounds in SCA3

By Henry Paulson, MD, PhD

University of Michigan, Ann Arbor, MI

*The following is a research summary of a grant funded by NAF for fiscal year 2012.*

This two year proposal has three aims, the first two of which we proposed to accomplish in the first year. The studies take advantage of two cell-based assays we developed, one of which assesses levels of the Spinocerebellar ataxia type 3 (SCA3) disease protein and one of which assesses the formation of early aggregates, or oligomers, by this disease protein.

Aim 1 seeks to confirm activity of identified compounds in follow-up screens employing cerebellar slice culture derived from an appropriate mouse model of SCA3. Aim 2 employs our two cell-based assays to screen custom libraries that include many modulators of protein quality control and a natural products collection of ~25,000 compounds. Aim 3 (second year of the proposal) seeks to test whether a promising

compound from Aims 1 and 2 mitigates disease in the SCA3 mouse model.

In year one, we largely completed aims 1 and 2. As we move into year two, we are moving toward clinical tests in an appropriate mouse model of SCA3. To achieve Aim 1, we first established an effective method for brain stem/cerebellum slice cultures derived for the SCA3 mouse model. Of the 10 promising compounds identified from our initial screens, nine compounds were tested in brain slices from the mouse model. At least two of the compounds were confirmed to reduce levels of the mutant disease protein. One of these FDA-approved compounds is active in the brain and widely used as a medication, thus is a promising compound to be tested in the coming year in the mouse model of SCA3.

In Aim 2 we proposed to screen custom libraries, including collections of known proteostasis modulators and natural products. In collaboration with the University of Michigan Center for Chemical Genomics (CCG) we assembled a set of focused libraries comprising 1,267 compounds. We successfully screened the focused libraries using one of our cell based assays. A subset of 120 compounds that showed more than 20% of disease protein reduction and good cell viability were then subjected to a dose-response screen (DRS). Analysis of the dose-response screen has been completed, and we are now determining which of the new compounds will be advanced to further studies in secondary screens in year two. ❖

## SCA Study

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

You will lie in the scanner for ~1.5 hour while listening to the music of your choice. Reimbursement for travel expenses is available and you will be compensated for your time.

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

Young Investigator Research Grant Award

# Diagnosis of Rare and Novel Genetic Cerebellar Ataxias Using Next-Generation Sequencing

By **Brent L. Fogel, MD, PhD**

*University of California, Los Angeles, CA*

*The following is a research summary of a grant funded by NAF for fiscal year 2012.*

I thank the National Ataxia Foundation for support of the work in my laboratory to identify and diagnose rare and novel genetic ataxias. I wish to take this opportunity to provide a brief summary regarding the progress we have made in 2012, as a second year of funding for this award is currently underway.

To better diagnose genetic ataxias and identify novel disease genes, my lab uses a technology called next-generation sequencing, which allows rapid and efficient examination of the more than 20,000 expressed genes in a patient's genome (termed the "exome"). This simplifies the challenge posed by the fact that at least 60 different genes cause dominant or recessive disease with cerebellar ataxia as a primary feature, and well over a hundred other diseases exist which may include cerebellar ataxia as an associated symptom. Although approximately 50% of familial cases are due to mutations in just a few genes (SCA1, SCA2, SCA3, SCA6, SCA7, and Friedreich ataxia), the remaining genetic cases individually account for 1% or less of all cases worldwide each, so testing of genes individually is unlikely to be helpful diagnostically. Exome sequencing provides a rapid and cost-effective means of viewing all ataxia genes at once, streamlining and expediting diagnosis.

In the first aim of this project, I proposed to use next-generation sequencing as a means of testing for known ataxia genes. Because the exome rep-

resents only 1-2% of the entire genome we must first isolate or "capture" that portion for sequencing, hence it is important to be certain we are not "missing" important sequences (i.e., a known ataxia gene). To test this, we compared exome data from six individuals and determined that, at a minimum, more than 80% of all targeted nucleotides (including all reported ataxia genes associated with protein-coding mutations) are being sequenced at least 10 times each, assuming that we can obtain an accurate picture of



**Dr. Brent L. Fogel**

the genetic variation within each individual and will effectively be able to identify coding mutation in known ataxia genes. We have now used these methods to examine several large families and individual patients with sporadic ataxia, identifying approximately 25% with suspected disease-causing mutations in rare ataxia genes. Of note, the majority of these mutations were novel, contributing to the diversity of known disease-

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*Continued on page 12*

*Fogel Research Summary*  
*Continued from page 11*

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casing variation for these genes.

The second portion of my proposal focused on work to identify the genetic cause of cerebellar ataxia in a series of families whose cause is currently unknown. We selected five families with dominant ataxia for the initial test of this strategy. Sequencing of the index cases in all families revealed that one family harbored a mutation of a known ataxia gene whereas the rest did not. Sequencing exomes from additional members of each family have allowed us to reduce the number of potential disease-causing variants to less than 10 in each family and we are currently performing detailed molecular analyses to determine the specific variant that is causing disease. The methods we are using to do this will be

readily applicable to the screening of potential disease-causing variants in future families that we and others study.

Once completed, the work begun during this project will provide exciting new information for the ataxia community. The validation of new diagnostic strategies and the identification of novel ataxia genes will ultimately provide physicians with new tools for diagnosing patients and, beyond that, will uncover new insights into the molecular etiologies of cerebellar ataxia to further advance our knowledge of how the cerebellum functions, what goes wrong in ataxia, and what we, as physicians and researchers, can do to someday cure these progressively debilitating illnesses. I thank the National Ataxia Foundation for helping me contribute to this important mission. ❖

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Research Grant Award

# RNA Interference Therapy for Spinocerebellar Ataxia 7 (SCA7)

*By Beverly Davidson, PhD*  
*University of Iowa, Iowa City, IA*

*The following is a research summary of a grant funded by NAF for fiscal year 2012.*

Spinocerebellar ataxia 7 (SCA7) is a neurological disease characterized by loss of motor coordination and vision loss. Currently there are no effective treatment strategies for this disease. SCA7 is caused by a mutation in the gene ataxin-7, which leads to the production of a toxic protein causing death of Purkinje neurons in the cerebellum and photoreceptors in the retina. Purkinje neurons play a major role in motor coordination and balance and hence SCA7 patients experience ataxia. We hypothesized that targeting the root of the problem, i.e., reducing the levels of the toxic protein in the Purkinje

neurons in the cerebellum and photoreceptors in the retina would alleviate the degeneration and improve disease phenotypes.

To address our hypothesis, we first obtained and characterized the phenotypes of a mouse model of SCA7 (SCA7-92Q) expressing the human mutant ataxin-7 gene. The ataxia phenotype of these mice was assessed by several behavioral assays to test motor coordination and balance. We observed that the onset of ataxia in the SCA7 mice occurs at ~20 weeks of age and progressively worsens, with death occurring ~45 weeks of age. To assess the retinal phenotype, ►

electroretinogram (ERG) recordings were taken at 10-week intervals. No abnormalities were noticed in the ERG recordings. Funduscopy and histological analysis at end stages (~45 weeks of age) were performed and no loss of cells or retinal phenotype was observed when compared to the non-diseased littermates. However, the human mutant ataxin-7 gene is expressed in the retina as seen by histological analysis and hence we tested our ability to reduce ataxin-7 in the retina as well.

We tested two different strategies; a) reducing the levels of mutant ataxin-7 as well as the normal mouse ataxin-7 and b) reducing the levels of mutant ataxin-7 alone.

When we reduced the levels of ataxin-7 in the Purkinje neurons of the cerebellum and the retina of the SCA7 mouse pre-symptomatically, we were able to demonstrate a significant reduction (~50%) in ataxin-7 expression levels in the cerebellum and in the retina. Long-term reduction in the levels of mutant and normal ataxin-7 in the cerebellum resulted in a significant

improvement of motor coordination, balance and gait. Histological analysis is currently being performed on the mouse cerebellar tissue to assess cerebellar morphology and toxicity. Retinal studies are currently being performed to assess long-term effects of reducing normal and mutant ataxin-7 in the retina.

NAF funding has enabled us to make significant progress to test our hypothesis: to identify a safe and effective treatment strategy for SCA7. Our studies indicate that partial reduction of both normal and mutant ataxin-7 expression in cerebellar Purkinje cells is safe and effective long-term in the SCA7-92Q mouse model. ❖



**Dr. Beverly Davidson**

## A Child's Perspective

*By Ellen Stamelos*



**Ellen Stamelos**

I have spinocerebellar ataxia type 6 (SCA-6). The first symptom we experience in my family is loss of balance, so several years ago I went to a physical therapist to get help. One of the exercises he gave me was to walk heel-to-toe. I had a ballet bar installed in a hallway in my house and I walk heel-to-toe, forward and backward a few times a week.

This summer I spent several weeks with my sister where we walk to a rec center that has an exercise room. There is a long ramp with hand rails that goes down to the swimming pool off of which there is an exercise room and an arts and craft room. As part of my exercise routine I walk heel-to-toe up and down that ramp.

One day the summer camp students walked down the ramp into the arts and crafts room while I was practicing my walking. One of the older boys, about 12 years old, lingered in the doorway watching me. Some other students came over to see what he was watching. One little girl whispered, "What's she doing?" He answered, "She's practicing tight rope walking." ❖



The following is a listing of other ataxia investigators who received tissue for their own research: Olaf Riess, Peter Bauer, Angela Berg, X-J Li, Huu Phuc Nguyen, Tübingen, Germany; Ilya Bezprovanny, Charles White, Dallas, TX; Albert LaSpada, Seattle, WA; Stefan Pulst, Los Angeles, CA (now Salt Lake City, UT); Christopher Gomez, Minneapolis, MN (now Chicago, IL); Daniel Geschwind, Giovanni Coppola, Los Angeles, CA; Gino Cortopassi, Sacramento, CA; Sonia Levi, Paolo Santambrogio, Milan, Italy; Luis Pereira de Almeida, Coimbra, Portugal; Shai Shoham, Jerusalem, Israel; Paul Hahn, Benoit Giasson, Philadelphia, PA; Grazia Isaya, Rochester, MN; Michael Kruer, Portland, OR; Miriam Cnop, Brussels, Belgium; Mark Payne, Indianapolis, IN; Erika Becker, Sydney, Australia; Partha S. Sarka, Galveston, TX; Marek Napierala, Houston, TX; Alice Pébay, Melbourne, Australia; Sheng Han-Kuo, New York, NY; and Xavier Roucou, Sherbrooke, QC, Canada.

### Insights gained from tissue donations

The list of hereditary and sporadic ataxias in Table 1 highlights the heterogeneity of SCA and sporadic cases. This heterogeneity is now well known from molecular genetics, a discipline that has led to the genetic definition of over 30 types of SCA. Nevertheless, the mutation has remained elusive in 10–25 percent of SCA. The systematic autopsy study of sporadic cases has established that most of these patients suffered from multiple system atrophy, and that the diagnosis was not always made during life. Most ataxia researchers focus on selected SCA or recessive ataxias, and there has been little attempt to explain the shared phenotype in all forms: ataxia. The investigator has used his abundant material in a much broader approach to define the ataxia-causing lesions in several forms of hereditary ataxia, irrespective of mutation or transmission. To this end, he examined three sites of the central nervous system, namely, cerebellar cortex, dentate nucleus, and inferior olivary nucleus in SCA-1, SCA-2, SCA-3, SCA-6, SCA-7, SCA-17, and Friedreich's ataxia.

The overall result of this work was that the key damage causing ataxia affects the dentate nucleus, rather than the cerebellar cortex or the inferior olivary nucleus. This observation has immediate implication for analysis of ataxia by magnetic resonance imaging (MRI). This imaging technology is quite capable to measure the size of the dentate nucleus, and visualization of the dentate nucleus may serve as a biomarker of disease progression.

### Impact of the program

For families, an organized program of tissue donation has provided a remarkable benefit. Statements have included “closure” though this word does not cover all positive effects. The stress of caring for a severely disabled spouse, father, mother, brother, sister, or child is very high. In addition to the elusive “closure,” the feedback to the investigator has often expressed the thought that the deceased family member did



**Dr. Arnulf H. Koeppe**

not live his or her life in vain. The benefit of an autopsy for families cannot be overstated.

For the principal investigator, the program gave him unequalled insight into the neuropathology of hereditary and sporadic ataxia. It was a continuing learning process. Meeting family members before and after the death of the ataxia victim also gave him insight into what must be done to support families. Such support may come from NAF and other organizations.

