

# Generations

**SPECIAL EXPANDED EDITION**



*The Official Publication of the National Ataxia Foundation*

*Volume 43, Number 3*

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## 2015 Ataxia Research Drive Begins October 15 with a \$200,000 Research Match Challenge

The National Ataxia Foundation's (NAF) Annual Ataxia Research Drive will begin on October 15. Funds received through this drive will be matched dollar for dollar up to \$200,000 by an anonymous donor and will support vital ataxia research later this year.

The NAF has received more than 100 Letters of Intent to apply for research funding through the NAF's five ataxia research programs. These researchers represent 16 countries including the USA, Korea, Australia, Germany, Spain, Italy, Portugal, France, Canada, Netherlands, Belgium, Cyprus, Brazil, South Africa, India,

and the United Kingdom.

This year's Research Letters of Intent focus on many types of SCAs, Friedreich Ataxia, Sporadic Ataxia, A-T, AOs, FXTAS, various SCARs, Gluten Ataxia, Episodic Ataxia, new gene discoveries, Autosomal recessive cerebellar ataxia, Ataxia with Vitamin E Deficiency, and others.

The National Ataxia Foundation offers five vital ataxia research programs to further our mission in ending ataxia. The research programs include:

- **Young Investigator (YI) Award:** One-year grants to encourage young investigators to pursue a career in the field of any form of ataxia research.
- **Research "Seed-Money" Grant:** One-year seed money grants for early or pilot phases of studies and ongoing investigations.
- **Pioneer SCA Translational Research Award:** One-year grants focusing on research investigations that will facilitate the development of treatments for the Spinocerebellar Ataxias (SCAs).
- **Young Investigator Award for SCA Research:** One-year grants to encourage young

### Inside This Issue

- **Research Summaries** begin on page 5
- Jon Rodis explains the importance of **Being Your Own Advocate** on pages 30-32
- **More 'Pearls of Wisdom'** can be found on page 36
- Updated information about the **2016 Annual Ataxia Conference (AAC)** starts on page 41
- Planning the rest of your year? Use the **Calendar of Events** on pages 59-62

*Continued on page 3*

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**Table of Contents**

**Annual Ataxia Conference (AAC)**

2016 AAC Announcement ..... 41  
2016 AAC Overview ..... 42  
Trip Planning Kit ..... 43  
Silent Auction ..... 44-45  
NAF Travel Grant Program  
Needs Your Support ..... 47  
AAC Exhibitors, Sponsors Wanted ..... 47  
2016 AAC Room Type Guide ..... 48-50

**Articles**

First Annual Disability Pride  
Parade and Festival ..... 29  
Being Your Own Advocate ..... 30-32  
Ataxia Researchers Honored with  
Prestigious Awards ..... 33-34

**International Ataxia Awareness Day**

How Did You Participate in IAAD? ..... 23  
Third Annual Walk for Dave ..... 32

**Membership Topics**

From the Desk of the Executive Director... 28-29  
Chapter and Support Group News..... 51-53  
NAF Directory of Chapters, Support Groups,  
Social Networks and Ambassadors..... 54-58  
Calendar of Events ..... 59-62  
Memorials and In Your Honor ..... 63

**Personal Stories & Poems**

Writing 'Necklace of Stones' ..... 35-36  
More Pearls of Wisdom ..... 36  
Ataxia and Distance Couldn't  
Stop Our Love ..... 37-38  
My Mantra: 'Use It or Lose It' ..... 39-40

**Research/Research Opportunities**

2015 Ataxia Research Drive ..... 1  
Researchers Describe How NAF Support Lever-  
aged Additional Research Funding ..... 3  
Pioneer SCA Translational Grant Awards ..... 5-9  
Genes Inherited  
Neurologic Disorders Study ..... 10  
Post-Doc Fellowship Awards ..... 9-14  
CoRDS Registry ..... 11  
Athena Alliance Program ..... 12  
Young Investigator SCA Research Awards ... 14-16  
Research Seed Money Awards ..... 17-25  
Young Investigator Awards ..... 26-27  
Friedreich Ataxia Tissue Donation ..... 35  
Weill Cornell Medical College FRDA Study .... 40  
Patients with Early Symptoms of  
Friedreich Ataxia Needed for MRI Study ..... 58

The deadline to submit materials for the winter issue of *Generations* is October 30, and is February 5, 2016 for the spring issue.

*2015 Research Drive...*  
*Continued from page 1*

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investigators to pursue a career in spinocerebellar ataxia (SCA) research.

• **Research Post-Doc Fellowship Award:**

One-year grants to post-docs who have shown a meaningful commitment to research in the field of ataxia.

In addition to these world-class research programs, the National Ataxia Foundation partners with other organizations in supporting additional meaningful and promising ataxia research.

Last year, through the generosity of our donors and partners, the NAF was able to support 24 exceptional ataxia research studies. Funding to support many of these promising studies were made available through the generosity of our donors who contributed to the annual ataxia research drive.

As these vital studies are being conducted today, please refer to this issue of *Generations* to find the research summaries of the studies conducted in 2014 beginning on page 5. Those studies were also made possible through the

generosity of our incredible donors who supported that year's annual ataxia research drive.

The NAF is very excited about the large number of quality Letters of Intent to apply for ataxia research funding as well as the number of countries represented. Many of these outstanding proposals are worthy of your support. We all have an opportunity to support the best science in the world by contributing to the NAF Annual Ataxia Research Drive.

Look for your 2015 Annual Ataxia Research Drive letter in the mail in mid-October. You will also be able to go on-line at [www.ataxia.org](http://www.ataxia.org) to make an on-line donation. Last year many of you encouraged friends and family to also support the ataxia research drive ... many heard your call and contributed. We ask that you do the same this year. The number of funded studies and the dollar amounts for these studies depends greatly upon you and your generous donations.

Please give to the 2015 NAF Annual Ataxia Research Drive. From October 15 through December 15, your donation will be matched up to \$200,000 ... "Research Today for a Hopeful Tomorrow." Thank you! ❖

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## Researchers Describe How NAF Support Leveraged Additional Research Funding

During 2012 and 2013, I was fortunate to be supported by the National Ataxia Foundation through the Young Investigator in SCAs Award. My project focused on understanding how the disease protein in SCA3/MJD functions and how to use our findings toward therapy for this debilitating disease.

During those two years, the \$100,000 (\$50,000 per year) provided by the supporters of the National Ataxia Foundation helped lead my newly established lab and me toward very exciting findings, which I was able to utilize to

prepare and submit a substantial grant application to the National Institutes of Health. I was fortunate to be awarded this grant.

The award – known as an R01 – generally provides support for five years in the neighborhood of \$2,000,000 for the investigator and her/his institution. It is a difficult award to secure, especially in recent years. Being awarded an R01 is essential for a young investigator – such as I was – to progress successfully and to develop

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*Continued on page 4*

*Researchers Describe How NAF Support...*  
Continued from page 3

her/his own independent research program. Recently, only about 8–15% of all applications are awarded. In some years, the cut-off line is lower.

Without the support of the National Ataxia Foundation I do not think that I would have been able to progress through the experiments that led to this award by the National Institutes of Health. That funding afforded me risks that I would have probably not taken otherwise, but which led to exciting findings and, ultimately, the R01 award.

I consider the funds from the NAF a modest investment with great returns towards a cure for ataxia. In fact, with the current funding by the National Institutes of Health we are making significant progress in this direction. I hope that members and donors of the National Ataxia Foundation will continue to provide great support for young investigators, to help them turn tiny morsels of novel ideas into fully fledged projects with clear insight into curing ataxias.



**By Sokol Todi, PhD**  
**Assistant Professor**  
**with Tenure**  
Department of  
Pharmacology  
Department of Neurology  
Wayne State University  
School of Medicine

I began my research on nucleotide repeat-based spinocerebellar ataxias back in 2008 under the mentorship of Dr. Henry L. Paulson. At that point, I relied on my gene therapy training to begin assessing the therapeutic value of viral-based RNA interference approaches to suppress

the expression of mutant proteins that cause ataxia.

Following successful preliminary studies funded by a research grant from the National Ataxia Foundation (*Generations*, 2009), Dr. Paulson and myself were able to secure a larger two-year grant (\$275,000) to perform more rigorous preclinical studies in mouse models of ataxia.

Subsequently, I received a Young Investigator Award from NAF (*Generations*, 2013) to develop a new mouse model of SCA6 in order to investigate a novel RNA interference approach to this ataxia. These funds were also leveraged to obtain a two-year grant (\$275,000) from the NIH to further validate and continue the development of therapeutic approaches to polyglutamine-based SCA.

Most recently, I was able to finish studies (*Altered miRNA Regulation in SCA1*) that had been initiated using a small research grant from NAF awarded to Dr. Beverly L. Davidson. I used the results from these studies in support of another two-year grant (\$275,000) from the NIH. New exciting data being generated by these studies should not only lead to the identification of novel therapeutic targets but should also provide the basis for additional research funding support from the NIH.

In summary, in the past six years, thanks to the generous support from NAF, we have been able to secure close to \$825,000 in additional ataxia research funds from the NIH.



**By Edgardo**  
**Rodriguez, PhD**  
**Assistant Professor**  
Department of  
Pharmacology and  
Therapeutics Center  
for Translational  
Research in Neuro-  
degenerative Disease  
University of Florida



Pioneer SCA Translational Grant Award

# Ataxin-7 Knock-Down Therapy: Preclinical Trial Validation in Mice

By **Albert La Spada, MD, PhD**

*alaspada@ucsd.edu*

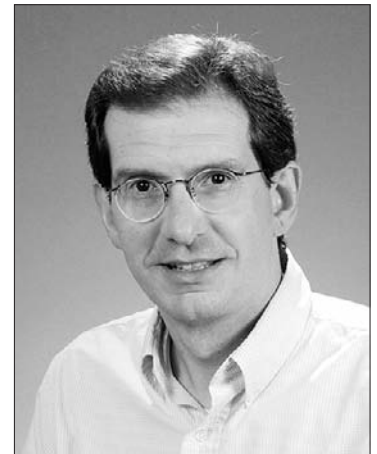
*University of California – San Diego, CA*

*The following is a research summary of a grant funded by NAF for fiscal year 2014.*

The purpose of this project was to develop a treatment for SCA7 patients. In this study, we took advantage of a powerful approach 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, had experience creating ASO therapy for ocular disease, with one drug approved by the FDA and currently in use in patients with CMV retinitis.** We thus developed ataxin-7 ASOs and CAG ss-siRNAs, validated them for use in mice, and performed preclinical trial validation studies in SCA7 mice to determine if oligonucleotide therapies can prevent blindness

and ataxia, or at least retard the rate of disease progression.

Over the course of this project, we pursued multiple experiments in SCA7 knock-in mice using different ASOs directed against either the ataxin-7 gene (non-selective knock-down) or the expanded CAG repeat (allele-selective knock-down). Our approach was to perform intravitreal injections into the eyes of SCA7 knock-in mice, injecting diluent in one eye and anti-ataxin-7 ASO or CAG repeat-targeting oligonucleotide in the contralateral eye. Preliminary results indicate significant reductions in the size and number of ataxin-7 protein aggregates in outer nuclear layer retinal photoreceptor cells in treated eyes, and reduced loss of photoreceptor cells. Based upon electroretinogram analysis, we documented retention of visual function in treated eyes within the short lifespan of the



**Dr. Albert La Spada**

*Continued on page 6*

*Ataxin-7 Knockdown Therapy...*  
*Continued from page 5*

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SCA7 knock-in mice. These experiments all indicated that non-allele selective ataxin-7 knock-down, even with an ASO that cross-reacts with the normal endogenous mouse ataxin-7 gene, can dramatically slow the progression of SCA7 retinal degeneration in mice. We also performed preclinical trials to determine if intracerebroventricular injection of these ASOs can retard the progression of SCA7 cerebellar and brainstem degeneration by assaying motor performance and examining neuropathology in cohorts of SCA7 mice that were either treated with experimental ASO or mock injected. We

needed to test additional ASOs and ultimately identified an ASO with limited neurotoxicity. These studies are still ongoing, as numbers of surviving treated mice were too low to draw any final conclusions.

Based upon our studies of ASO therapy, we hope that this research will ultimately lead to a human clinical trial. Importantly, a clinical natural history study of SCA7 retinal degeneration and cerebellar ataxia is now underway at the NIH, and is being led by Dr. Brian Brooks. The plan is to recruit 20-25 SCA7 patients and follow them over the course of three to five years, in the hope that the study can transition to a clinical trial by 2018 where we will test knock-down therapy as a treatment in human patients. ❖

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Pioneer SCA Translational Grant Award

# Translating RNAi Therapy for Spinocerebellar Ataxia 1 (SCA1) to the Clinic

**By Beverly Davidson, PhD**

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*The Children's Hospital of Philadelphia (CHOP), Philadelphia, PA*

*The following is a research summary of a grant funded by NAF for fiscal year 2014.*



**Dr. Beverly Davidson**

This proposal had two aims. The first was to optimize the material that will be used for delivery in humans. The second aim was to determine how much drug to infuse into the brain for optimal coverage and activity at the intended site, the cerebellum. We completed the first aim and successfully built a construct that can be used in humans safely. We completed the second aim using the earlier forms of the drug (not the one that will be used for human use) because the earlier form expressed a foreign protein that allowed us to “see” where the drug went. We found a dose that provided extensive coverage of the cerebellum and safely reduced the expression of the gene we are trying to knock down. This Pioneer Award was instrumental in moving this preclinical program forward to the clinic. In future studies we will use the optimized material in final dosing studies in our mouse models, and in the monkeys. ❖

Pioneer SCA Translational Grant Award

# Preclinical Development of NS13001 for SCA2

**Ilya Bezprozvanny, PhD**

*Ilya.Bezprozvanny@UTSouthwestern.edu*

*UT Southwestern Medical Center at Dallas, Dallas, TX*

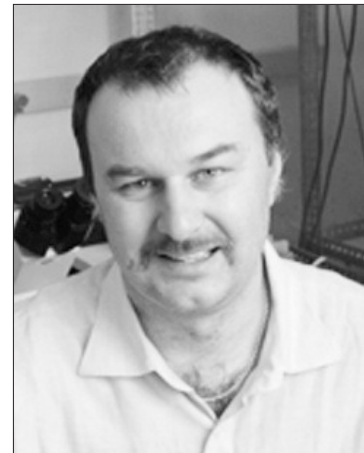
*The following is a research summary of a grant funded by NAF for fiscal year 2014.*

This research work was performed in collaboration with biopharmaceutical company Ataxion. The main objective of our study was to test the hypothesis that novel specific positive allosteric modulators (PAMs, compound NS13001 and its analogs) of small conductance calcium-activated potassium channels (SK channels) exert beneficial effects in spinocerebellar ataxia type 2 (SCA2) by normalizing firing rates of cerebellar Purkinje cells (PCs). Initial support to this hypothesis is based on the results of the experiments with a use of patch clamp method *in vitro* on live cerebellar slices which were recently published (Kasumu et al (2012) *Chem Biol* 19, 1340-53). However, it's very important to know what is going on in intact cerebellum of living animal and this information can be acquired via *in vivo* recording method. For this reason we started to perform *in vivo* recording experiments on transgenic SCA2 mice and their wild type (WT) littermates. Extracellular recording technique revealed alterations in spontaneous activity of PC cells in SCA2 mice. Obtained results showed that in the case of SCA2 mice there are more PCs with bursting and irregular firing patterns and less PCs with tonic activity in comparison with WT mice.

We have shown that the valuation of the SK channel inhibitor NS8593 influence on the PC firing rate is coordinated with data from analogous experiment conducted on C57BL/6 mice with *in vivo* recording of the electrophysiologi-

cal activity of Dopamine neurons in the substantia nigra (Herrik et al., 2010). Obtained data identify that we can perform not only positive modulation of SK channels activity but also the negative modulation and this is the another proof that the drug molecules hit the target.

Moreover, before start the novel specific drug testing we have performed *in vivo* recording experiments with well known SK channel activator chlorzoxazone (CHZ) testing. We obtained that the CHZ effect starts in 30 minutes after intraperitoneal injection and ends in 60 minutes after injection. These data are coordinated with data obtained in patch clamp experiments and it supports the fact that CHZ is non-effective SK channel activator. In further experiments we have shown that novel PAMs reduce PC cells firing rate in laboratory mice *in vivo* and reveal prolonged effect in comparison with well-known SK channels modulators. Experiments on SCA2 aged mice indicated that



**Dr. Ilya Bezprozvanny**

*Preclinical Development of NS13001 for SCA2*  
Continued from page 7

CHZ and also some candidates selected from novel PAMs can normalize firing activity of PCs by converting bursting patterns of SCA2 PC into a tonic pattern. From these results we concluded that novel PAMs are more potent because effective concentrations of these compounds are half of CHZ concentration.

The behavior studies showed that injections

with selected PAM improve motor performance in SCA2-58Q mice. Though the results obtained in beamwalking and rotarod assays are promising with selected compound, these experiments need to be repeated when mice reach an age of nine months, which should result in more severe phenotype.

These results suggest that PAM modulators of SK channel activity offer a promising therapeutic approach for treating ataxia patients. ❖

Pioneer SCA Translational Grant Award

# Pharmacological Activation of Autophagy to Alleviate Machado-Joseph Disease

By **Luis Pereira de Almeida, PhD**

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*Center for Neuroscience and Cell Biology of the University of Coimbra, Portugal*

*The following is a research summary of a grant funded by NAF for fiscal year 2014.*

Machado-Joseph disease (MJD) is a hereditary neurodegenerative disorder with severe clinical features, being the most common autosomal dominant spinocerebellar ataxia (SCA) worldwide. This disease is caused by the overrepetition of the



**Dr. Luis Pereira de Almeida**

CAG trinucleotide in the ATXN3/MJD1 gene, which translates into an expanded polyglutamine tract within the affected protein ataxin-3 (Kawaguchi et al., 1994). The mutant ataxin-3 protein becomes prone to misfolding, accu-

mulating as nuclear and intracellular inclusions, and acquires toxic properties which lead to neuronal dysfunction and cell death.