For other ataxia investigators who received tissue samples, access to autopsy tissues provided and will continue to provide an opportunity to take research from in-vitro experiments or study of transgenic animals to a translational stage. ❖

## Research Grant Award

# National Ataxia Database

**By Susan Perlman, MD**

*University of California Los Angeles*

*The following is a research summary of a grant funded by NAF for fiscal year 2012.*

Funding from the National Ataxia Foundation has allowed us to provide a collaborative database application that serves as a powerful research tool for ataxia scientists, and encourages data sharing and collaboration among researchers and institutions. The database has tools for improving the quality of the data, analyzing the data, and displaying data and analysis results. NAF funding has allowed us to undertake the major task of migrating data from the Clinical Research Consortium for Spinocerebellar Ataxias (CRC-SCA) natural history study, previously housed in the Rare Disease Network (RDCRN) database, into the National Ataxia Database. This undertaking included:



**Dr. Susan Perlman**

• Creating 35 new user accounts at 13 institutions

• Creating 21 new data entry forms

- Creating data structures for 2,623 variables
- Performing extensive testing of new data structures and forms
- Programming bulk import routines for mass import of data from the RDCRN database
- Coordinating data migration with RDCRN personnel
- Installing a major upgrade of the statistical analysis functions, with five new analysis options
- Creating a customized version of the database manual for Ataxia Consortium users
- Expanding and updating on-line help pages
- Hosting nine training webinars for SCA-CSA users at 13 sites
- Holding phone consultations as needed with consortium leadership and users at various sites
- Fielding and implementing user requested updates to the database
- Modifying data entry forms in response to user requests

An example of a user requested upgrade to the database application software is a feature added allowing the user to choose from a number of “views” that offer a variety of ways to summarize the data entered in the database. This acts as a valuable project management tool, and allows project coordinators to visualize the progress of their study.

We also offer the registry to other ataxia research groups at major institutions such as Johns Hopkins. The architecture of the database facilitates collaboration and sharing of data. The funding we receive from these other groups, together with the generous support of the NAF, allows us to enable collaboration among ataxia scientists and accelerate the pace of research in the field. ❖

## Matching Gifts

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

Research Grant Award

# Non-Viral Gene Therapy for the Correction of Friedreich Ataxia iPS Cells

**By Joseph Sarsero, PhD**

*Murdoch Children's Research Institute, Parkville, VIC, Australia*

*The following is a research summary of a grant funded by NAF for fiscal year 2012.*

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 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.

Stem cell therapy has the potential to repair or replace damaged tissues and restore organ function in individuals with Friedreich ataxia. Major advances in stem cell technologies have led to the development of embryonic-like cells from adult human tissue. These cells, known as induced-pluripotent stem (iPS) cells, have essentially the same properties as embryonic stem cells, and thus can be used to derive any mature cell type.

Prior to the transplantation of nerves or heart cells derived from Friedreich ataxia iPS cells, it will be necessary to restore frataxin protein to levels compatible with normal cell function. An essential prerequisite for the clinical application of human iPS cell therapeutics will be assurance that iPS cells and derivatives do not contain genetic abnormalities introduced during their establishment or modification. The process of gene correction itself should also not contribute

unnecessary operational DNA sequences into the genome or modify extrinsic gene expression patterns.

In this project we have developed a means to correct the defect inherent in Friedreich ataxia iPS cells by a gene therapy approach that will restore normal Friedreich ataxia gene expression and does not leave any "genetic scars" in the cells. The strategy addresses major safety concerns for the clinical use of iPS cells and should facilitate compliance with regulatory requirements for the approval of the use of these cells in transplantation medicine.



**Dr. Joseph Sarsero**

The successful use of the technique developed in this project is not only relevant to the treatment of Friedreich ataxia but demonstrates the feasibility of a clinically appropriate method for the correction of stem cells of any genetic disorder that is amenable to regenerative medicine.

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

Research Grant Award

# Pilot Study of the First Knock-In Animal Model of SCA28, Harboring the M666R Mutation

By *Filippo Tempia, MD, PhD*

*Neuroscience Institute of Turin (NIT), University of Turin, Turin, Italy*

*The following is a research summary of a grant funded by NAF for fiscal year 2012.*

The spinocerebellar ataxia type 28 (SCA28) is due to mutations of the AFG3L2 gene, which cause degeneration of neurons of the cerebellum. The aim of this pilot project was to validate and study the first SCA28-knock-in mouse, which bears one of the mutations found in patients. Previous studies relied on animal models lacking the gene, which in patients is present but mutated. The first step of the validation was based on the detection of symptoms consistent with a diagnosis of ataxia. In line with the adult-age onset of SCA28 in patients, knock-in mice displayed the first motor symptoms at the age of seven months, which corresponds to middle-aged adults. At eight months of age, initial signs of damage of cerebellar neurons were detected, validating this model of ataxia. These results have been presented as preliminary data in applications for two larger grants on ataxia, which have been successful. The first grant is from the Telethon Foundation-Italy, for a three-year study on the causes of SCA28 ataxia and for the development of a new therapeutic strategy. The second grant is from the Italian Ministry of University and Research, for a three-year study on the mechanisms and the possible ways to prevent or treat several forms of ataxia including SCA28.



**Dr. Filippo Tempia**

We are very grateful to the National Ataxia Foundation for making it possible for us to acquire preliminary data, which allowed us to obtain funding for the next three years for research in the field of ataxia. ❖

## Remembering NAF in Your Will

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

Each of these gifts, which have ranged from a

thousand dollars to nearly one million dollars, have enabled NAF to fund promising ataxia research and provide meaningful programs and services to ataxia families. Their forethought and benevolence in helping others is truly their legacy. Please consider remembering NAF in your will. Thank you.

Young Investigator for SCA Research Award

# Molecular Pathogenesis Studies of Spinocerebellar Ataxia Type 1

By *Janghoo Lim, PhD*

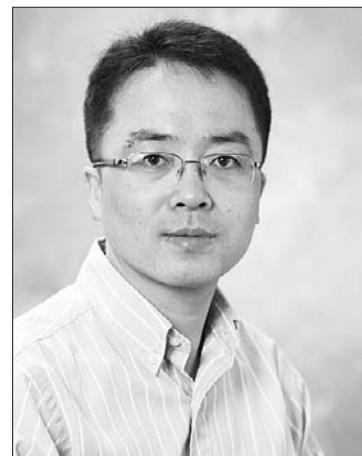
*Yale University, New Haven, CT*

*The following is a research summary of a grant funded by NAF for fiscal year 2012.*

The hereditary cerebellar ataxias are a genetically heterogeneous but clinically similar group of disorders that share many neurological and pathological features, such as loss of balance and coordination, as well as cerebellar Purkinje cell loss.

We have utilized spinocerebellar ataxia type 1 (SCA1) as a prototype of dominantly inherited cerebellar ataxias. By investigating the fundamental mechanisms of SCA1 pathogenesis, we hope to gain insight into the common key features of this and several other neurodegenerative diseases. SCA1 is caused by a polyglutamine expansion in the Ataxin1 protein.

With the National Ataxia Foundation support, we investigated the possibility that SCA1 affects Wnt signaling pathway. We found that disease-causing mutant Ataxin1 affects the activity of the Wnt- $\beta$ -catenin signaling pathway and this may cause or modulate the SCA1 disease pathogenesis. We believe that this study will lead us to better understand the pathogenic mechanisms of SCA1 and other hereditary ataxias, which we hope will open the possibility of future therapies. ❖



**Dr. Janghoo Lim**

## Tissue Donation Program

The National Ataxia Foundation has supported a Tissue Donation Program for all forms of ataxia for many years. Currently the program is undergoing some changes, but the importance of brain tissue donation upon death continues to be an important research tool that will improve the chances of finding treatments for these devastating disorders.

Dr. Arnulf Koeppen continues to oversee and facilitate a tissue donation program for Friedreich ataxia. If you have Friedreich ataxia and are interested in learning more about how to donate tissue, please contact Dr. Koeppen at [arnulf.koeppen@va.gov](mailto:arnulf.koeppen@va.gov) or (518) 626-6377.

If you have one of the SCAs, sporadic/idiopathic ataxia or multiple system atrophy or a recessively inherited ataxia other than Friedreich ataxia and would like to learn more about the brain donation program for these forms of ataxia, please contact the National Ataxia Foundation at [naf@ataxia.org](mailto:naf@ataxia.org) or (763) 553-0020.

We honor the many individuals, with the support of their family members, who gave the gift of tissue donation upon their deaths and those who have put a plan into place for tissue donation when they die. This is truly a heroic act.

Young Investigator for SCA Research Award

## Spinocerebellar Ataxia Type 28, from Molecular Hypothesis to Preclinical Treatment

By **Francesca Maltecca, PhD**

*San Raffaele Scientific Institute, Milan Italy*

*The following is a research summary of a grant funded by NAF for fiscal year 2012.*

Spinocerebellar ataxia type 28 (SCA28) is a novel form of juvenile–adult onset, slowly progressive, cerebellar ataxia characterized by unbalanced standing, gait incoordination, nystagmus, ophthalmoparesis and pyramidal signs. Several disease-causing mutations have been identified in the AFG3L2 gene. The encoded protein, AFG3L2, resides in the mitochondrion and controls multiple functional aspects of this organelle. Indeed, AFG3L2 is essential for energy production and also regulates mitochondrial morphology. We characterized a mouse model of SCA28 that recapitulates the features of patients. In fact, it shows progressive ataxia due to degeneration and loss of Purkinje cells (PCs), the typical neuropathological hallmark of SCAs. We found that in SCA28 PCs undergo “dark degeneration” since they appear shrunk, atrophic and dark. This degeneration, which generally follows increased calcium concentration associated to dysfunction of the glutamatergic system, is quite particular in SCA28, since it originates from mitochondrial dysfunction. We hypothesize that an inefficient calcium internalization operated by damaged mitochondria is one of the early events in the pathogenesis of SCA28. This defect can increase calcium concentration in PCs, thus triggering dark degeneration. Recently obtained data support our pathogenetic hypothesis. Indeed, we found that mitochondria in which AFG3L2 is dysfunctional have decreased ability to internalize calcium. We defined that this defect is closely related to an alteration of mitochondrial morphology, which is in turn dependent on inefficient ATP production. Moreover, we successfully concluded a pharmacological trial on SCA28 mice, which may make closer therapies for this disease. ❖



**Dr. Francesca Maltecca**

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Sign up today and indicate that National Ataxia Foundation is your favorite cause. It is free with no hidden fees and provides support for the important work of NAF.

Young Investigator for SCA Research Award

# Development of a Mouse Model for SCA6

**By Edgardo Rodriguez, PhD**

*Research Assistant Professor, University of Iowa*

*The following is a research summary of a grant funded by NAF for fiscal year 2012.*

Spinocerebellar Ataxia type 6 (SCA6) is a dominantly inherited form of ataxia caused by a mutation in the CACNA1A gene that encodes for a calcium channel known as Cav2.1. As it is the case with so many other ataxias, there is no effective treatment for SCA6. In addition to being an ataxia, SCA6 belongs to the family of neurological diseases known as the CAG triplet repeats disorders. Because the clinical severity of these neurodegenerative diseases, including SCA6, is linked to the presence of a “toxic” protein, turning off production of the disease protein is a promising route to therapy. We have pioneered the use of RNA interference (RNAi) as a means to block the expression of toxic disease genes in the brain. Our goal is to carry out the preclinical studies needed to bring RNAi therapy to the clinic for patients with SCA6 and other forms of dominantly inherited ataxia (i.e. SCA1, SCA2, SCA3, SCA7).

To accomplish this goal, we proposed to generate a new genetic mouse model of SCA6 that could serve as an accurate biological platform on which to test promising therapeutic interventions, including RNAi. During the past year, with funds from the Young Investigator SCA Award, we were able to generate one transgenic mouse line, called SCA6TG72, which expresses the human mutant Cav2.1 calcium channel gene carrying a disease-causing CAG repeat expansion. SCA6TG72 mice express the human mutant Cav2.1 protein in cerebellar Purkinje cells, the most vulnerable neuronal cell type in SCA6. Importantly, molecular, pathological and behavioral analyses revealed that SCA6TG72

mice mimic important aspects of human SCA6. For example, we can detect the presence of protein aggregates in SCA6TG72 Purkinje cells, a pathological hallmark of the human disease. We also measured a progressive loss of cerebellar Purkinje cells in SCA6TG72. Finally, we were able to quantify a progressive impairment in motor coordination using three different motor behavior tests.