In recent years we have shown that activating the lysosomal-macroautophagy pathway leads to elimination of these aggregate-prone intracytosolic proteins and alleviation of neurodegeneration in MJD (Nascimento-Ferreira et al., 2011; 2013). Recent evidence suggests that carbamazepine (CBZ), a commonly used as anticonvulsant and mood-stabilizer is able to activate autophagy and clearance of aggregate-prone proteins (Hidvegi et al., 2010). Given that carbamazepine is an FDA-approved drug able to cross the blood brain barrier it appears as a candidate for therapy of MJD.

Therefore, during the last year, with the support of a Pioneer Award from NAF we investigated whether carbamazepine would ►►

activate autophagy in the brain and alleviate Machado-Joseph disease. We found that Carbamazepine was able to promote the activation of autophagy and consequently the degradation of mutant ATXN3 in mouse models of MJD. Treatment with CBZ was able to hamper the progression of neuropathology in the lentiviral mouse model, observed by a decrease in number of ataxin-3 aggregates and an improvement of

neuronal dysfunction while the long-term use of CBZ in the transgenic model resulted in improvement of motor performance as well as a decrease in the cerebellar atrophy.

This study provides evidence that low dosage CBZ mediates the alleviation the neuropathology of disease and that this pharmacological approach may provide a therapy for MJD. These results are under preparation for publication. ❖

## Post-Doc Fellowship Award

# Dendritic Transport Dysfunction in a Novel *Drosophila* Model of SCA5

By Adam W. Avery, PhD

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University of Minnesota, Minneapolis, MN

*The following is a research summary of a grant funded by the NAF in partnership with the Bob Allison Ataxia Research Center*

Spinocerebellar ataxia type 5 (SCA5) is a progressive neurodegenerative disorder that causes disability by loss of coordinated movements and slurred speech. Prominent neuronal targets in SCA5 pathogenesis are Purkinje cells of the cerebellum. In a healthy state cerebellar Purkinje cells extend elaborate dendritic arbors that are critical for proper function of neurons and the brain. In SCA5 pathogenesis, the dendritic arbors of Purkinje cells undergo dramatic atrophy. SCA5 stems from mutations in the *SPTBN2* gene that encodes the protein  $\beta$ -III-Spectrin. The overall goal of this project is to understand the molecular mechanisms by which SCA5 mutations in the target protein  $\beta$ -III-Spectrin cause dendritic arbor atrophy of cerebellar Purkinje cells.

One SCA5 mutation is a L253P substitution in the actin binding domain (ABD) of  $\beta$ -III-Spectrin. The position of this mutation suggests

that it causes pathogenesis by disrupting the interaction of  $\beta$ -III-Spectrin with actin or actin related protein 1 (ARP1). ARP1 is a component of the Dynactin complex that links membrane cargoes to the microtubule



**Dr. Adam W. Avery**

motor Dynein. A current model is that  $\beta$ -III-Spectrin lining the outside of membrane cargoes binds ARP1 and thereby facilitates transport of membrane cargoes by Dynein. I am specifically

*Continued on page 10*

*Dendritic Transport Dysfunction...*  
*Continued from page 9*

interested in testing the hypothesis that SCA5 mutations disrupt Dynein/Dynactin mediated dendritic membrane transport.

This project takes advantage of a novel SCA5 disease model that I developed in the fruit fly *Drosophila melanogaster*, an organism in which sophisticated genetic studies can be easily performed. *Drosophila* contains a population of neurons, called dendritic arborization (da) neurons, which like Purkinje cells, extend elaborate dendritic arbors. Expression of the L253P SCA5  $\beta$ -Spectrin mutant protein in *Drosophila* da neurons causes dendritic arbor atrophy. The first aim of this project was to test whether intracellular transport is disrupted in this novel SCA5 model. I have generated significant data toward

completion of this aim. These data show that SCA5  $\beta$ -Spectrin disrupts multiple membrane trafficking pathways in ways that are consistent with loss of Dynein function. The second aim was to test whether the SCA5 mutation disrupts the physical interaction of  $\beta$ -III-Spectrin with Dynein/Dynactin complex. Work for this aim is currently in progress. My current model is that SCA5  $\beta$ -Spectrin impairs Dynein mediated membrane transport processes required for efficient membrane delivery to dendrites.

I am very appreciative of the support that I received from the National Ataxia Foundation and the Bob Allison Ataxia Research Center for my postdoctoral work last year. I am excited about how this project has progressed and look forward to continued work to understand the molecular mechanisms underlying SCA5. ❖

### **Genes in Inherited Neurologic Disorders Study #HUM00041414**

Dr. Burmeister at the University of Michigan is recruiting individuals with ataxia for the research study Genes in Inherited Neurological Disorders. This study is designed to find what and how changes in the genetic material (DNA) cause inherited neurologic disorders, such as ataxia. We are recruiting individuals with inherited ataxia, their affected relatives (such as a brother or sister, a cousin, or a parent), and their unaffected family members, where possible. We are currently recruiting persons with an unknown form of ataxia, so at least one affected in your family should first be tested for the most common known causes of ataxia and found to be negative. We are recruiting both subjects with or without other affected family members.

In this study, you will be asked to provide information about your symptoms and diagnosis, if other relatives are similarly affected, and about your ethnic background. You will also be asked to donate a blood sample (up to 8 teaspoons of blood) for DNA testing and related experiments. The blood sample can be drawn by your local physician; you will not need to travel to the University of Michigan.

The lab has already identified several novel ataxia genes, and additional cases with newer known ataxia genes as well as mutations in genes causing other diseases involving ataxia and other, seemingly unrelated, symptoms such as tooth problems, although most subjects in our study have ataxia as main symptom.

More detailed information about this study is available in the consent forms: Affected Subjects Consent, Unaffected Relatives Consent.

If you would like further information or are interested in participating, please contact:

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5063 BSRB, 109 Zina Pitcher Place  
Ann Arbor MI 48109-2200  
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## Post-Doc Fellowship Award

# CRISPR-Modified ATXN1 in SCA1 Patient-Derived iPSC Cells

By Harry Orr, PhD

orrxx002@umn.edu

University of Minnesota, Minneapolis, MN

*The following is a research summary of a grant funded by NAF, received by Nissa Mollema, PhD, in the laboratory of Dr. Harry Orr for fiscal year 2014.*

Spinocerebellar Ataxia Type 1 (SCA1) is a neurodegenerative disease caused by a CAG expansion in the gene *ATXN1* (commonly referred to as Ataxin-1). We collected skin sample donations from adult individuals affected and unaffected by SCA1. Cells found in the skin samples were reprogrammed to stem cells (iPSCs) using genetic techniques. To date, we generated 11 iPSCs; seven from individuals affected with SCA1 and four from unaffected individuals. Of note, seven of these iPSCs were generated from a single large sibship (brother-sisters from a single family) with four from affected and three from unaffected members of the family.

One goal was to modify the Ataxin-1 gene in a set of these patient-derived stem cells to genetically attach a fluorescent marker to the Ataxin-1 gene in order to allow separation of the diseased copy of the gene from the unaffected copy of the gene. While this goal remains to be accomplished, we are the process of setting up the experiments.

We recently obtained supplemental funding from the NIH based on the SCA1 iPSCs we generated through the support of NAF. This funding will be used to grow large amounts of a select group of the SCA1 iPSCs that will then be provided to the NeuroLINC program. This program will perform extensive transcriptomic, proteomic and epigenomic characterization of the SCA1 iPSCs. Thus, funds from the NAF through this fellowship enabled us to undertake a new line of investigation. The SCA1 iPSCs generated from these NAF funds provided a novel platform for studying this form of ataxia. ❖

CoRDS Registry

Coordination of  
Rare Diseases at Sanford



 **National Ataxia  
Foundation**  
www.ataxia.org

Everyone who has any form of ataxia or who is at risk for ataxia is encouraged to enroll in the CoRDS/NAF ataxia patient registry.

To register in the CoRDS ataxia patient registry, go to [www.ataxia.org](http://www.ataxia.org) and click on “**Ataxia Patient Registry**.” If you prefer to enroll by postal mail, please contact CoRDS personnel.

For more information on CoRDS and/or enrollment, visit [www.sanfordresearch.org/cords](http://www.sanfordresearch.org/cords) or call (605) 312-6413. Thank you for participating in this important research tool.

Post-Doc Fellowship Award

# Regulation of Organismal Proteostasis by Integrated Stress-Response Networks

By **Jian Li PhD**

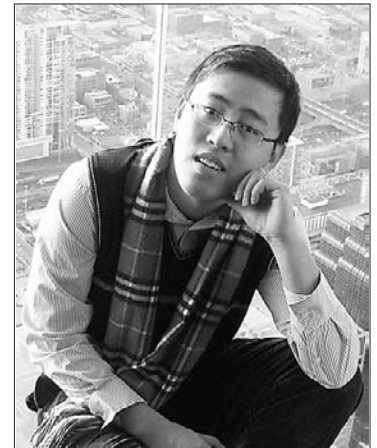
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*Northwestern University, Evanston, Illinois*

*The following is a research summary of a grant funded by NAF for fiscal year 2014.*

Proteins are essential building blocks and chief actors of the cell. To perform their cellular functions, proteins need to be maintained at proper concentrations and in a folded soluble state with desired conformations, which is referred as protein homeostasis (proteostasis). Underlying the pathologies of late-onset neurodegenerative diseases such as multiple types of spinocerebellar ataxia (SCA) is the age-associated collapse of proteostasis. Many SCAs are polyglutamine diseases in which the disease-associated proteins contain polyglutamine expansions (polyQ) that are highly prone to aggregation. Aggregation of these polyQ-containing proteins initiates a cascade of protein damage that results in aggregation of other proteins and eventually leads to neuron degeneration.