We are currently using SCA6TG72 mice to perform the first preclinical RNAi therapy-based trial for SCA6. Within the next year we hope to report on our findings in a peer-reviewed scientific journal. The data we have gathered

thus far has also served as the basis for research grant applications to the National Institutes of Health. For example, this past summer we submitted a proposal for the development of two additional SCA6 transgenic mouse lines that will carry two different CAG repeat sizes, one with 11 CAG repeats (not expected to develop disease) and one with 24 CAG repeats (to more closely model the disease-causing allele in SCA6). It is our goal to continue studies towards the understanding of the pathogenic mechanisms that underlie SCA6 and the preclinical development of new therapeutic strategies. ❖



**Dr. Edgardo Rodriguez**

Young Investigator for SCA Research Award

# Isoforms and Polymorphisms of Ataxin-3 as Modifiers of the Pathogenesis in Spinocerebellar Ataxia Type 3

By **Thorsten Schmidt, PhD**

University of Tuebingen, Germany

*The following is a research summary of a grant funded by NAF for fiscal year 2012.*

Spinocerebellar ataxia type 3 (SCA3) or Machado-Joseph disease (MJD) is caused by an expanded number of repetitions of the three DNA elements CAG within the so called ataxin-3 gene. Everybody in the general population has between 12 and 40 repetitions of CAG in one's own ataxin-3 gene. SCA3 patients, however, have more than 62 of these CAG repeats. Everyone has two copies of the ataxin-3 gene,



**Dr. Thorsten Schmidt**

one inherited by the mother, one inherited by the father but only one of these two copies contain an expanded repeat. Statistically, patients with a higher number of CAG repeats develop first symptoms of the disease at an earlier age and patients with less have first symptoms later in life. However, this is a statistical correlation and it is not possible to predict the exact age of the onset

from just the number of CAG repeats.

For example, a SCA3 patient with 71 CAG repeats may get first symptoms as early as 25 years or not until 60 years of age. In order to improve the prediction when first symptoms may occur, we analyzed whether additional variations of the ataxin-3 gene—beside the CAG repeat—influence the age of onset. We observed that each patient has a specific combination (a so-called “haplotype”) of these different variants both in the normal and the expanded ataxin-3 copy. Interestingly, 2% of the European patients with one specific haplotype had a much later (five years later) onset of symptoms.

In this project, supported by The National Ataxia Foundation, we want to find out why this specific haplotype is protective. Within the first year of this project, we discovered that the variations of ataxin-3 modify important cellular processes causing the disease symptoms including the formation of so called protein aggregates. Interestingly, the non-affected copy of ataxin-3, with the normal CAG repeat, seems to modify these processes. The 2% of European patients with a later onset of symptoms seem to have variations of the affected protein which specifically work together to protect themselves from their toxic effect.

The results of our project will help in understanding the processes which lead to SCA3, that may lead to a better prediction of the age of onset and may point to novel targets for a possible future therapeutic intervention. ❖

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Young Investigator for SCA Research Award

# Mechanisms of Neuroprotection in Spinocerebellar Ataxia Type 3

By Sokol V. Todi, PhD

Wayne State University School of Medicine, Detroit, MI

*The following is a research summary of a grant funded by NAF for fiscal year 2012.*

Spinocerebellar Ataxia Type 3 (also known as Machado-Joseph Disease; SCA3/MJD) is perhaps the most common dominant ataxia in the world. SCA3/MJD is a progressive loss of full control of bodily movements. It arises from the expansion of a region of the ataxin-3 protein beyond normal levels from 12-42 to over 60 repeats of the amino acid glutamine. Such expansions affect several areas of the brain and the spinal cord. We do not understand well how ataxin-3 functions in cells. If we know the roles of ataxin-3, then we can explore what goes wrong in SCA3/MJD.

Our studies toward understanding the normal functions of ataxin-3 have provided clear insight into its biology. Our findings detail how ataxin-3 functions in neurons, interacts with specific protein partners, and controls how different cells, including neurons, respond to toxic stress. We are continuing our explorations into the function of ataxin-3 to understand how pathogenic mutations change its normal activities.

The second component of our work was to identify genes that we can target for SCA3/MJD therapy. We conducted, and are further expanding, a search for genes whose function we can inhibit to relieve degeneration from toxic ataxin-3. So far we have found eight enzymes that, when inhibited, rescue neurons from ataxin-3-dependent neurodegeneration.

We are now working to understand how these enzymes function and how to best design molecules to inhibit their activities as a potential treatment. ❖



Dr. Sokol V. Todi

## Friedreich Ataxia Study

Patients with early symptoms of Friedreich Ataxia ages 10 and above are needed for an MRI study to evaluate the chemistry and connectivity of the brain and spinal cord in Friedreich's ataxia at the Center for Magnetic Resonance Research at University of Minnesota.

You will lie in the scanner for ~1.5 hour while listening to the music of your choice.

Reimbursement for travel expenses is available and you will be compensated for your time.

Please note that we cannot scan you if you have Harrington rods, and we cannot scan people with diabetes at this time.

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

NAF Research Fellowship Award

# Identification of the Mutation Causing Progressive Purkinje Cell Degeneration in the Shaker Rat

By *Sukanya Karan, PhD, and Stephen Hansen, PhD*  
*University of Utah, Salt Lake City, UT*

*The following is a research summary of a grant funded by NAF for fiscal year 2012. We are very grateful for the support from NAF for this young investigator. Dr. Karan left the laboratory in August of 2012 and Dr. Stephen Hansen carried out the studies in the remaining four months. The final progress report lists the accomplishments by specific aim.*

***Aim I: Identification of a candidate region <10Mbp of the rat X-chromosome.***

To find the region of linkage, we developed a panel of 44 microsatellite markers informative that were known to be polymorphic between the WF and BN strains. We used this panel to examine 80 F2 animals generated by F1 sib-sib matings. The F1s were generated by crossing affected male WF rats with wt BN females. Shared haplotypes of WF alleles delineated the candidate region as being on rat distal Xq.

***Aim II: Characterization and identification of the shaker mutation by RNA sequencing.***

Given the recessive X-linked segregation of the shaker phenotype it is likely that the mutational mechanism is loss of gene function by missense, frame-shift, splice-site or indel mutations. RNA sequencing and analysis of expression levels may not only define secondary effects of the shaker mutation, but may provide a direct way to identify the mutant gene. We isolate RNAs from wt and shaker cerebellum at four weeks prior to onset and subjected the RNAs to deep sequencing. We focused our bioinformatics analysis on distal Xq. Very few consistent changes were identified and only one in a coding region of a gene. The respective gene is involved in calcium homeostasis. The amino acid substitution is not found in the 10K exome variants and is absent in wild-type Wistar-Furth rats.

***Aim III: Sequencing of the target region and bioinformatic analysis of variants.***

It was possible that the shaker mutation would have been outside exonic regions. Whole genome sequence analysis would have identified different kinds of mutations and different mutation locations. We did not have to use WGS as the RNA-seq approach has likely identified the mutation.

***Future work:*** We have begun cloning wild-type and mutant alleles into expression vectors to confirm whether the shaker variant is indeed a disease-causing mutation. These experiments include testing of the subcellular distribution of the respective proteins as well as their effect on cytoplasmic calcium levels.

***Overall Significance:*** No genetic variants causing PC degeneration in the rat have been identified. Compared with the mouse, the rat offers unique opportunities for the study of cell-based and device-based therapies owing to the larger size of the cerebellum and the recognized behavioral sophistication of the rat. Our deep RNA-sequencing approach appears to have identified a mutation rapidly and points to the importance of collecting human autopsy material for gene identification. Our identification of a naturally occurring mutation in the rat causing cerebellar degeneration may help the development and testing of therapies in humans. ❖

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

By *Michael Parent, NAF Executive Director*

In each issue of *Generations* I have the privilege to update you on the various activities of the National Ataxia Foundation. Today, I would like to focus on NAF's research efforts and the importance of supporting the 2013 NAF Annual Ataxia Research Drive.

NAF has been a pioneer in supporting and encouraging ataxia research since 1957. Today, NAF utilizes a multi-pronged approach to help fast-track ataxia research:

- Direct funding of ataxia research through its five research programs
- Hosting the International Ataxia Investigators Meetings (AIM)
- Sponsoring/Co-Sponsoring Medical and Scientific Conferences on Ataxia
- Partnering and Cooperation among researchers and organizations

Within the five research programs, one focus is supporting Young Investigators to encourage these scientists to pursue a career in ataxia research. Another focus has been in translational research to foster growth in the development of treatments for the ataxias. Innovative studies funded through the NAF Research "Seed Money" program gives investigators an opportunity to pursue ongoing, as well as, pilot studies. NAF's Research Fellowship Award serves as a bridge from post-doctoral positions to junior faculty positions and helps increase the possibility of these researchers to establish an independent ataxia research program.

The Fifth International Ataxia Investigators Meetings (AIM) will be held in March 2014. More than 120 of the world's leading ataxia clinicians and scientists, as well as the most

promising young investigators from around the world will attend this three day scientific conference. The AIMs are designed to help accelerate world-wide ataxia research efforts with emphasis on cooperation and collaboration within the ataxia research community.

Along with NAF initiated scientific conferences on ataxia, NAF sponsors and co-sponsors various scientific meetings each year to bring researchers together for presentations and discussion on leading-edge research on the ataxias.

In pursuit of answers to end ataxia, NAF continues to partner with other ataxia organizations, the American Academy of Neurology's American Brain Foundation, and industry leaders in support of ataxia research and scientific and medical symposiums.

To support these programs, NAF gratefully acknowledges our anonymous donor who again has so generously supported this year's research funding, The Michael and Patricia Clementz Family Fund for SCA3 Research for their continued financial commitment. To all who so generously support NAF through Walk n' Rolls, other events, our corporate and foundation friends, and to our amazing individual, family and group donors who support the annual ataxia research drive, thank you. Each of you is making a difference in bringing meaningful ataxia research forward.

October 15 will be the starting date for the 2013 NAF Annual Ataxia Research Drive. This annual research drive has proven time and time again how important each research dollar raised is in supporting promising ataxia research. Last year, due to the overwhelming response of



**Michael Parent**

*From the Desk...*

*Continued from page 25*

so many of you who generously supported the research drive, NAF was able to support 21 ataxia research studies totaling \$1 million dollars.

This year your support is even more important. NAF is currently reviewing 81 quality ataxia research proposals from 14 countries and five continents. They are worthy of your support, and will give us more answers in our fight to end ataxia.

Together we can build on our research efforts in funding the best science in the world, supporting promising translational research, bringing young investigators into the field of ataxia research, supporting innovative and cutting-edge studies to bring us closer in finding effective

treatments and ultimately a cure. Please support this year's NAF Annual Ataxia Research Drive.

This year's Research Theme is "Research ... Finding Answers." Your support of the 2013 NAF Annual Ataxia Research Drive will give us more answers in ending ataxia. Please give as generously as you can. Thank you. ❖

## E-mail Blasts

E-mail blasts from the National Ataxia Foundation are sent out periodically on ataxia research, events and other timely issues of interest. Please email your e-mail address to [julie@ataxia.org](mailto:julie@ataxia.org) so you don't miss out on important information.

# Keep Going

*Written by Cathy DeCrescenzo*

*Dedicated to my husband Joe, and all the incredible, courageous people we've met over the years through the NAF*

As morning breaks, we awaken with the unknown upon us.

We hope and pray for the best – sunshine and warmth – though, if clouds and rain are meant to be, we dig deep into our being to bring out the positive in whatever the day has up its sleeve.

We are strong, we are resilient – we keep going.

We do not falter, we do not complain – we keep going.

We do what we must to make the day bright – we do what we must to rest peacefully at night.

We gather as one to share our lives – we gather as one to continue our fight.

We hold on to each other with dignity as our journey moves forward – we hold onto each other and we do not allow fear to control us.

We are thankful for each and every day – we are thankful for our loved ones and friends who encourage us along the way.

At the end of the day, we may say a prayer or two – and, at the end of the day, with hope in our hearts, we are focused on the dawning of a new day... Tomorrow!



❖ Joe DeCrescenzo

# Anatomy of a Job Interview

By Vicki Pavilonis

I have yet to meet anyone who likes interviews. If they awarded statuettes for “Worst Interview of the Year” I have one that I feel would be in the running.

I was escorted into the interview (trying to smile and walk a straight line – felt like a Miss America contestant), and introduced to not one, not two, but THREE women conducting the interview (as if one isn’t intimidating enough), who were seated at one end of a long table. I was asked to sit at the other end – I felt like I was facing a parole board ... or a firing squad!

Not only that, but they all had long dark hair and were dressed in black – a picture of the three witches in Shakespeare’s “Macbeth” flashed into my mind. All that was missing was the boiling cauldron.

To add to the mix – as a bit of side fun to ataxia – at times, without any warning, your speech starts to slur. So, not only do I walk like I’m drunk, but I talk like it too! I discovered that drinking ice water tends to lessen the slur (docs don’t know why, but say if it works, keep doing it). So I had brought along a large cup of water with lots of ice and downed it in the car before I went in, just to be on the safe side. The interviewers were running a bit late, and so, as I was waiting to be called in I was getting nervous, which had two consequences:

- I needed to go to the bathroom after all the water, but didn’t want to leave the waiting room;
- I could feel my tongue starting to get “heavy,” a sign that soon I would start slurring my words. (Two more reasons why I wanted this to be a very quick interview.)

In previous interviews I have felt I was babbling uncontrollably (something I do when nervous), and my mind kept screaming “SHUT-UP!” but my mouth just kept talking (you know you’re in trouble when the interviewer looks at his watch).

So this time I was determined to stick to the point and give short answers (you know – name, rank, serial number), which may have come across as a bit un-cooperative (I can’t win!).

I had prepared for some questions I thought I might be asked (which, fortunately, I was), but they got me with “give three adjectives that best describe you.” My mind went totally blank, and all I could think of was “what the heck is an adjective?” Didn’t matter that I had been a literature major in college all those years ago. After a



**Vicki Pavilonis**

long pause, I said “adaptable” (they seemed to like that one). Then a longer pause and I came up with ... “flexible.” (Huh? Made me sound like I was trying out for the circus.). Then after an even longer pause, with three pairs of expectant eyes burning into my brain, the ticking of the wall clock pounding in my ears, and sweat starting to drip down my armpits, I opened my mouth and out popped ... “happy.” WHAT? I almost broke out laughing because I felt as if I had just named three of the seven dwarfs in Snow White!

I did not get called back for a second interview. ❖

## BOOKS

### — ATAXIA RESOURCES —

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

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

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

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

by Martha Nance, MD

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

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

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

This 60-page booklet is an excellent resource for those who struggle with speech and/or swallowing problems. Includes helpful suggestions. Second edition updated in 2006. \$7.50

## VIDEO/CD

#### **Ballads of a Family Man CD**

10 songs in memory of Billa Ballard. \$5

#### **“Together There is Understanding” VHS or DVD**

Discussion of ataxia. 50 minutes.

VHS \$20; DVD \$25

### — 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

## SHIRTS / MISCELLANEOUS

#### **Original NAF IAAD T-Shirt**

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

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Velcro closure. Navy embroidered logo. \$10

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

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

# Merchandise

## SHIRTS/MISCELLANEOUS

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Available in youth L, and adult small to XXX-large (XXL currently out of stock). \$10

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Limited years and sizes available. You pick the size and we'll pick the AMM. \$1 each while supplies last!

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### "Ataxia is Not a Foreign Cab"

#### Refrigerator Magnet

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#### Window Cling or Bumper Sticker

\$1 ea. or 6 for \$5

#### NAF Ataxia Awareness Band Blue

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#### NAF Ataxia Awareness Ribbon Magnet

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#### Reusable Grocery Bag with NAF and Cab Logos

\$5

#### NAF Lapel Pin \$5

#### Magnetic Power Clip

Strong magnet for super holding power featuring rubber grips. \$3

#### "Know Ataxia" Backpack

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



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# The End of a Career

By Handoyo “Trip” Triputra

My name is Handoyo “Trip” Triputra, I am the youngest of four children. I was born in Semarang, Indonesia. My parents, a successful contractor and a famous clothing designer, moved our family to the U.S. in 1980. It was a great sacrifice. My parents wanted their children to have more opportunity.

I realized in the early 90’s that I was interested in pursuing a career in law enforcement. Where I came from, being a police officer was not a highly respected career choice because of the corruption, but my parents were very supportive. I was hired as a fulltime paid reserve police officer in 1997 and worked several other jobs before finally being offered a position as a deputy sheriff in 2001. I continued in law enforcement with various positions until 2012.

In the meantime, I noticed that something was wrong with my balance. I would walk in the hall-

way and would run into the walls, start losing my balance when I got out of the car, or got up out of a chair or couch. For several years I would complain to my doctors and they would say that they believed I had “vertigo.”

I made an appointment with a general doctor whom I explained my symptoms and he immediately made me a follow-up appointment for a CAT scan, MRI and a neurologist. After reviewing the MRI, CAT scan and my symptoms they believed that I had a rare condition called “cerebellar ataxia.”

I had genetic testing done, and the results of those tests were negative. There’s a list of other reasons on how you can get this condition and all but one had been ruled out. There was “chemical exposure” on the list. After being exposed to

lots of chemicals on the job, many of the chemicals that are used in the making of methamphetamine drugs and chemicals that are found in the cultivation of marijuana, that was the only thing that made sense. (I conducted over 50 extractions of methamphetamine while assigned to the Gang Task Force.) Even my neurologist said that it is possible for me to get this condition from chemical exposure from my job as law enforcement officer.

I was formally diagnosed in May 2011. In October 2011, I was transferred from patrol to personnel for modified duty. I was at personnel for about six months (March 2012), when the county notified me via e-mail that, since my condition was “permanent and stationary,” they were going to end my modified duty status. March 27, 2012 was my last day at work. Around the same time, I filed a workers’ compensation ►►



Handoyo “Trip” Triputra

## Planning Your Trip to Vegas?

Request a “Las Vegas” guide book provided by the Las Vegas Convention and Visitors Authority to help you plan your journey! The complimentary guide book is filled with information about the city. This free guide can be requested by calling 1-877-847-4858 or you may request or download a copy at [www.lasvegas.com/planning-tools/free-visitors-guide/](http://www.lasvegas.com/planning-tools/free-visitors-guide/).

To find out more about the 2014 NAF Annual Membership Meeting, visit NAF’s website [www.ataxia.org](http://www.ataxia.org).

claim, which the county denied. I received an e-mail from County Human Resources on November 13, 2012 that the county had elected to retire me as of November 15. The county gave me a two-day notice and retired me, denied my request to cash out my Catastrophic Time Bank where the county and the department had collected 600 hours, and put my family into great financial (and medical) stress.

Fortunately, my fellow law enforcement family and the County Deputy Sheriff Relief Foundation have helped me fill part of my financial gaps with donations. The support I have received has been incredible and awe inspiring. My family and

I are blessed and grateful to be part of such a community.

Unfortunately, in a law enforcement career, we spend a lot of time trying to please others at the expense of our immediate family. Working weekends, birthdays, holidays, graveyards, swing shifts, etc., can be very stressful and affect the whole family. However, while going through this ordeal, I have learned that I can always count on my family, whether my immediate family or my extended law enforcement family and the Sheriff's Association.

If you are interested in more of my story I can be contacted at [triputra3@gmail.com](mailto:triputra3@gmail.com). ❖

## Tripped Up by Ataxia

By Jason Wolfer

I find one of the best ways to combat this dreaded marauder known as ataxia (in all its various forms) is to point out life's little challenges and laugh at them. It's either that or cry. I find it very hard to have a positive attitude or to be of help to another if I'm crying. Besides, crying would be an admission of defeat and I won't accept that. So, with that in mind, I would like to present the top five things that are a constant source of frustration and angst for me:

1. When putting a twist cap back on a bottle I would like to be able to hold on to it and not drop it on the floor five or six times ... once I manage to wrestle the thing on, I should be able to twist it straight the first time instead of making it crooked and having to re-twist another five to six times.

2. When bending over to recover the bottle cap, it would be nice not to fall forward ... banging my head into various pieces of furniture and

kitchen appliances, all of which seem to have sharpened their edges when they saw my head approaching.

3. When putting a twist tie back on the loaf of bread or other bag, it would be very helpful not to feel like I am wearing ski gloves ... or like

I need a degree in structural engineering to manipulate a two-inch piece of paper-covered wire.

4. When inserting a key into a lock I would be exceedingly happy if I could do so without the requisite two to three minutes of poking and prodding ... causing scratches that all my locks and doors can testify to ... and even when I force the key into the hole it doesn't always slide in easily because I'm applying some new kind of angle that would take a lengthy math equation to explain.

5. I would really, really like to be able to brush my teeth without also brushing my chin, cheeks, nose, forehead, and hair. ❖



Jason Wolfer

# Four Components to an Effective Physical Therapy Program for Ataxia

By Polly Swingle, PT  
The Recovery Project, LLC

*This is the first of a two-part edited excerpt of the presentation given by Polly Swingle at the 2013 Annual Membership Meeting in Detroit, MI on the essential components of an effective physical therapy program for ataxia patients. Polly Swingle is a physical therapist at Project Recovery in Detroit. In this first part, Polly addresses physical issues related to ataxia, research, the physical therapist's evaluation, characteristics of an effective program and measures used to determine improvement.*

My name is Polly Swingle and I am a local Physical Therapist (PT) in practice for over 25 years. I work for a practice called the Recovery Project in the Detroit Area. I'm also the PT who evaluates everyone who comes through the MDA clinic in Detroit. At the practice where I work, we specifically see people with neurological deficits and many of the ataxic disorders.

Many people who come to our MDA clinic are from very rural areas in Michigan and their therapists, who have gone to school and are licensed, have not seen a patient with Friedreich ataxia or the other ataxias and they are "clueless".

The following will give you information that you can take back and ask your therapist, "Can you test me on this?" or "How about if my exercise program is an hour long instead of 30 minutes?" or "How about if we address strengthening and flexibility for this amount of time?"

Ataxia is a movement disorder resulting from the incoordination of movements and inadequate postural control, which presents in balance and walking disturbances.

Cerebellar Ataxia is due to dysfunction of the cerebellum.

- Dysfunction of the vestibulocerebellum causes impaired balance and control of eye movements.
- Dysfunction of the spinocerebellum presents with wide based "drunken sailor" gait, characterized by uncertain starts and stops, lateral devi-

ations, and unequal steps.

- Dysfunction of the cerebrotocerebellum presents with intention tremors, writing abnormalities, dysarthria and dysdiadochokinesia.

When I ask patients who come to see us, "Why are you here?" the majority of them say, "Because I'm falling." So that is often the first thing; the need to get better at fall prevention because they can hurt themselves. The second thing is that ataxia is affecting their functioning and mobility.

Many patients say that they are really strong, but they keep falling. What we notice is that when we individually test the muscle strength when sitting, they are very strong, but it is the lack of coordination of their strength when walking, standing or having to use the postural muscles with the leg muscles that causes problems. It is important to address strengthening for those with ataxia.

## What does the research say?

There is on-going research in physical therapy for those with balance problems.

- Neuroplasticity evidence (via MRI) indicates balance exercises improve balance, mobility, gait, and endurance.
- Multifactorial intervention study with balance training as core component in a community-based program concluded that it "safely and effectively reduced the number of falls" ►►

in the elderly.

- Balance training shows, “encouraging results and very low risk of injury which in this study suggests that this strategy for fall prevention may be recommended for use by physical therapists.”

Research is saying that with repetition, with exercise, with doing the same normal pattern of movement over and over and over again, we can make a change. This means that it is important not to be sedentary and to exercise. I hope you understand that you need to do something and if you don't, you will lose it. We also know that if we work on strength and balance that it will reduce the risk of falling.

### **What a Physical Therapist Evaluates**

When you go to see a physical therapist, they will evaluate you in all the following areas.

- Range of Motion (ROM) of all of your joints. You need to have full range of motion with your hips, your knees, your ankles and your upper extremities, to make sure that you can functionally reach and do things with your arms.

- Strength of everything in your body.

- Foot deformities with your shoes and socks off.

- Scoliosis by looking at your spine. If you have a sign of scoliosis, that will tell us about any of the muscle imbalance of your core and which side is stronger or weaker. It is important for us to look at the activation of your core and the strength of your core.