Our lab has previously identified a group of molecular chaperones, or proteins that assist folding and assembly of other proteins, as prominent suppressors of protein aggregation and toxicity associated with polyQ and other disease-associated proteins. This group of molecular chaperones that we call “core chaperome” decreases dramatically during brain aging and in diseases, however the mechanism was unknown. In this project, I have identified a stress response factor that controls the expression of the “core chaperome.” Interestingly, the activity of this factor at “core chaperome” genes is uncoupled from its response to environmental stimuli but rather replies on a signal from animal development. These results provide a reasonable explanation for the dynamic change of “core chaperome” in life and point out a potential strategy for amelioration of polyQ toxicity by increasing the expression of “core chaperome” through modulating the developmental signal. ❖



**Dr. Jian Li**

## Athena Alliance Program

Athena Diagnostics has recently launched a more accessible and affordable diagnostic testing program called the Athena Alliance Program, created to expand patient access to diagnostic testing, especially for rare disorders. The new tiered financial assistance program is based on income levels, with improved financial assis-

tance available for families.

For individuals who have faced financial barriers to accessing the diagnostic tests necessary to get a diagnosis, the Athena Alliance Program may help.

For more information, please go online to [www.athenadiagnostics.com/aap](http://www.athenadiagnostics.com/aap).

Post-Doc Fellowship Award

# 5hmC-Mediated Epigenetic Modulation in rCGG-Mediated Neurodegeneration Associated with FXTAS

By **Bing Yao, PhD**

*bing.yao@emory.edu*

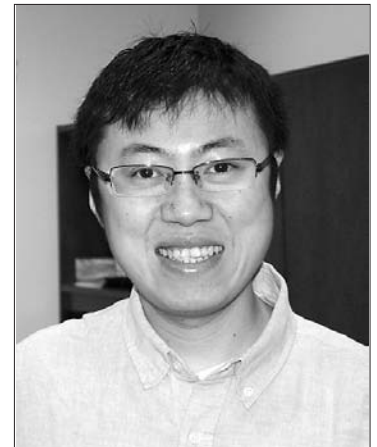
*Department of Human Genetics, Emory University School of Medicine, Atlanta, GA*

*The following is a research summary of a grant funded by NAF for fiscal year 2014.*

Fragile X tremor and ataxia syndrome (FXTAS) and Spinocerebellar ataxia (SCA) are heterogeneous groups of neurodegenerative diseases caused by expanded trinucleotide repeats, such as “CGG” or “CAG”, in various regions of putative genes. Depending on where these excessive repeated nucleotides reside, either RNA- or protein-mediated toxicity in molecular level can be readily linked to the etiology of specific types of ataxia-related diseases. However, common symptoms such as progressive degeneration of gait, poor coordination of hands, speech and eye movements, as well as shared pathology features of motor neuron degeneration imply not-yet identified common molecular mechanisms underlying these distinctive diseases. It will be pivotal to identify the common mechanisms shared among Ataxia diseases for development of general and effective diagnosis and prognosis tools as well as therapeutic revenues.

It has been well established that epigenetic plasticity in DNA methylation-related regulatory processes influences activity-dependent gene regulation, learning and memory, and aging in central nervous system. Recent findings that 5-methylcytosine (5mC) can be oxidized to 5-hydroxymethylcytosine (5hmC) present a particularly intriguing epigenetic regulatory paradigm in mammalian brain. We previously generated genome-wide maps of 5hmC of different brain regions, including cerebellum,

during brain development and aging, providing a detailed epigenomic view of regulated 5hmC in central nervous system (CNS). Our analyses suggest a highly dynamic regulation of 5hmC during cerebellum maturation and aging. In particular, 5hmC is highly enriched in motor neuron cells called Purkinje cells, which are the cell type primarily affected in SCAs. Funded by National Ataxia Foundation, we first identified loci with altered 5hmC modifications in the cerebellum of FXTAS mouse model by using cutting-edge high-throughput genome sequencing. The changes of 5hmC occurred on genes and their regulatory regions were highly related to key neuronal function. Aberrant 5hmC levels resulted in the mis-regulation of these gene expression and caused disease onset. We went on to identify common 5hmC-mediated epigenetic alterations in FXTAS and multiple SCA mouse models, which suggest a potential role of 5hmC



**Dr. Bing Yao**

*Continued on page 14*

*5hmC-Mediated Epigenetic Modulation...*  
Continued from page 13

alteration in the etiology of ataxia in general. Furthermore, we validated the disease-modulating functions of these gene loci using fruit fly ataxia disease animals. Our data, for the first

time, reveal a common epigenetic mechanism that contribute to the pathogenesis of ataxia-related disorders and present key gene loci that undergo dynamic 5hmC alteration that related to ataxia disease onset and development. These results shed light on the development of effective therapeutic treatments. ❖

Young Investigator SCA Research Award

## The Role of Ataxin-2 in the Regulation of Circadian Behavior and Sleep in Mice

By Yong Zhang, PhD

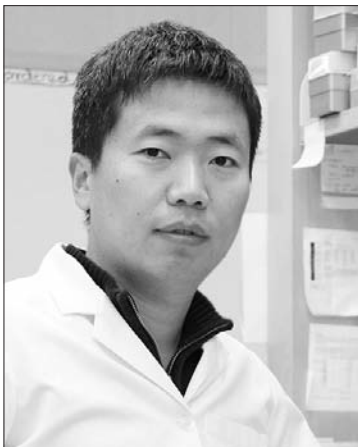
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University of Nevada Reno, Reno, NV

*The following is a research summary of a grant funded by NAF for fiscal year 2014.*

Spinocerebellar Ataxia Type 2 (SCA2) is an inherited neurodegenerative disease caused by an elongated stretch of glutamine amino acids in the Ataxin-2 protein. SCA2 patients usually have uncontrolled muscle tensing and other movement incoordination symptoms, as well as sleep disorders. Sleep is tightly regulated by circadian clocks, which drive 24-hour physiological and behavioral rhythms in human and most animals. Interestingly, we have found that Ataxin-2 is a crucial regulator of circadian clocks in the fruit fly *Drosophila melanogaster* (Zhang et al., 2013, Science), which is a powerful model organism to understand circadian rhythms in animals, including humans. Since Ataxin-2 (ATXN2) proteins and the mechanisms controlling circadian behavior are well conserved between fruit flies and humans, we hypothesize that Ataxin-2 also regulates circadian behavior and sleep in mammals.



**Dr. Yong Zhang**

With collaboration of Dr. David Weaver, I studied the role of ATXN2 in the control of circadian behavior using ATXN2 deficiency mice from Dr. Stefan Pulst. My result suggested that ATXN2 deficiency mice do not have obvious circadian locomotor defects. This result may be due to functional redundancy between ATXN2 and a gene closely related to ATXN2, named ATXN2-like. I have generated specific Adeno-Associated virus (AAV), which allows me to deplete ATXN2-like. In

the future, I will inject these AAV to brain regions regulating circadian behavior in mice and investigate the function of ATXN2/ATXN2-like family in circadian rhythms. In conclusion, my work should elucidate the role of the Ataxin-2 family of proteins in the control of circadian behavior and may establish a direct link between circadian dysfunction, sleep disturbances and SCA2 disease. ❖

Young Investigator SCA Research Award

# Molecular Pathogenesis Studies of Spinocerebellar Ataxia Type 1

By Janghoo Lim, PhD

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The following is a research summary of a grant funded by NAF for fiscal year 2014.

The human inherited 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 neuron degeneration.

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 protein Ataxin-1. With the National Ataxia Foundation support, we have investigated the possibility that SCA1 affects Wnt- $\beta$ -catenin signaling pathway in the cerebellum. We found that disease-causing mutant Ataxin-1 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

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The National Ataxia Foundation Research drive will begin on October 15 and continue through December 15, 2015.

Through the generosity of our donors and partners, NAF has supported nearly 90 ataxia research studies, nearing four million dollars, over the past four years to support scientists working world-wide to find answers to end ataxia.

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Young Investigator SCA Research Award

# Pathogenesis and Disease Course of Spinocerebellar Ataxia Type 14 in a Mouse Model

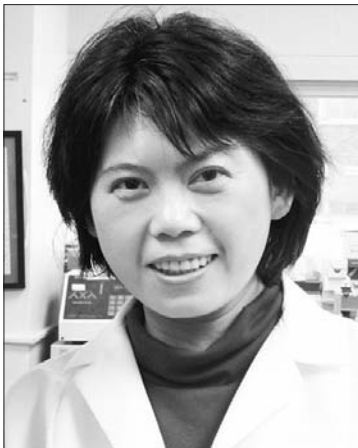
By *Dong-Hui Chen, MD, PhD*

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*University of Washington, Seattle, WA*

*The following is a research summary of a grant funded by NAF for fiscal year 2014.*

SCA14 shares many clinical and pathologic features with other autosomal dominant SCAs, but may have additional phenotypes of myoclonus (spasmodic jerky contraction of muscles) and a variety of cognitive impairments. We previously discovered that SCA14 is caused by mutations in the protein



**Dr. Dong-Hui Chen**

kinase C gamma (PKC $\gamma$ ) gene. The gene belongs to a serine/threonine kinase family and plays a role in diverse processes such as signal transduction, cell proliferation and differentiation. The mechanism of how the mutations in PKC $\gamma$  lead to neuronal death and how the disease develops is unknown. An animal model of SCA14 would be invaluable for such investigations. To achieve a mouse model that recapitulates SCA14, we have generated the transgenic mice to carry human PKC $\gamma$  with a disease-causing mutation found in SCA14 patients and then we have altered the relative number of copies of the human and mouse PKC $\gamma$  genes. The study in these mice have found pathologic abnormalities in Purkinje cells at early ages, including aggregates and dendrites abnormality. Neurological testing showed poor performance in motor coordination, e.g. rotarod testing, footprints.