- Cardiovascular endurance using tests to assess what kind of shape you are in. This can make up a baseline for you that can be used during your therapy to see if you are improving or not.

- Balance using specific tests that evaluate balance.

- Gait by looking at the speed, quality, and

safety of your gait.

If you are ambulatory it's also important to look at your standing ability at a counter, parallel bars or at a standing frame. A standing frame is a piece of equipment that completely supports you. It supports your hips in front and behind, as well as your knees so that you can stand-up.

### **Why is Physical Therapy and Exercise Important?**

- To prevent falls; so much of it is related to safety.

- To maintain the function that you currently have.

- To determine if there is a need for adaptive equipment.

- To remain as independent as possible.

If you are sitting using a scooter or power chair, you need to have supported seating to prevent scoliosis and to help support your trunk. When you are supported and sitting upright you are going to be better at breathing, talking, eating, swallowing and using your upper extremities.



**Polly Swingle**

### **Characteristics of an Effective Physical Therapy Program**

- Intense strength training
- Dynamic balance training
- Cardiovascular training
- Gait training
- Stretching
- Long-term participation

Have you heard from your PT that you have plateaued or that you are not making any more progress, so they need to discharge you? This is very frustrating and it is part of the industry and the way that insurance companies seem to be cutting insurance benefits for physical therapy.

*Four Components...*  
*Continued from page 33*

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Home Exercise Program (HEP) and community fitness programs are options for a long-term plan that remains effective when you are discharged from physical therapy. Work with your PT to find those programs. We tend to see people with ataxia who come back at least one time per year, kind of like a yearly tune-up. They come in, we are very familiar with them, and we see how things are progressing and adjust their HEP as needed.

Some of the community-based organizations are putting in equipment that assist people who have balance deficits or who use wheelchairs. Check with your local organizations about what they have to offer so you can go outside of your home for additional exercise.

For an effective physical therapy program there are some standardized tests that your PT can do for patients with ataxia. It gives objective information of what your status is when you start physical therapy. Then you can be objectively tested as you go through physical therapy to show change. As mentioned, you may have heard from your therapist that you are not showing any change, so they have to discharge you. With standardized testing that we are now seeing in physical therapy, the testing does show some changes which is a justification to keep you in therapy. Knowing this terminology will help you to stay in physical therapy for as long as possible.

## **Outcome Measures**

### **The Berg Balance Scale**

- A 14-item scale, rated 0-4 for each item
- Designed to assess static and dynamic balance
- Predicts multiple falls in community dwelling and institutionalized older adults
- Has strong validity and reliability
- Maximum score of 56 points
- A score of less than 45 indicates adults who are at risk for falls

This is a specific balance test. You are evaluated sitting, standing, standing on one leg, standing on two legs, with eyes open, with eyes closed and doing some reaching activities. It is an objective test that gives the participant a score on a point scale. If you have ataxia, you will probably score in the less than 45 point range.

As you go to therapy and work on strengthening, balancing and other aspects these areas should improve and this test will show a change in your score. Make sure that your therapist documents your scores and sends it to your insurance company so that you can remain in therapy.

Another positive thing is when I haven't seen my patients for six months, I will retest them. It will show if they have declined or improved. This is another positive indication that will provide justification for your physician or insurance company that you need to continue with therapy.

### **Timed Up and Go Test**

- Used to assess balance, functional mobility, and determine fall risk
- Involves timing an individual as they rise from a chair, stand, walk three meters, return and sit
- Good intra- and inter-rater reliability
- Score of 13.5 seconds indicates a fall risk in older adults

This is a common standardized test in the physical therapy industry which can be done with people who are ambulatory. You sit in a chair, and we time you as you get up, walk three meters, turn around, come back and sit down. This is another measurement that gauges your progress.

### **Six Minute Walk – the Sixth Vital Sign**

- Measures distance walked in six minutes
- Valid, reliable, sensitive, and specific confidence
- Correlates with functional ability and balance confidence



- Data on age-related norms
- Has potential to predict future health status and functional decline including:
  - Hospitalization and discharge location
  - Mortality

This is a standardized test that measures endurance. Cardiovascular endurance is one of the components that we definitely see in the population of ataxic patients. If you are affected it is usually because you are not as active or as mobile

as you were. For this test you walk for six minutes and we measure how far you walk. There is a scale that will show where you score, based upon your age.

*The second part of Polly’s presentation will be published in the Winter 2013-14 issue of Generations and will include a description of exercises with complete instructions for a 60-minute physical therapy session.* ❖



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## How Big Is a Sparrow’s Cerebellum?

*By Pete Meyerhoff – July 2013*

I am sitting in my wheelchair in front of the glass sliding door that opens to my balcony. I am fascinated by a sparrow perched on the railing.

He sees me but is unconcerned because the door is closed. Then he does a 180-degree jump-turn landing back on his two feet on the railing. It is a smooth maneuver, no struggling, no spreading his wings to maintain balance. Any human balance beam gymnast would garner a “10” in Olympic competition. He

then hop-hop-hops along the railing with little effort.

I am jealous.

He then flies off into a nearby tree full of branches. He must have done this a thousand times without getting seriously hurt. He accomplishes these feats with a cerebellum no larger than a pinhead.

I am jealous.

DEAR SPARROW,  
CAN I BORROW YOUR  
CEREBELLUM? ❖



# ASENT Annual Meeting Provides Valuable Information

*Submitted by Jenean McKay*

With the support of the National Ataxia Foundation, I have attended the ASENT (American Society for Experimental NeuroTherapeutics) annual meeting for the last five years. I am a mother with a son with sporadic ataxia. I am retired living in Washington, DC. The conference is held in the Washington, DC area. Approximately 300 attend, a highly professional group of people from all aspects of neurological research – NIH and FDA researchers and grants administrators, patient advocates, pharmaceutical companies (start-ups to the largest) and researchers from all over the world. I am not a researcher, but the mix of people leads to fascinating discussions and I feel very privileged to be there.

Here are some of the events that I found very informative:

- MIT researchers showed a paralyzed woman, who could not speak, move a bottle of water to herself by using her brain to tell the equipment what to do. This was a fascinating program and has a LOT of potential for ataxia people.

- There was a half-day panel discussion about the patient's role in research, and it was clear that patients are far more willing to take higher risks than the researchers are. Another panel was on how patient-advocate groups successfully find people for clinical trials. These groups are far more successful than very expensive ads in research journals.

- “Pipeline” events – These are five-minute

research presentations in early developmental stages, with five minutes for questions from the audience. The subject areas are varied with topics like chronic cough and the design of pain pills that won't allow a user to abuse them. About 30 topics are covered.

- Poster sessions by researchers from all over the world.

- I also have a table with ataxia materials, representing NAF at the conference. Here I don't have to explain what ataxia is, which always cheers me up.



**Jenean McKay**

The discussions about the various presentations are terrific. The best example of this is where a panel discussion about statistical evidence, the FDA had recently taken a drug off the market, with a senior FDA manager and a statistician from a major research university, and in the discussion by the attendees, there was a general agreement with the FDA action. It was a civil discussion with different opinions shared.

Because I am not a researcher, it is a real stretch for me to follow some of the presentations. But the participants are very willing to explain things. One of the researchers actually congratulated me for hanging in there in one of the very long pipeline sessions. I also make an effort to encourage the young researchers to continue their research. It is my belief that all brain research will eventually help those with ataxia.

So I encourage all of you non-researchers out there to attend scientific conferences. They need us as much as we need them!



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

57th Annual Membership Meeting  
“**Betting on Ataxia Research**”  
March 21-23, 2014



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<http://www.totalrewards.com/hotel-reservations?propCode=BLV&groupCode=SBNAF4>.

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

Request rooms in the North Tower to be closest to convention spaces. Please note all ADA rooms have been reserved. To inquire about ADA room availability or to be placed on the waiting list contact (763) 553-0020 or [lori@ataxia.org](mailto:lori@ataxia.org). Reservations at group rate will be available until

Tuesday, February 18, 2014. The NAF group rate is \$99+tax Sunday-Thursday nights and \$149+tax Friday-Saturday nights. Please note there is limited availability on discounted rate rooms.

**Meeting Registration:** Registration for the 2014 NAF AMM will open in mid-December. You are encouraged to register before February 15, 2014 to receive the early registration discount rate. In addition, members of the NAF pay a lower registration fee to attend the annual membership meeting. If you are not currently a member of the Foundation 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.

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

For more information on Las Vegas visit [www.lvcva.com](http://www.lvcva.com). For the latest information on conference registration, program schedule, and area information keep checking [www.ataxia.org](http://www.ataxia.org).

**2014 NAF Annual Membership Meeting “Support Our Conference” Campaign**  
<https://naf.myetap.org/fundraiser/14AMM/>

## The National Ataxia Foundation 57th Annual Membership Meeting

# *“Betting on Ataxia Research”*

**Las Vegas, NV – March 21-23, 2014**

The National Ataxia Foundation (NAF) Board of Directors and the NAF Western United States Ataxia Support Groups invite you to save the date to attend the 57th Annual Membership Meeting at Bally’s Las Vegas, NV. Be part of the largest ataxia gathering in the world.

When registration opens, you are encouraged to register before February 15, 2014 to receive the early registration discount rate. In addition members of the National Ataxia Foundation pay a lower registration fee to attend the annual membership 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 2014 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 an application by mail. The deadline to submit an application is January 24, 2014.

The complete meeting schedule, events and registration forms will be listed in the winter 2013-14 issue of *Generations* which will be mailed in mid-December and posted on NAF’s website in early January, however, a brief program overview is provided below:

### **Thursday, March 20**

#### **Pre-Meeting Activities**

- Exhibitors: 12 – 5 p.m.
- Fundraising Meeting: 4 – 5 p.m.
- Poster Session (Meet Researchers): 5:15 – 6:15 p.m.

### **Friday, March 21**

- Exhibitors: 8 a.m. – 5 p.m.
- General Sessions: 8:30 a.m. – 12:30 p.m.
- Activity Room: 10 a.m. – 2 p.m.
- Birds of a Feather (Small Groups): 2 – 5 p.m.
- Welcome Reception: 7 p.m.

### **Saturday, March 22**

- Exhibitors: 8 a.m. – 5 p.m.
- General Sessions: 8:30 – 11:30 a.m. and 1:45 – 4:45 p.m.
- Silent Auction Bidding: 8:30 a.m. – 12:30 p.m.
- Activity Room: 10 a.m. – 2 p.m.
- Saturday Evening Banquet: 7 p.m.

### **Sunday, March 23**

- Exhibitors: 8 – 11 a.m.
- Business Meeting: 8:45 – 9 a.m.
- General Sessions: 9 a.m. – 1 p.m.
- Meeting adjourns – See you next year! ▶▶

## About Las Vegas

Please visit [www.visitlasvegas.com](http://www.visitlasvegas.com) and [www.lasvegas.com/travel-professionals/agent-tools/special-needs-visitors/](http://www.lasvegas.com/travel-professionals/agent-tools/special-needs-visitors/) for a complete list of attractions and planning information.



## Bally's Las Vegas

Bally's Las Vegas is the official conference hotel of the 2014 NAF Annual Membership Meeting and is located directly on the Vegas Strip just minutes from the McCarran International Airport at 3645 Las Vegas Boulevard S., Las Vegas, NV 89109.

For your stay planning purposes at Bally's, the following information is provided. Complete details will be listed in the Winter 2013-2014 issue of *Generations* and on the NAF website.

- NAF AMM attendees staying at Bally's Las Vegas will enjoy complimentary internet access in their guest rooms for one device.
- Valet parking and self-parking are available. Both are complimentary with a clearance of seven feet.
- Oversized parking is available in Bally's east lot. RV's are welcome, however, no hook-ups are available.
- A service dog relief area at Bally's is located outside the Food Court Entrance on the lower level.
- For room reservation information please refer to the AMM announcement on page 37.
- If you need ADA equipment you are encouraged to bring those items with you or make arrangements to rent equipment locally. NAF is unable to provide ADA equipment however the hotel may have some extra shower chairs, grab bars, or detachable shower heads available. Be

sure to request these items when making your reservation if needed. The width of the bathroom door in the standard guestrooms is 26 inches.

## Transportation and Getting There

Bally's Las Vegas does not provide transportation from the airport. Available resources will be listed in the winter 2013-14 issue of *Generations* and posted on NAF's website.

## Las Vegas Area Services and Resources

The following information can be used as a guide as you plan for your needs in Las Vegas. The National Ataxia Foundation does not endorse products, therapies, services, or manufacturers. Those mentioned below are included for your information only. The NAF assumes no liability for the use or contents of any product or service mentioned

## Personal Care Attendants

If you need a personal care attendant, please make arrangements prior to attending the meeting to have someone accompany you or have a PCA hired before you arrive in Las Vegas.

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

### Comfort Keepers

(702) 385-1000 Fax: (702)452-1001

<http://www.comfortkeepers.com/office-142>

### Nurse Core

(702) 458-1137 Fax: (702)458-1423

<http://www.nursecore.com/>

### Professional Healthcare Services

(702) 362-0711

<http://professionalhealthcareserviceslv.com>

### Right At Home

(702) 367-3400

<http://www.rightathome.net/lasvegas/>

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

Ability Center

1-800-546-7622 Local: (702) 434-3030  
<http://www.abilitycenter.com/lasvegas.php>

Better Life Mobility Center

1-888-540-8267  
<http://www.betterlifemobility.com>

Desert Medical Equipment

(702) 876-9171  
<http://www.desertmedicalequip.com/>

Freedom Medical Supply and Equipment

(702) 386-9997 Fax: (702) 228-9996  
<http://www.freedommedicalsupply.com/pages/>

Las Vegas Scooters

1-866-775-4381 Local: (702) 610-4905  
<http://www.702scooters.com/>

Scootaround Inc.

1-888-441-7575  
<http://scootaround.com/>

### **ADA Assistance Office**

Las Vegas Convention and Visitors Authority  
ADA Coordinator – (702) 892-0711

Nevada Relay Service

Voice/TTY: 1-800-326-6888 or Dial 711  
<http://www.lasvegas.com/travel-professionals/agent-tools/special-needs-visitors> ❖

## **AMM Exhibitors and Sponsors Wanted**

The National Ataxia Foundation is looking for companies or individuals who have products or services that would be helpful for those with ataxia to submit an exhibitor application to exhibit at "Betting on Ataxia Research," the Foundation's 57th Annual Membership Meeting (AMM). The 2014 AMM will be held in Las Vegas, NV on March 21-23, 2014. Please e-mail [joan@ataxia.org](mailto:joan@ataxia.org) for an exhibitor application.

NAF is grateful to those organizations that have provided generous support of the annual membership meeting. Please consider being a

sponsor of the 2014 Annual Membership Meeting. For information on becoming a sponsor please contact Lori Shogren at [lori@ataxia.org](mailto:lori@ataxia.org).

Ataxia researchers who have an IRB-approved study and would like to recruit participants for research are invited to contact Sue Hagen at [susan@ataxia.org](mailto:susan@ataxia.org) for information about having an exhibit table at the meeting.

If you are affected by ataxia or are a caregiver and know of a product or service that has been helpful to you, please let us know by calling (763) 553-0020 or e-mail [joan@ataxia.org](mailto:joan@ataxia.org).

## **Silent Auction**

The Silent Auction held during the National Ataxia Foundation Annual Membership Meeting is a fun way to support NAF by bidding on quality items from various states and countries. This long-standing NAF tradition begins Saturday March 22, 2014 at 8:30 a.m., with the final bidding ending at 12:30 p.m. the same day.

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

getaways.

Items being donated for the Silent Auction should be dropped off at the registration area on Thursday or Friday. If you are not able to attend the meeting, but have a quality item that you would like to donate, please contact NAF at (763) 533-0020 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 items!

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



# Chapter and Support Group News from Around the Country

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**Denver Ataxia Support Group**

*Submitted by Charlotte DePew*

The July meeting, which is always light, had about 25-30 attend. The speaker on Medicare and Social Security did not arrive. It was a fortunate opportunity for socialization and learning from each other. Many great topics including home management, government support and emotional issues were shared.

We discussed our upcoming Third Annual Run, Walk 'n Roll for Ataxia in Honor of Jim Lehr at City Park on September 8. Mike William's father, Bob, said that a simple Facebook posting yielded \$500 in donations with no further fundraising efforts on their part in the past.

Members were also informed that our next social event, organized by Nanette Redman, would be at the Chatfield Reservoir on September 14. Sailing, boating and other water activities plus a picnic were all part of a great outing for all who attended for the \$8 park entry fee. We'll have pictures to post!

.....  
**Northeast Florida Ataxia Support Group**

*Submitted by Mac Kelso*

The Northeast Florida Ataxia Support Group met at Baptist South Hospital on August 24. Our meeting had 13 attendees. Cory Hannan discussed several topics in *Generations*, citing some very interesting information for ataxians, such as enrolling in the CoRDS registry, what an MRI can show and how a toe wedge may help your balance. He encouraged all members to get their *Generations* copy by joining the National Ataxia Foundation.

Next Cory informed the group that the venue for the "Walk n' Roll" for International Ataxia Awareness Day had changed to Bowl America in Mandarin. On-site registration would start at 12 p.m. Guest speaker Dr. Subramony will address participants at 12:30 and bowling will take place from 1-3 p.m.

Bowl America will be offering food and beverages at great prices. There will be raffles throughout the day and the prize for the top bowling score for the day will be an autographed Mickey Mantle baseball. All participants who give a \$20 donation to NAF will receive a free "Walk n'Roll and Bowl" T-shirt at the event. Cory assured members that handicap accessibility to the bathrooms and bowling lanes were adequate. To help with donations to Jacksonville's "Walk n'Roll and Bowl," NAF has designed a website. Mac Kelso briefly gave a tutorial to maneuver around the website at [www.ataxia.org/walk/jacksonville](http://www.ataxia.org/walk/jacksonville).

In closing, special recognition goes to Sonia Hannan for her healthy snacks served up after the business meeting. The group decided to meet at Bowl America Mandarin in recognition of International Ataxia Awareness Day for good food, fun and socializing on the September 21.

The next proposed on-site meeting will be November 2 at 1:45 p.m. in the Azalea, Begonia and Camellia Rooms at Baptist South.

.....  
**West Central and South Florida Ataxia Support Group**

*Submitted by Linda Farrow, Secretary*

On Saturday, July 13 we had our meeting at

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Morsani Hall on the University of Southern Florida campus in Tampa, FL. There were 20 in attendance.

We were introduced to Tricia Shuster, an RN, certified yoga instructor and founder of Zirit Life, by Cindy Ziegler. Tricia spoke to us about mindful meditation – paying attention to the present moment and being aware of what’s going on around you. She led us through some breathing exercises that we were very able to do by ourselves then through some relaxation exercises. She told us about something that generated a lot of interest – the occipital ridge – the place on either side of the spine where the skull and the spine meet. It’s a relaxation point, and when stimulated by massage, can release endorphins ... the body’s anti-pain chemical. She passed out tennis balls in a sock and showed us how to use them. Lying on your back, place the ball under your head at the occipital ridge and move your head around until it’s in contact and then relax! The pressure will help to relax the area around the base of the skull and spinal cord. A fine time was had by everyone there and Tricia has agreed to come back to our meeting the first Saturday in September to share some more information with us.

Cindy also was asking for some support in finding topics for our bi-monthly meetings and what the group would like to do for International Ataxia Awareness Day in September. There were a couple of suggestions of incorporating an activity on the cruise to raise funds. More thought and/or discussions will be needed.

Cindy spoke briefly about the upcoming Second Annual “Cruise to Create Ataxia Awareness” sailing in January. She is actively attempting to create Ataxia Awareness. If you need information about the cruise, please contact her at [www4ataxia@yahoo.com](mailto:www4ataxia@yahoo.com).

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**New Hampshire Ataxia Support Group**

*Submitted by Jill Porter*

It was great to see those who were able to attend the meeting. We covered a lot of ground regarding the Walk N’ Roll website and discussed using the e-mail tabs to send a second e-mail out to folks who had not responded, whether or not they had looked at the webpage. We felt a follow-up e-mail did not need to focus on a donation and we might want to reach out and ask if there were any problems navigating the webpage. We considered adding something about our enthusiasm to get the word out about ataxia and that we hoped to hear from them.

We waited for more information from Senator David Boutin on the signing of the Proclamation on September 18 and asked that the date be available, should our request for a public signing be granted.

John Mauro was working on an idea to incorporate the shape of the state of New Hampshire and Massachusetts to add to the graphics on the back of the W n’ R event shirt.

We now have a new meeting location – Hannafords at the Bedford Shopping Mall.

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**Central Pennsylvania Ataxia Support Group**

*By Chris Rakshys*

We had our second meeting on July 27 at the Muhlenberg Library in Laureldale (just outside of Reading). We had a small audience (five regulars and three first-timers); it was a perfect setting for a casual and intimate discussion with our guest speaker.

Kate Reed, a genetics counselor from Johns Hopkins Ataxia Clinic, joined us for a laid back discussion. Rather than having a formal presentation, Kate sat with us and fielded many questions, ranging from personal to general, that were genetics and/or ataxia-related: to test or not to test, family planning, nutrition and genetics, individuality, and responses to environmental ►►

triggers, nomenclature, and more. It was a very informative time and one that will never be forgotten – thanks a million, Kate!

In closing, we discussed ideas for our free potluck picnic in September for IAAD, our meeting in October, the new CoRDS ataxia patient registry and next year’s NAF AMM in Las Vegas. It was a very good meeting and we look forward to reaching out to more ataxians in our area.

**Central New York Ataxia Support Group**

*Submitted by Mary Jane Damiano*

The CNY Ataxia Support Group met on Saturday, June 22. Five members were present. We discussed the diet for ataxia with the information prepared by NAF. We talked about our upcoming raffle for a quilt which was donated to our group by Judy Tarrants’ sewing group. The proceeds from our raffle will be donated to NAF. The raffle tickets are \$1 each or six for \$5.

Our next meeting was on September 28, with a pot luck luncheon and raffle drawing to celebrate IAAD.

**Greater Atlanta Ataxia Support Group**

*Submitted by Lynn, Dave and Greg*

Thanks everyone for a GREAT meeting on Saturday. We had our biggest group yet with about 40 people attending. We would also like to send out a special thanks to Jade Perry and



**Jade Perry (left) and Megan Kokaras with their Great Dane service dogs at the July Greater Atlanta Ataxia Support Group meeting**

Megan Kokaras who come to our meeting as guests from out of town with their two Great Dane Service Dogs.

Thank you Dr. Chip Wilmot for your excellent update on ataxia. You are always welcome at our meetings.

**Tri-State Ataxia Support Group Meeting**

**March 14 and May 9 Meetings**

This is information from our last two meetings in March and May. A few new members were

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**The Greater Atlanta Ataxia Support Group at their July meeting**

*Chapter and Support Group News*  
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welcomed at each meeting. It's always wonderful to see different faces and know that we are spreading the word by getting people to come to our meetings.

In March, Julian spoke about his trip to Washington, D.C., and everyone was encouraged to write letters to congress. Addresses can be found by going online at [www.senate.gov](http://www.senate.gov).

In May it was discussed that Johns Hopkins is doing a lot of ataxia research and everyone can continue to check the website for any upcoming clinical trial information.

We also talked about the BalanceWear® Vest. You can visit the website, see some videos and read testimony from satisfied patients. The web address is [www.motiontherapeutics.com](http://www.motiontherapeutics.com). Carol was getting hers by the end of May and will hopefully attend July's meeting with her vest.

Another new product we talked about and were treated to actually view were the skele-toes shoes (thanks Denise!). Some of the different manufacturers are Fila and Vibram. You can Google and check them out. Remember to give us any feedback.

Exercise for all was encouraged and we were treated to stories about how everyone stays active.

Some of the events highlighted were the 2014 Membership Meeting to be held in Las Vegas and the Macy's "Shop for a Cause" Day on August 24. Anyone can go online to purchase a

card for \$5. You receive a 25% discount throughout the store for the entire day ... what a bargain!

### **July 11 Meeting**

*Submitted by Kathleen Gingerelli*

We started our meeting off by welcoming everyone. We had a full house with some new members so introductions were made around the room with everyone explaining what brought them to our meeting. We went over everyone's day-to-day activities, including housework, child care and exercise. As in every meeting, the importance of any type of daily exercise was stressed and we all spoke of the different types each person does.

A new topic of discussion was about the BalanceWear® Vest. The website to check out some patient testimonials, videos and contact information is [www.motiontherapeutics.com](http://www.motiontherapeutics.com). We have a few members of our group who were trying for the vest and we hope to hear some of their personal stories at future meetings.