With this mice model, now we can further study progression of neurologic impairments. We will also investigate the pathologic sequelae of mutations. The mice model will provide us a useful system toward reaching our long-range goal of discovering therapeutic interventions that may slow down or reverse the neurologic deterioration. I'm thankful for the National Ataxia Foundation for providing me the funding to conduct this research. I'm also looking forward to provide my contributions to NAF and to ataxia patients. ❖

## Thrivent Choice Works

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Research Seed Money Award

# Episodic Ataxias: Looking for New Genes by Next Generation Sequencing Approach

**By Elide Mantuano, PhD**

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*National Research Council of Italy, Institute of Translational Pharmacology, Rome, Italy*

*The following is a research summary of a grant funded by NAF for fiscal year 2014.*

The Episodic Ataxias (EA) are a group of rare hereditary neurological diseases. Only 20–30% of EA patients clinically diagnosed have a molecular diagnosis. So far, a large part of EA molecular causes are unknown and a lot of patients are waiting for molecular diagnosis. The possibility to increase the knowledge on the molecular defects of the disease will help to understand how the dysfunctions of certain genes result in Episodic Ataxia pathway, as well as contribute to identify therapeutic targets for patients who do not respond to conventional therapies.

The aim of this project is to identify new genes responsible for EA in order to:

- improve the possibility of molecular diagnosis,
- expand the comprehension of genetic causes of the disease,
- indicate new perspective to search for therapies.

Using a next generation sequencing approach (Whole Exome Sequencing) we analyzed some families, in order to identify causative gene variations. The preliminary data are promising. The results indicate a set of several possible candidate genes, to be confirmed as disease genes. If the results of this study have a positive outcome, new metabolic pathways might be highlighted and pathogenic mechanism would be elucidated, improving diagnostic criteria for Episodic Ataxia and new target for pharmacological therapies. ❖



**Dr. Elide Mantuano**

## Brain Donation Program

Scientific discoveries from studies of post-mortem human brain tissue have provided significant contributions to better understand ataxia.

If you would like to learn more about setting up a plan to donate your brain upon death, please e-mail [susan@ataxia.org](mailto:susan@ataxia.org) or call the NAF office at

(763) 533-0020 to request a *Brain Donation Pre-Plan Form*. Forms can also be found on the NAF's website at [www.ataxia.org/research/ataxia-tissue-donation.aspx](http://www.ataxia.org/research/ataxia-tissue-donation.aspx).

The National Ataxia Foundation honors the courage of making this deeply personal decision. Thank you for your interest in this program.

Research Award

## National Ataxia Database

**By Susan Perlman, MD**

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*University of California - Los Angeles*

*The following is a research summary of a grant funded by NAF for fiscal year 2014.*



**Dr. Susan Perlman**

The Natural History Study of and Genetic Modifiers in Spinocerebellar Ataxias (ClinicalTrials.gov Identifier: NCT01060371), under the direction of Dr. Tetsuo Ashizawa at the University of Florida, Gainesville, continues to recruit subjects and monitor changes in their neurologic examinations. The participating 12 sites see and examine subjects and enter data into the National Ataxia Database (housed at UCLA under the direction of Dr. Jeanette Papp in the Department of Genetics). The Database has served as a valuable repository for data collected in this important collaborative project that has enrolled over 400 individuals with Spinocerebellar Ataxia types 1, 2, 3, and 6. There are over 15,000 patient forms entered in the National Ataxia Database. ❖

Research Seed Money Award

## Transplantation of Neural Stem Cells (NSC) as a New Therapeutic Strategy for Machado-Joseph Disease (MJD)

**By Liliana Simões Mendonça, PhD**

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*The following is a research summary of a grant funded by NAF for fiscal year 2014.*

Machado-Joseph disease (MJD) is a progressive neurodegenerative disease, originally described in people of Portuguese ancestry, and caused by a mutation on the ATXN3 gene translating into a mutant ataxin-3 protein. Mutant ataxin-3 protein is toxic causing neuronal dysfunction and degeneration in specific brain regions and leading to motor symptoms (incoordination,

spasticity, scanning speech, dysphagia and ocular complaints) and non-motor symptoms (minor cognitive and behavioral abnormalities, verbal and memory deficits and chronic pain), with large variability in severity and type of symptoms between patients.

There is no specific and effective treatment able to delay and stop the progression of this ►►

disease. Moreover, in symptomatic patients, already with extensive neuronal loss, cell replacement strategies, such as the transplantation of neural stem cells (NSC), are very promising therapeutic strategies holding the promise of neuroregeneration. In fact, it has been demonstrated that after brain transplantation these cells exert a substantial beneficial and therapeutic effect through differentiation into neural cells, production of neurotrophic factors and reduction of neuroinflammation which rescue/improve the damaged neuronal network.

Therefore, this work aimed to evaluate if the transplantation of NSC into the cerebellum of MJD transgenic mice leads to a decrease in MJD-associated neuropathology and motor coordination impairments. Additionally, we assessed if the transplantation of NSC leads to modifications in the levels of neurotrophic factors and inflammatory mediators.

For this purpose, we injected cerebellar NSC (cNSC) in the cerebellum of adult Machado-Joseph disease transgenic mice and assessed the effect in the neuropathology, neuroinflammation mediators and neurotrophic factor levels and motor coordination. We found that upon transplantation into the cerebellum of adult Machado-Joseph disease mice, cNSC differentiate into neurons, astrocytes and oligodendrocytes. Importantly, cNSC transplantation mediated a significant and robust alleviation of the motor behavior impairments, which correlated with a preservation from Machado-Joseph disease associated neuropathology, namely reduction of Purkinje cells loss, reduction of cellular layers shrinkage and mutant ataxin-3 aggregates. Additionally, a significant reduction of neuroinflammation and an increase of neurotrophic factors levels were observed,

indicating that transplantation of cNSC also trigger important neuroprotective effects. Thus, cNSC have the potential to be used as a cell replacement and neuroprotective approach for Machado-Joseph disease therapy.

#### **More important references:**

**Paper:** Liliana S. Mendonça, Clévio Nóbrega, Hirokazu Hirai, Brian Kaspar, Luís Pereira de Almeida, “Transplantation of cerebellar neural stem cells improves motor coordination and neuropathology in Machado-Joseph disease mice,” *Brain*. 2015 Feb; 138(Pt 2):320-35.

**Press Release:** “Transplantation of Neural Stem Cells Improves Motor Coordination, Neuropathology in Mouse Model of Machado-Joseph Disease,” Liliana

S. Mendonça, Clévio Nóbrega, Hirokazu Hirai, Brian Kaspar, Luís Pereira de Almeida, Society for Neuroscience’s annual meeting, 15-19 November 2014, Washington DC, USA.

**Oral Presentation:** “Transplantation of cerebellar neural stem cells alleviates motor coordination and neuropathological deficits of a transgenic mouse model of Machado-Joseph disease,” Liliana Mendonça, Clévio Nobrega, Hirokazu Hirai, Brian Kaspar, Luis Pereira de Almeida, International Ataxia Research Conference 2015, 25-28 March 2015, Beaumont Estate Windsor, UK. ❖



**Dr. Liliana Simões Mendonça**

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Research Seed Money Award

# Unraveling Expression Profiles in Human SCA3 Brain Pathology: A Pilot Study

**By Henry Houlden, PhD**

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*University College London Institute of Neurology, London, UK*

*The following is a research summary of a grant funded by NAF for fiscal year 2014.*



**Dr. Henry Houlden**

Spinocerebellar ataxia type 3 (SCA3), also known as Machado-Joseph disease, is a neurological disorder affecting the brain and the spinal cord of individuals with the disease. The first symptoms usually start around the age of 40 years and include difficulty walking, but in some cases the disease appears much earlier (four years) or much later (70 years). Other complications, such as problems with vision, speech, and swallowing, among others, may also occur and range in severity. The disease is progressive and many patients ultimately need a wheelchair or become bedridden, as there is no treatment currently available. This is a genetic disorder that can be transmitted from one generation to another. The genetic defect that will determine if a person will have the disease is already known, and having just one copy of this defect is enough to cause the disease. However, the cellular mechanisms that lead to disease are largely unknown. To get insights on this, we conducted a pilot study using post-mortem brain tissues of individuals with SCA3 (the damaged part of the body in SCA3). We investigated whether there are changes in gene expression patterns that can be relevant to the disease. To do so, we compared gene expression profiles between brain tissue derived from individuals with and without SCA3. This pilot study revealed that several biological mechanisms, including intracellular protein transport and catabolism as well as gene expression regulation, are compromised in individuals with SCA3. The data produced by this pilot study constitutes a valuable resource for further research on the mechanisms underlying ataxia and related diseases. ❖

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Research Seed Money Award

# The Role of Ataxin-2 in in Machado-Joseph Disease: A Molecular Therapy Approach with Viral Vectors

By Clévio Nóbrega, PhD

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*The following is a research summary of a grant funded by NAF for fiscal year 2014.*

Machado-Joseph disease (MJD) or spinocerebellar ataxia type 3 (SCA3) is a dominantly-inherited disorder originally described in people of Portuguese descent, and associated with the expansion of a (CAG) $n$  tract in the coding region of the causative gene MJD1. The abnormal over-repetition of the CAG-trinucleotide is translated into an expanded polyglutamine tract within ataxin-3, a protein whose physiological function has recently been linked to ubiquitin-mediated proteolysis, resulting in severe clinical features and leading to death. There is no therapy for this fatal disease.