I've also recently reached out and spoke with a health educator from the John Hopkins Ataxia Center ([www.hopkinspdmd.org](http://www.hopkinspdmd.org)). I will be bringing some correspondence as handouts for our next meeting.

As is the case in all meetings, everyone is encouraged to become a NAF member and sign up for the registry at [www.ataxia.org](http://www.ataxia.org), keep up on all new information and also receive the quarterly newsletter *Generations*, which is part of the NAF membership. ❖

## **ShopNAF.org**

Wish you could support your favorite cause while shopping online? You can at [www.ShopNAF.org](http://www.ShopNAF.org). You will find great deals on top brands and every purchase you make will help support the important work of the National Ataxia Foundation.

## **Deadline**

The deadline to submit materials for the Winter edition of *Generations* is Friday, November 1. Submit content by e-mail to [joan@ataxia.org](mailto:joan@ataxia.org), or by mail to National Ataxia Foundation, 2600 Fernbrook Lane, Suite 119, Minneapolis, MN 55447-4752.

# 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

### NAF BULLETIN BOARD

Moderator – Atilla and Bear

[www.ataxia.org/forum/toast.asp](http://www.ataxia.org/forum/toast.asp)

### NAF CHAT ROOM

Moderator – Della ([ddpokernut@yahoo.com](mailto:ddpokernut@yahoo.com))

[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 FANS

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

### NAF YOUTUBE CHANNEL

[www.youtube.com/user/NatlAtaxiaFound?feature=mhum](http://www.youtube.com/user/NatlAtaxiaFound?feature=mhum)

## Chapters, Support Groups and Ambassadors

### – ALABAMA –

#### ALABAMA SUPPORT GROUP LEADER

Becky Donnelly

Hoover, AL

(205) 987-2883

E-mail: [donnely6132b@aol.com](mailto:donnely6132b@aol.com)

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

#### AMBASSADOR

Dianne Blain Williamson

Huntsville, AL

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

E-mail: [diannebw@aol.com](mailto:diannebw@aol.com)

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

### – ARIZONA –

#### PHOENIX AREA SUPPORT GROUP LEADERS

Mary Fuchs

Sun Lakes, AZ

(480) 883-7633

E-mail: [mary11115@msn.com](mailto:mary11115@msn.com)

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

Rita Garcia

Chandler, AZ

(480) 726-3579

E-mail: [rtg22@cox.net](mailto:rtg22@cox.net)

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

#### AMBASSADOR

Bart Beck

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(520) 885-8326

E-mail: [bbeck15@cox.net](mailto:bbeck15@cox.net)

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

### – ARKANSAS –

#### AMBASSADORS

Judy and David King

Hot Springs Village, AR

E-mail: [drkingpd@suddenlink.net](mailto:drkingpd@suddenlink.net)

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

### – CALIFORNIA –

#### LOS ANGELES AREA SUPPORT GROUP LEADER

Sherry McLaughlin

Altadena, CA

(626) 791-1558

E-mail: [ccherilynmc@yahoo.co](mailto:ccherilynmc@yahoo.co)

Web: <http://laasg-ca.info>

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

#### N. CALIFORNIA AREA SUPPORT GROUP LEADER

Joanne Loveland

Danville, CA

E-mail: [joanneloveland@gmail.com](mailto:joanneloveland@gmail.com)

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

#### ORANGE COUNTY AREA SUPPORT GROUP LEADER

Daniel Navar

Montebello, CA

(323) 788-7751

E-mail: [danieln27@gmail.com](mailto:danieln27@gmail.com)

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

#### AMBASSADORS

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Deborah Omictin

Hayward, CA

(510) 783-3190

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[www.ataxia.org/chapters/Deborah0/default.aspx](http://www.ataxia.org/chapters/Deborah0/default.aspx)

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 (Earl: emclaugh@cox.net)  
[www.ataxia.org/chapters/SanDiego/default.aspx](http://www.ataxia.org/chapters/SanDiego/default.aspx)

**Martha Elliott**

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

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

Aurora, CO  
 (720) 379-6887  
 E-mail: cldepew77@comcast.net  
[www.ataxia.org/chapters/Denver/default.aspx](http://www.ataxia.org/chapters/Denver/default.aspx)

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

(212) 720-2179  
 E-mail: markmeghan@aol.com  
[www.ataxia.org/chapters/Tri-State/default.aspx](http://www.ataxia.org/chapters/Tri-State/default.aspx)

**AMBASSADOR****Terre Di Placito**

Torrington, CT  
 (860) 489-5092  
[www.ataxia.org/chapters/TerreDiPlacito/default.aspx](http://www.ataxia.org/chapters/TerreDiPlacito/default.aspx)

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

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**— FLORIDA —****NORTHEAST FLORIDA SUPPORT GROUP LEADERS****Cory Hannan**

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**John & Sherri Richwine**

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# Calendar of Events

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

## SUPPORT GROUP MEETINGS

– **Wednesday, October 9, 2013** –

### Willamette Valley Ataxia Support Group Meeting

**Time:** 11:30 a.m. – 1 p.m.

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

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

– **Saturday, October 12, 2013** –

### Central MN Ataxia Support Group Meeting

**Time:** 10 a.m. – noon

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

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

### Kansas City Ataxia Support Group Meeting

**Time:** 2 – 4 p.m.

**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.

### North Texas Ataxia Support Group Meeting

**Time:** 10 a.m. – noon

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

**Details:** For additional information contact David Henry Jr. at [cheve11e@sbcglobal.net](mailto:cheve11e@sbcglobal.net).

– **Saturday, October 19, 2013** –

### Delaware Area Ataxia Support Group Meeting

**Time:** 10 a.m. – 1 p.m.

**Location:** Christiana Hospital, Newark, DE

**Details:** Guest speaker will be Carol Barnett, who has over 30 years experience working with the Division of Services for Aging and Adults with Physical Disabilities for the State of Delaware. For more information contact Joe DeCrescenzo at (302) 369-9287 or [jdecr@comcast.net](mailto:jdecr@comcast.net).

### Denver Area Ataxia Support Group Meeting

**Time:** 1 – 4 p.m.

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

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

### Middle Tennessee Area

#### Ataxia Support Group Meeting

**Time:** 2 p.m.

**Location:** Amerigo Restaurant, Cool Springs, TN

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

### Orange County Ataxia Support Group Meeting

**Time:** 2 – 4 p.m.

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

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

### Twin Cities Ataxia Support Group Meeting

**Time:** 10 a.m.

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

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

– **Tuesday, October 22, 2013** –

### Cleveland Area Ataxia Support Group Meeting

**Time:** 6:30 – 7:30 p.m.

**Location:** Mayfield Branch – Cuyahoga County Library, medium conference room, 500 SOM Center Rd., Mayfield Hts., OH

**Details:** For more information or to RSVP contact Carmen Pieragastini at (216) 272-5588 or [willow\\_pier@roadrunner.com](mailto:willow_pier@roadrunner.com).

– **Saturday, October 26, 2013** –

### Alabama Ataxia Support Group Meeting

**Time:** 10 a.m. – 2 p.m.

**Location:** Covenant Presbyterian Church, Homewood, AL

**Details:** For more information, contact Becky Donnelly at (205) 987-2883 or [donnelly6132b@aol.com](mailto:donnelly6132b@aol.com).



**Central PA Ataxia Support Group Meeting****Time:** Noon – 2 p.m.**Location:** Muhlenberg Community Library, 612 Kutztown Rd., Laureldale, PA 19605**Details:** For more information contact Chris Rakshys at (610) 395-6905 [rakshys@ptd.net](mailto:rakshys@ptd.net).**Detroit Area Ataxia Support Group Meeting****Time:** 1 – 4 p.m.**Location:** The Barbara Ann Karmanos Cancer Institute at Wayne State University in the Warts Classroom, 4100 John R St., Detroit, MI 48201**Details:** For more information contact Tanya Tunstull at (313) 397-7858 or [tinyt48221@yahoo.com](mailto:tinyt48221@yahoo.com).**New Hampshire Ataxia Support Group Meeting****Time:** 10 a.m. – noon**Location:** Hannafords at the Bedford Shopping Mall, 5 Colby Ct., Bedford, NH 03110, (603) 625-5431**Details:** For more information contact Jill and Ken Porter at (603) 626-0129 or [jilleporter@comcast.net](mailto:jilleporter@comcast.net).**– Monday, October 28, 2013 –****Cleveland Area Ataxia Support Group Meeting****Time:** 6:30-7:30 p.m.**Location:** Brook Park – Cuyahoga County Library, large conference room, 6155 Engle Rd., Brook Park, OH**Details:** For more information or to RSVP contact Carmen Pieragastini at (216) 272-5588 or [willowpier@roadrunner.com](mailto:willowpier@roadrunner.com).**– Saturday, November 2, 2013 –****Greater Atlanta Ataxia Support Group Meeting****Time:** 1 p.m.**Location:** Emory Center for Rehabilitation Medicine, 1441 Clifton Rd. NE, Room 101, Atlanta, GA**Details:** For more information contact the Greater Atlanta Support Group at [atlantaataxia@gmail.com](mailto:atlantaataxia@gmail.com).**Boston Area Ataxia Support Group Meeting****Time:** Noon – 3:00 p.m.**Location:** Yawkey Bldg 2nd floor, room 220 at Mass. General Hospital.**Details:** For more information or to RSVP contact Donna Gorzela at (978) 475-8072 (home), (978) 490-9552 (cell), or [donna.gorzela@gmail.com](mailto:donna.gorzela@gmail.com).**Northeast Florida Ataxia Support Group Meeting****Time:** 2 – 4 p.m.**Location:** Baptist South Hospital. Azalea, Begonia and Camellia conference rooms**Details:** For more information contact Steve and Carole Brown at (352) 591-5095 or [bike4brown@aol.com](mailto:bike4brown@aol.com).**West Central Florida****Ataxia Support Group Meeting****Time:** 12:30 – 3 p.m.**Location:** The Morsani Center, 13330 USF Laurel Dr. #1013, Tampa, FL 33612**Details:** Election of Officers. For more information contact Cindy Steever-Ziegler at (239) 878-3092 or [www4ataxia@yahoo.com](mailto:www4ataxia@yahoo.com).**– Saturday, November 9, 2013 –****Central MN Ataxia Support Group Meeting****Time:** 10 a.m. – noon**Location:** Liberty Savings Bank (1st Floor Community Room), 111 Seventh Ave. S., St. Cloud, MN. Entrance is in the rear of building for mobility issues.**Details:** For more information please contact Marsha Binnebose at (320) 248-9851 or [marsha\\_binnebose@yahoo.com](mailto:marsha_binnebose@yahoo.com).**Los Angeles Ataxia Support Group Picnic/Concert****Time:** 2 – 4 p.m.**Location:** Northridge Hospital, 18300 Roscoe Blvd., Northridge, CA 91328**Details:** Dr. Brent Fogel will be the guest speaker. For more information or to RSVP 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**Location:** Las Colinas Cancer Center, 7415 Las Colinas Blvd., Irving, TX 75039. The parking is free and the building is handicap accessible (behind the Regions Bank).**Details:** For additional information contact David Henry Jr. at [cheve11e@sbcglobal.net](mailto:cheve11e@sbcglobal.net).**– Wednesday, November 13, 2013 –****Willamette Valley Ataxia Support Group Meeting****Time:** 11:30 a.m. – 1 p.m.**Location:** Albany General Hospital, 1046 Sixth Ave. SW, Albany, OR 97321**Details:** For more information contact Ivy Stilwell at (541) 812-4162 or [istilwell@samhealth.org](mailto:istilwell@samhealth.org).**– Thursday, November 14, 2013 –****Tri-State Ataxia Support Group Meeting***Continued on page 52*

*Calendar of Events**Continued from page 51***Time:** 6:30 – 8:30 p.m.**Location:** Beth Israel Medical Center, Phillips Ambulatory Care Center (PACC), Second Floor Conference Room (Room 3), 10 Union Square East, New York, NY 10003**Details:** For more information contact Denise Mitchell at [markmeghan2@gmail.com](mailto:markmeghan2@gmail.com) or Kathy Gingerelli at [kgingerelli@msn.com](mailto:kgingerelli@msn.com).**– Saturday, November 16, 2013 –****Twin Cities Ataxia Support Group Meeting****Time:** 10 a.m.**Location:** Langton Place in Roseville at 1910 W. County Rd. D, Roseville, MN. 55112**Details:** Please join us and make new connections. For more information contact Lenore Healey Schultz at (612) 724-3784 or [cshultz.lenore@yahoo.com](mailto:cshultz.lenore@yahoo.com).**– Saturday, November 23, 2013 –****JHU Ataxia Support Group Meeting****Time:** Noon - 2 p.m.**Location:** Johns Hopkins at Green Spring Station Pavilion II, 1st floor conference room behind the café, 10753 Falls Rd., Lutherville, MD 21093**Details:** Guest speaker: Jennifer Millar, PT, Johns Hopkins Physical Therapist. For more information contact Bailey Vernon, Health Educator, at (410) 616-2811 or [bvernon1@jhmi.edu](mailto:bvernon1@jhmi.edu). Please RSVP if planning to attend.**New Hampshire Ataxia Support Group Meeting****Time:** 10 a.m. – noon**Location:** Hannafords at the Bedford Shopping Mall, 5 Colby Ct., Bedford, NH 03110, (603) 625-5431.**Details:** For more information contact Jill Porter at (603) 626-0129 or [jilleporter@comcast.net](mailto:jilleporter@comcast.net).**– Saturday, December 7, 2013 –****Greater Atlanta Ataxia Support Group Meeting****Time:** 1 p.m.**Location:** Emory Center for Rehabilitation Medicine, 1441 Clifton Rd. NE, Room 101, Atlanta, GA**Details:** For more information contact the Greater Atlanta Support Group at [atlantaataxia@gmail.com](mailto:atlantaataxia@gmail.com).**Orange County and L.A. Ataxia Support Groups Joint Holiday Gathering****Time:** 2:00 p.m.**Location:** Alpine Village Restaurant, 833 Torrance

Blvd., Torrance, CA 90502

**Details:** For more information contact Daniel Navar at (323) 788-7751 or [danieln27@gmail.com](mailto:danieln27@gmail.com).**– Wednesday, December 11, 2013 –****Willamette Valley Ataxia Support Group Meeting****Time:** 11:30 a.m. – 1 p.m.**Location:** Albany General Hospital, 1046 Sixth Ave. SW, Albany, OR 97321**Details:** For more information contact Ivy Stilwell at (541) 812-4162 or [istilwell@samhealth.org](mailto:istilwell@samhealth.org).**– Saturday, December 14, 2013 –****Central MN Ataxia Support Group Meeting****Time:** 10 a.m. – Noon**Location:** Liberty Savings Bank (1st Floor Community Room), 111 Seventh Ave. S., St. Cloud, MN. Entrance is in the rear of building for mobility issues.**Details:** For more information please contact Marsha Binnebose at (320) 248-9851 or [marsha\\_binnebose@yahoo.com](mailto:marsha_binnebose@yahoo.com).**Kansas City Ataxia Support Group Meeting and Holiday Luncheon****Time:** 2 – 4 p.m.**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.**North Texas Ataxia Support Group Meeting****Time:** 10 a.m. – noon**Location:** Las Colinas Cancer Center, 7415 Las Colinas Blvd., Irving, TX 75039. The parking is free and the building is handicap accessible (behind the Regions Bank).**Details:** For additional information contact David Henry Jr. at [cheve11e@sbcglobal.net](mailto:cheve11e@sbcglobal.net).**– Saturday, December 21, 2013 –****Twin Cities Ataxia Support Group Meeting****Time:** 10 a.m.**Location:** Langton Place in Roseville at 1910 West County Rd. D, Roseville, MN. 55112**Details:** Please join us and make new connections. For more information contact Lenore Healey Schultz at (612) 724-3784 or [cshultz.lenore@yahoo.com](mailto:cshultz.lenore@yahoo.com).**Saturday, December 28, 2013****Detroit Area Ataxia Support Group Meeting****Time:** 1 – 4 p.m.**Location:** The Barbara Ann Karmanos Cancer ▶▶

Institute at Wayne State University in the Warts Classroom, 4100 John R St., Detroit, MI 48201

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

### **New Hampshire Ataxia Support Group Lunch Meeting**

**Time:** 11:30 a.m. for lunch

**Location:** The Puritan Back Room, Manchester, NH

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

## **INFORMATIONAL AND AWARENESS EVENTS**

– **Saturday, October 5, 2013** –

### **Central Massachusetts**

#### **Third Annual Walk n' Roll for Ataxia**

#### **IAAD Event and Fundraiser**

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

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

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

– **Saturday, October 12, 2013** –

### **“The Lou” Annual Lou Coletti Memorial Golf Tournament**

**Time:** 12:30 p.m.

**Location:** Bellair Country Club, Country Club Lane, Bellair, FL 33756-2098.

**Details:** For more information or to participate contact Scott Coletti at (727) 372-0091 or [baywest.npr@gmail.com](mailto:baywest.npr@gmail.com). All proceeds benefit the National Ataxia Foundation.

– **Saturday, October 19, 2013** –

### **Tea Time for Ataxia**

**Time:** 11 a.m. – 1 p.m. and 1:30 – 3:30 p.m.

**Location:** The Aubrey Rose Tea Room, La Mesa, CA

**Details:** Please help us fill the tea room at both sittings. Ask your friends to join you and plan now to attend. The cost is \$35 per person. All proceeds benefit the National Ataxia Foundation. For more information contact Jane Jaffe at (619) 286-9745 or [sicilianmother@cox.net](mailto:sicilianmother@cox.net).

– **Friday-Sunday, November 22-24, 2013** –

### **Abilities Expo**

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

**Location:** San Jose McEnergy Convention Center, San Jose, CA

**Details:** Admission is free. [www.abilitiesexpo.com](http://www.abilitiesexpo.com)

– **Saturday, February 22, 2014** –

### **Ataxia Caregivers Conference**

**Time:** 9:00 a.m. – 3:00 p.m.

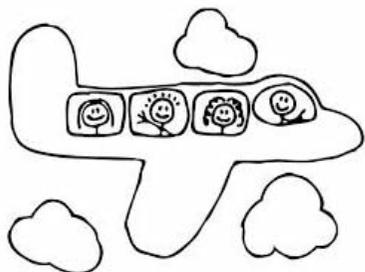
**Location:** Grace Fellowship Church at 9505 Deereco Rd., Lutherville-Timonium, MD 21093

**Description:** This event is for family and friends who care for those with ataxia. There will be several presentations and facilitated discussions on coping skills, future planning, communication, and strategies for providing care.

**RSVP:** Pre-registration is required by February 18. Bailey Vernon, Health Educator, (410) 616-2811 or [bvernon1@jhmi.edu](mailto:bvernon1@jhmi.edu). ❖

## NAF's Travel Grant Program Needs Your Support

For those with ataxia, traveling to the National Ataxia Foundation's Annual Meeting (AMM) may be financially difficult.



Our travel Grant program was created to assist individuals with some of the costs associated with attending the AMM.

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 who may not have been able

to attend without your help. ❖

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

Cheryl Ackerman	Mrs. Harold Crawford	John Hays	Walter Lowry
Paul Aiello	Clarence Crossley	Helen Henry	Marilyn
David Alessi	Russ Crystal	David Henry Jr.	Ludlow-Stevens
Crystal Allsopp	Russell Crystal	David Henry Sr.	Adrian Lund
Glenn Anderson	Beatriz Dalferro	Alice Hicks	Michael Lundquist
David Ashley	Mary Danson	George Hicks	Charles Luttrell
Sharon Baggett	Cathy DeCrescenzo	Dewayne Hite	Marilyn Macklin
Jeffery Barberi	Joseph DeCrescenzo	Johnny Hogan	Caryn Mahaffy
Stephen Barth	Michelle DeLarosky	Hsi-Hsien Hu	Olivia Mantovani
John Bates	Bernadette DeLuca	Charlene Hughes	Patricia Marr
Sharon Bauman	DeMint Family	Krista Humes	Massanova Family
Gerald Bender	Gretchen Deniger	Howard Hunnius	Masserant Family
Jerry Bender	Connie DiVincentis	Dorothy Jaber	Bradley, Brent and
Donald Beneski	Tom Dolan	Jessica Jerke	Bryan Masserant
Theresa Bent	Fred Donnelly	Kerry Johnson	Bud Maultra
Sandee Berst	Rick Donnelly	Terry Johnson	John Mauro
Joseph Black	Olivia Douglass	Yvonne Johnson	Alisa McFarland
Fred Blasberg	Denise Drake	Dick Joyce	Earl McLaughlin Jr.
Carol Brand	Naomi Droz	Richard Joyce	Robert McMurtry
Donald Britt	Andrew Egeressy	Keiko Kain	Harvey Millburg
Louise Brown	Daniel Eustache	Norman Karas	Refiye Miller
David BrownSr	Trinity Falk	James Kardos	Ellen Moetsch
Ruth Buckley	Vincent Ferranti	Lisa Kelso	Earl Moore
Alice Buergmeyer	Kevin Fleming	Erin Kiermam	Jack Moore
Barbara Call	Rita Fleming	Jamie Kosieracki	Carol Mullen
Kenny Canter	Cindy Fondulis	Patty Kosieracki	Dolores Nagle
Benjamin Cantor	Ligaya Frediani	Steve Kozan Family	John Noonan
Terrence Carroll	Steve Frediani	Mary Lapham	John Norton
Phyllis Celio	Albert Frei	Ruth Lapp	H.P. Avelleda
Bob Chaplin	Terry Frey	Lealan LaRoche	Wallace Peebles
William Chwee	Penny Golminas	Gerlad Laukhuf	Michael Peter
JoAnn Ciecierski	Brenda Graner	Lorrie Laukhuf	Peterson Family
Eugene Clark	Lawrence Graner	Jen Leader	Eric Peterson
Ben Clevenger	Larsen Gregory	Jim Lehr	Gordy Pfaffendorf
Karen Cocquyt	Richard Gregory	Tony Lewendon	Doris Pinkston
Coffey Family	Trish Gresham	Steven Lief	Pogulis Family
Catleen Coffey	Bradd Guenser	Phyllis Lindberg	Nello Poli
Joe Coffey	Sean Guilbeau	Bernice Linnerooth	Ted Poli
Roger Cooley	Annie Gulliver-Reed	Doug Linnerooth	Victor Poli
Scott Cooper	Harriet Haas	Peggy Littlejohn	Ken Porter
Carol Cornell	Madonna Haase	Rita Lobascio	Rita Powell-Lobascio
Bruno Corsini	Sarah Hale	Joyce Lokken	Wilbur R. Hackett
Bill Covert	Bernice Hartley	Mike Long	Ron Randol
Catherine Covert	Mary Hartmann	Kristie Logan	Charity Ranger
Elizabeth Cox	Gary Hartsock	Kathleen Lowry	Sally Ratica

Jim Richards  
 Sherry Richwine  
 Geoffrey Riefe  
 Elizabeth Riley  
 Janet Riley  
 Don Rollheiser  
 Patricia Rymut  
 Santa Croce Family  
 Ace Santa Croce  
 Frederick Santa Croce  
 Donald Santa Croce Jr.  
 Tom Sathre  
 Bobbi Saunders  
 Ed Schmidt

Mary Schmidt  
 Bruce Schneider  
 John Schooley  
 Joe Schott  
 Derek Semler  
 Dana Simpson  
 Rayland Skala  
 Kathryn Smithers  
 Joey Staiger  
 Charles Stebbins  
 Rollin Stoddard  
 David Summers  
 Tom Summers  
 Kyle Swier

Ernest Talarico  
 Tiffinay  
 Talarico-Compiano  
 Deane Taylor  
 Karen Taylor  
 Patricia Tobias  
 Aymee  
 Torres-Michels  
 Margaret Tseng  
 Nancy Van Twuyver  
 Cletus  
 Vasconcellos  
 Janet Veal  
 Anna Vibberts

Eleanor Vibberts  
 Mary Viscido  
 Laura Volker  
 Jeanne Walter  
 Owen Walter  
 Aimee Wentzell  
 Jeff Wentzell  
 David Westrick  
 Connie Wolff  
 Lee Wyckoff  
 Sophie Yi  
 Taylor Young  
 Monica Yurong  
 Jon Zilles



# International Ataxia Awareness Day

— Wednesday, September 25, 2013 —



## How Did You Participate in IAAD?

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

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



**Thank you to all those recognizing IAAD with your ataxia awareness efforts. Because of your efforts the world is better informed about ataxia and those affected by ataxia.**



## National Ataxia Foundation

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

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