Ataxin-2 (Atx2) is a protein whose function has been linked to translational regulation or certain transcripts. In this project we explored the idea of a potential link between Atx2 and the mutant Atx3. We found that in MJD patients and animal models the levels of Atx2 are reduced. Interestingly, we found that was mutant Atx3 aggregation in the nucleus that lead to a decrease in those levels. Using lentiviral mediated expression, our data showed that restoration of Atx2 levels reduce the mutant Atx3 levels and also decrease the neuropathological abnormalities MJD-associated.

The data produced in this project shows that Atx2 could play a key physiological role in MJD pathogenesis and open a new avenue for future studies concerning therapeutic strategies targeting Atx2 in spinocerebellar ataxias. ❖



Dr. Clévio Nóbrega

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Research Seed Money Award

# Silencing Machado Joseph-Disease/ Spinocerebellar Ataxia Type 3 Through the Systemic Route

By **Rui Jorge Nobre, PhD**

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*The following is a research summary of a grant funded by NAF for fiscal year 2014.*

Machado-Joseph disease (MJD) or spinocerebellar ataxia type 3 is a dominantly-inherited neurodegenerative disease with high prevalence in some regions of Portugal. It affects mostly the cerebellum and is the most common dominantly-inherited ataxia worldwide. MJD is associated with the expansion of a (CAG) $n$



**Dr. Rui Jorge Nobre**

tract in the coding region of the causative gene MJD1. The abnormal over-repetition of the CAG trinucleotide is translated into an expanded polyglutamine (polyQ) tract within ataxin-3, conferring toxic properties to this protein,

resulting in severe clinical features and leading to death. There is no therapy for this fatal disease.

Our group has recently showed that intracranial injection of lentiviral vectors encoding silencing sequences targeting ataxin-3 significantly decreased the severity of the neuropathological abnormalities in rodent models of MJD (Alves et al., 2008, 2010, Nóbrega et al., 2013). Despite these recent successes, several hurdles and limitations need to be addressed. The aforementioned experiments involved craniotomy, general

anesthesia and in situ injection of viral vectors in the brain parenchyma. Therefore, there is a need to develop alternative systems, able to cross the blood-brain barrier (BBB) by less invasive routes of administration, such as injection in the systemic circulation, and that may diffuse over larger areas of the brain.

The aim of this research study was to develop a viral-mediated system to deliver RNA interference-based treatments to the Machado-joseph disease (MJD) mouse brains by intravenous injection. For that, we made use of adeno-associated viral vector serotype 9 (AAV9), a non-pathogenic viral vector that has a remarkable *ability to bypass* the blood-brain barrier (BBB) and transduce neurons and astrocytes in the central nervous system (CNS) of mice, cats and non-human primates.

This project comprised two tasks. The first task aimed at designing and testing recombinant AAV9 vectors encoding the silencing sequences that we have previously shown to efficiently abrogate MJD (Alves et al., 2008). In the second task, the ability of these recombinant AAV9 vectors to transverse the BBB, to transduce neurons and to silence mutant ataxin-3 and the resultant neuropathology was tested in a transgenic mouse model of severe MJD (Torashima et al., 2008). Wild-type and MJD neonate mice (postnatal day 1) were intravenously injected in the temporal facial vein with rAAV9 vectors encoding a ►►

control sequence or an artificial microRNA targeting mutant ataxin-3 mRNA. Forty days after the viral injection, behavioral tests were performed to monitor disease state before sacrifice.

A postnatal day-one intravenous injection of rAAV9 targeting mutant ataxin-3 demonstrated a widespread transduction of mice brain, including spinal cord, medulla, hippocampus, and cerebellum, in wild-type animals. Although a lesser transduction was detected in the cerebellum of transgenic MJD mice, this was enough to reduce the number of aggregates and intranuclear

inclusions leading to an alleviation of the MJD-associated motor impairments.

Overall, this study generated compelling evidences that a single systemic administration of the AAV9 system at postnatal day one is able to transpose the BBB, to transduce the brain of MJD mice, to silence mutant ataxin-3 in some cerebellar regions, and to alleviation of MJD motor phenotype and neuropathology. This constitutes the first proof of concept of effective gene silencing by a non-invasive route for the treatment of MJD. ❖

## International Ataxia Awareness Day

— Friday, September 25, 2015 —



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Research Seed Money Award

# Annotation and Analysis of Pre-mRNA Splicing Elements in Ataxia Genes

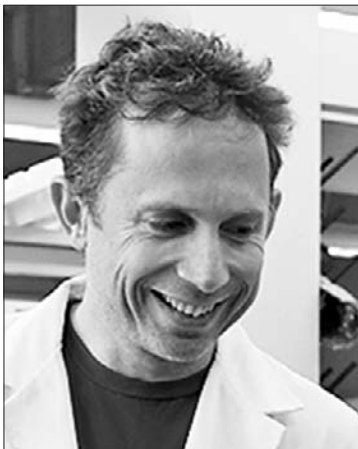
By *William G. Fairbrother, PhD*

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*The following is a research summary of a grant funded by NAF for fiscal year 2014.*

The ataxic disorders reflect a heterogeneous group of progressive cerebellar degenerative disorders characterized by a broad set of symptoms relating to a lack of coordination of voluntary movements. More than 50 different types of hereditary degenerative ataxias have been identified, each with a distinct genetic cause. Nonetheless, for a number of patients with symptoms of an ataxic disorder, the causal gene has not been identified. We are entering the age of precision medicine in which genomes will be sequenced as part of routine medical care. The techniques and methods of precision medicine are especially appropriate for the study of rare disorders, such as hereditary ataxias. However, sequencing studies conducted as part of precision medicine typically indicate hundreds of genomic positions at which the patient's sequence differs from the human reference sequence. Thus, determining which mutation or mutations are in fact causal becomes a daunting task. A huge bottleneck in workflow lies in the analysis of these variants. Many clinical groups may limit their analyses to mutations that are likely to lead to defects in the encoded protein, such as amino acid changes, insertions, or deletions. However, a large percentage of hereditary disease mutations affect genetic processes that occur before the protein is generated. One such process is the "splicing" together of pieces of genetic information (i.e., RNA exons) that will encode for a protein.



**Dr. William Fairbrother**

Using a combined approach of high-throughput splicing assays and computational methods, the research group of Dr. William G. Fairbrother of Brown University in Providence, RI, analyzed the effects of genetic variants considered causal of hereditary ataxic disorders on the splicing process. Using these high-throughput assays, Dr. Fairbrother's team detected splicing defects, including a reduced efficiency in splicing, for a number of ataxia-related gene variants. These defects might then lead to changes in the amount or structure of proteins and, as a result, in the ability of cells to function appropriately. Additional studies are underway to determine whether and how these splicing defects might contribute to various forms of inherited ataxias. With the data acquired to date in hand and future studies planned, the Fairbrother research group is further developing and refining software tools the group has designed for analyzing, visualizing, and predicting the effects of ataxia-related gene variants on splicing. In the end, Dr. Fairbrother hopes to create a tool that will help physicians and clinicians more effectively use patient sequencing data in determining whether a gene variant is likely to be deleterious or benign and what personalized treatment options might be available and most appropriate. ❖

Research Seed Money Award

# iPSC-derived Neurons from Friedreich's Ataxia (FRDA) Patients as a Model to Characterize Pathological Mechanisms and Devise Neuroprotective Strategies

By Franca Codazzi, PhD

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*The following is a research summary of a grant funded by NAF for fiscal year 2014.*

Friedreich's ataxia (FRDA) is a rare autosomal recessive hereditary disorder characterized by progressive neurological disability, hypertrophic cardiomyopathy and increased risk of diabetes mellitus. FRDA is caused by a reduced expression of frataxin, a mitochondrial protein involved in important biochemical pathways, including the iron-sulfur cluster biogenesis. The molecular mechanisms responsible for neurodegeneration are still poorly known, mainly because of the lack of appropriate human neuronal models that recapitulate the disease-specific pathology.

Aim of this study was to characterize neurons from reprogrammed cells (iPSC-derived neuronal cells) obtained from patients (FRDA-neurons) or healthy subjects, to unveil phenotypic alterations related to the disease.

By using videomicroscopy analyses and specific fluorescent probes, we observed a higher susceptibility of FRDA-neurons to oxidative stress conditions with ensuing death. This can be ascribed, on the one hand, to an impaired ability of these cells to handle cytosolic iron with consequent oxidative stress, on the other hand, to a reduced level of endogenous detoxifying molecule that makes FRDA-neurons more prone to produce reactive radicals, even in response to exogenous pro-oxidant stimuli.

Finally, we evaluated the protective effects of molecules able to upregulate frataxin expression. This treatment appeared to prevent not only the production of reactive radicals, but also the neuronal death promoted by oxidative conditions.

Overall, we provide experimental evidence of cellular mechanisms involved in FRDA pathology. Moreover, we show that FRDA-neurons represent a suitable model to test potentially protective molecules and to identify new potential therapeutic targets, a condition necessary to make progress in the clinical rescue of the affected neurons.



**Dr. Franca Codazzi**



Young Investigator Award

# Genomic and Epigenomic Analysis in an Induced Pluripotent Stem Cell Model of ADCA-DN

By **Alexander E. Urban, PhD**

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*The following is a research summary of a grant funded by NAF for fiscal year 2014.*

Autosomal-Dominant Cerebellar Ataxia, Deafness and Narcolepsy (ADCA-DN) is a disease of the nerve system that begins late (30-40 years of age) in carriers of a point mutation in the gene DNMT1. The mutation is very penetrant, meaning so far all known carriers have developed the disease from a certain age on, and the symptoms are ataxia (loss of control over movements), and also deafness and narcolepsy-cataplexy (sleep attacks).



**Dr. Alexander E. Urban**

We have found the location of the gene mutation that causes this disease. DNMT1 is a gene of great importance to the normal development and functioning of all organs in the human body. However, it is unknown how the mutation leads to ADCA-DN. How does the mutated DNMT1 gene behave differently inside the nerve cells compared to the same gene without the mutation?

Funding from the National Ataxia Foundation has allowed us to develop a way to study the effects of the changes in DNMT1 on nerve cells. We used the funding to take cells from the skin of a person suffering from ADCA-DN – cells which will therefore carry the mutation even if it has no effect in this particular type of cell – and reprogrammed them into a state that is very similar to stem cells. Stem cells are the cells that turn into all the other cell types of the human body, including nerve cells. That means we can now make nerve cells in a dish that carry the ADCA-DN mutation. We have made multiple lines of stem cell like cells with the DNMT1 mutation and have begun turning them into nerve cells and studying the effects of the DNMT1 mutation in the process.

DNMT1 is a gene that is responsible for leaving control marks on the entire DNA sequence in all human cells, marks that will then act similar to an on-off switch for other genes. Using the stem cell like cells that we have made with the funding from the National Ataxia Foundation we are now studying how these marks change in nerve cells with the mutated DNMT1 gene. And we are also observing how the changes in these marks then affect many other genes in their activity. We expect that this research will shed light on how mutations in DNMT1 cause ataxia, first in ADCA-DN but then later we hope that this knowledge will provide an additional piece to the puzzle of ataxia in general.



Young Investigator Award

# Cellular Signaling Mechanisms Underlying EA1 in Cerebellum

By Jason Christie, PhD

[jason.christie@mpfi.org](mailto:jason.christie@mpfi.org)

Max Planck Florida Institute, Jupiter, FL

*The following is a research summary of a grant funded by NAF for fiscal year 2014.*

Episodic ataxia type-1 (EA1) is a neurological disorder characterized by recurrent bouts of uncontrolled motor movements. EA1 results from mutations in a particular gene encoding an ion channel called Kv1.1. This type of ion channel is known to play a critical role in damping the excitability of neurons following stimulation. The motor deficits associated with EA1 indicate that neuronal excitability in the cerebellum, a brain region used for motor learning and refinement of movement, is likely affected in this pathological condition. While the connection between mutant Kv1.1 channels and EA1 is well-understood, it remains unknown how specific EA1 mutations manifest into altered cellular excitability in cerebellar neurons. To effectively treat this disorder, the etiology of EA1 must be understood in detail – beyond that of genetics alone – including the cellular basis for excitability changes in cerebellar neurons.

Mouse models replicating human EA1 mutations provide an excellent opportunity to study the cellular basis of EA1. Therefore, we made electrical recordings from cerebellar neurons in EA1 mice. Because Kv1.1 is primarily expressed in molecular layer (ML) interneurons in the cerebellum, we recorded from this particular cell type. We find that in these local inhibitory cells, EA1 mutant channels likely result in an increase in excitability in a subregion of the cell called the axon, a specialized projection from the cell body that controls signaling to downstream neurons.

Interestingly, our data suggest that the strength of signaling from the axon onto other neurons is not altered. Rather, we find the frequency of the signals may be enhanced in effected cells due to the lack of dampening as a result of EA1 mutations in Kv1.1 channels. Restoring normal “dampened” activity to the axons of these inhibitory cells therefore might help ameliorate motor dysfunctions associated with EA1. It will be interesting to examine how effectively current therapeutics are at diminishing axonal excitability and inhibitory signaling in the cerebellum of EA1 mice. ❖



Dr. Jason Christie

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

Autumn is the start of a new season ... a new beginning. It's a time of harvest and gathering, the rewards given to those who have worked so very hard. It is also the time of the year for the annual ataxia research drive: an opportunity for new beginnings for ataxia research.

This year the NAF Annual Ataxia Research Drive will begin on October 15 and continues through December 15. Due to the continued generosity of an anonymous donor, research funds received during this time will be matched dollar for dollar up to \$200,000.

Through the generosity of our donors and partners, the National Ataxia Foundation has supported nearly 90 ataxia research studies, nearing four million dollars, over the past four years to scientists working world-wide to find answers to end ataxia.

This year the National Ataxia Foundation has received more than 100 Letters of Intent from researchers in 16 countries applying for research funding to our five ataxia research programs.

Their research focus is a broad scope of the ataxias including many of the SCAs, Friedreich Ataxia, AOA, ARCAs, A-T, and others. Many of the post-docs who have submitted Letters of Intent for the NAF Post-Doc Fellowship Awards are completing their research in the labs of leading ataxia researchers in the world.

The annual ataxia research drive plays a critical role in our ability to fund these essential studies in moving ataxia research forward. NAF utilizes a multi-pronged approach in supporting ataxia research by bringing in young investigators into the field of ataxia research, supporting new and innovative studies, and supporting translational research to bring us closer to treatments and ultimately a cure.

A number of the young investigators who the NAF had funded years ago are now established senior investigators who have made exceptional contributions to the field of ataxia research, identifying ataxia genes, creating a better understanding of gene functions, and exploring compounds for the treatment of ataxia, as well as mentoring the next generation of ataxia researchers.

The funds that support NAF-funded researchers also have a multiplying affect. Many times a funded NAF researcher is able to leverage additional support from other sources once they receive a NAF research grant. Often times a 5–10 fold increase in funding is realized, sometimes as substantial as 100 fold increase. Please go to page three to read two stories of how impactful the NAF research program is in furthering promising ataxia research.

To assure that the most promising ataxia research studies are funded, the NAF has created a multi-level peer review system.

Peer reviewers independently and thoroughly evaluate each assigned research proposal. These reviews are then assessed by the NAF's Scientific Review Panel, who also review the proposals independently and as a group. The final results and scores for each research application are presented to the NAF Board of Directors who make the final funding decision in December of each year.

It is never clearer as to the importance of research donations than during the Board meeting when the final funding decisions are made. Each research dollar is so very important as we look at studies worthy of our support. Too often, important studies go unfunded because of the lack of available funds.

Each of us has an opportunity to make a ►►



**Michael Parent**

difference by supporting crucial ataxia research. The NAF Annual Ataxia Research Drive begins on October 15. Please help us support the best science in the world by contributing through this crucial drive. Autumn is upon us, and as the Fall harvest begins so does the opportunity to reap

the rewards in funding promising ataxia research. Please encourage your friends, family, neighbors, co-workers, and employers to also support the NAF Annual Ataxia Research Drive. Each research donation will be matched dollar for dollar up to \$200,000. Thank you. ❖

## First Annual Disability Pride Parade and Festival

*By Kathleen Gingerelli*

On July 26, 1990, President George W. Bush signed the Americans with Disabilities Act (ADA) into law. This year is the 25th anniversary of the ADA and New York City was celebrating with events throughout the month, including the First Annual Disability Pride Parade and Festival.

The Tri-State Ataxia Support Group participated in the Disability Pride NYC Parade on July 12. The day started at 10 a.m. in Madison Square Park on the main stage watching/listening to the hip-hop duo 4 Wheel City while they warmed up the crowd. There were remarks from Mayor Bill DeBlasio and other public officials including former U.S. Senator Tom Harkin who helped author the ADA in 1990. They touched on subjects ranging from NYC's current goal of 50% accessible taxicabs by the year 2020 and focusing on finding good job opportunities for people with disabilities. It was stated that the unemployment rate for adults with disabilities who are willing and able to work is around 60% compared to the national unemployment rate of 5%. Harkin went on to praise several large employers for committing to hire more disabled people.

The parade continued down Broadway with many spectators on the sidelines cheering, waving and encouraging the disabled community who had come together to "walk, ride and roll" to Union Square Park where the parade ended and the celebration continued with live entertain-

ment, activities, information and fun giveaway.

The parade included people with disabilities, their advocates and spectators who all said the event was a public celebration for a community that often remains hidden and invisible. With more than 3,000 participants using wheelchairs, scooters, walkers, canes and guide dogs, the day was a success.



**(Left to right) Ed Brand, Judy & Kathleen Gingerelli, Nicco (dog) and Michael Acevedo**

The day was a celebration of people with disabilities and all they have accomplished both prior to the ADA 25 years ago and all the civil rights activity that led to it.

Overall, it was a great day for the Tri-State Ataxia Support Group to join with the disabled community, celebrate our diversity, feel empowered and show ourselves and others what WE CAN DO! ❖

# Being Your Own Advocate

By Jon Rodis

Wow! How many times have you or loved one or a friend been told something totally wrong about your condition from a doctor? Of course, I know the answer ... many, many, many times.

The worst imaginable place to hear it is from an emergency room doctor. (I have been there, seen it done.) Having been down that road so many times, I realized I had to fine tune my skills to advocate not only for myself but for future patients who have rare disorders and face the blank look and lack of knowledge or, worse yet, the attitude and ego issues that can prevent us from receiving the clinical care and information that we need.

Being your own advocate not only improves the quality of your care in the future, but also provides your local caregivers, physicians and hospital staff a better understanding of what your disorder or condition is and makes it a little easier for the next rare disorder patient coming through their door.

One of the first ways I began to advocate for myself was to pull together information on my condition(s) that were written by doctors and specialists who are caring for those who have these disorders and the researchers who are studying the diseases.

The next step was to compile a complete outline of my health issues and diagnosis in an outline form using my complete medical records. I strongly recommend having your medical records on a disc or flash drive. I basically took my medical records and made a trimmed-down chronological list: by year/type of test/tests results/emergency room (ER) visits/diagnosis/medications/therapies, etc. The outline format

is easy to read and doctors can get a very clear picture of your medical history and health status. Once completed, your outline can be put onto a flash drive or disc for you to give to future doctors or carry when you are traveling or, heaven forbid, you have to go to an ER.

Being an advocate for myself also required me to be firm during any medical dealings with health care providers but I always remained respectful and kept calm. It is indeed easier to get what you want with sugar than it is with vinegar.

Another big piece to being your own advocate is to seek out doctors who are willing to be supportive of your needs. It would be great to have a local doctor who was experienced in your condition however if they are not experienced but they are willing to learn and help you, it is an important step. These are the doctors who you want to provide with the research and information specific to how you are affected. Also, it is wise to have them utilize the national

experts in the specialty being reviewed.

In the ER, being your own advocate can be difficult since you may be in bad shape. This is where you need to be very specific as to what is going on with you and what key information they should know in an ER setting. Be respectful but firm in taking the right steps. It also helps to have someone who understands your condition advocate for you as well. They must know the short list of what to do and what not to do. This preparation is very important.

Being your own advocate in an educational setting is another important step in raising awareness and the quality of care of your ►►



**Jon Rodis**

condition within the medical community and the world around you.

Sometimes it can seem pretty daunting when you think of contacting the medical community, whether it be a hospital, a medical school, a local health fair, a private medical practice or your own healthcare provider's office. In the last 15 years of working on various forms of medical advocacy, I have found, through trial and error, some useful steps in obtaining the best results in each area of the medical community and all health related entities.

Many of the tools that I discussed on ways to advocate for yourself are also useful in advocating with the medical community. I am going to discuss each opportunity (mentioned above) and the process to help bring you the best results on raising awareness and providing key points on a particular condition and/or group of symptoms that the medical community should know.

When contacting a hospital, there are many factors to consider. First, what type of hospital are you contacting? Is it a stand-alone hospital or is it affiliated with several other hospitals as part of a health network? Is it a teaching hospital? If so this means it would be affiliated with a medical school. Whichever type you are contacting, it's important to speak with the person who handles medical education programs for the hospital.

There are several things you can suggest to the hospital's representative regarding medical advocacy and education:

- Having an awareness table at the hospital on your condition staffed by knowledgeable support staff and/or volunteers.
- Having an opportunity to tell your personal story and answering questions from individual departments/staffs at the hospital.
- Providing literature to the various depart-

ments on the condition that pertain to their particular specialty.

- Creating a new opportunity for the hospital to help better understand and serve the rare disorder community.

One way to improve your chances of gaining an opportunity for advocacy is to ask your doctors to help, especially if they are affiliated with a local medical school or have good contacts at the hospital and/or medical school where you would like to advocate. They may teach or present at affiliated hospitals and medical schools. They may know doctors or key administrative representatives who they could introduce you to who could help you with your advocacy work.

**“  
It also helps to  
have someone who  
understands your  
condition advocate  
for you as well.  
”**

The message is a powerful and important one when it comes from your own or a close loved ones experiences who have the condition for which you are advocating. Having the condition, knowing all the facets of its symptoms and the key factors that doctors and medical students may not know should be an

integral part of your message.

Along with hospitals and medical schools, there are other opportunities for advocacy, including local health fairs, medical conferences and other medical educational programs/initiatives. Having an awareness table is one of the main goals you should try to achieve. However, if you can't get a table, you can attend the event and go around and talk to the variety of attendees such as doctors, nurses and administrative staff who are attending, educating them on your disease, exchanging information and helping to further your advocacy to their respective institutions.

Sometimes when people advocate for their conditions they neglect to contact the private

*Being Your Own Advocate*  
Continued from page 31

medical practices in their area or the smaller medical clinics. These opportunities require a bit more personal attention and effort but can be well worth the outreach.

No matter what type of medical advocacy you want to start, the first task is to take time to consider what message best fits the individual or organization you are interested in contacting. It's always a good idea to step back and ask yourself, "What might they be interested in learning from me about my condition that they could utilize to help future patients they may see who have the same condition?"

Being your own advocate to the medical

community is a big step in raising awareness of your condition. Armed with factual information and the power of your own story is key to improving not only the awareness of your condition in the medical community but hopefully the quality of care for all those with your condition who walk through their doors in the future.

In closing, I would also recommend working with local support groups and local and national organizations that represent and support your condition. Working together can make anything possible so don't hesitate to reach out. In closing, I wish you the very best in your advocacy work.

If you are interested or have any questions and would like to contact Jon, please e-mail him at [wsalmgcdjm@comcast.net](mailto:wsalmgcdjm@comcast.net) and/or visit his website, [www.jrmarfan58.com](http://www.jrmarfan58.com). ❖



Participants in the Third Annual Walk for Dave held in Liverpool, NY.

## Third Annual Walk for Dave

*Submitted by Marc Alessi*

The Third Annual Walk for Dave took place at the Ononsaga Lake Park in Liverpool, NY on August 8. The walk, dedicated in memory of Dave Alessi, was organized by Marc Alessi, Dave's son. The event had a registration fee of \$10 with each participant receiving a t-shirt. The front had "JUST DAVE IT" and the back of the shirts had a sponsor listing. To represent the NAF at the walk was John Mauro, NAF Board Member. The event raised over \$5,000 and we could not have asked for a more beautiful day!

If you would like to see more information about the walk, please check out this video: <http://youtu.be/n4qwQ7q4OTs>. ❖

# Ataxia Researchers Honored with Prestigious Awards

The National Ataxia Foundation congratulates Huda Zoghbi, MD and Laura Ranum, PhD, who each received the prestigious Javits Neuroscience Investigator Award from the Neurological Disorders and Stroke (NINDS). The award was established by the U.S. Congress in honor of the late Senator Joseph Javits, who was a passionate advocate for support of research of disorders of the brain and nervous system.

This seven-year research grant is given to scientists for their superior competence and outstanding productivity. Its initial period is for four years with an additional project period added after administrative review. The Javits award recognizes a body of work from an investigator with a history of exceptional talent, imagination, and preeminent scientific achievement.

Dr. Huda Y. Zoghbi is professor of molecular and human genetics, neurology, neuroscience, and pediatrics at Baylor College of Medicine; director of the Jan and Dan Duncan Neurological Research Institute at Texas Children's Hospital; and a Howard Hughes Medical Institute investigator. Dr. Zoghbi serves on the NAF's Medical Research Advisory Board and has a long history with the NAF. In 1991, the National Ataxia Foundation awarded Dr. Huda Zoghbi a \$10,000 Research Grant for her project titled Molecular Studies of HLA-Linked Spinocerebellar Ataxia. The Javits Investigator grant will support research into spinocerebellar ataxia 1, the



**Dr. Huda Y. Zoghbi**

first gene she identified and a major focus of her laboratory for more than two decades.

"When I started my lab, packages for physician-scientists were not the norm so I had to get as many small grants as possible to complement the funds from my R01. The award from the NAF was one of those critical early awards that helped me get the work done. I am grateful to the NAF and to the ataxia families and friends for helping advance ataxia research." said Dr. Zoghbi.



**Dr. Laura P.W. Ranum**

a research project titled "Genome Screening of Autosomal Dominant Ataxia (non-SCA1) Kindsreds" from the National Ataxia Foundation.

Dr. Ranum received her PhD from the University of Minnesota in 1989 and did her postdoctoral work with Dr. Harry Orr on the identification and characterization of the SCA1 gene (1989-1994). Dr. Ranum is currently the Director of the Center for NeuroGenetics and a Professor of Molecular Genetics and Microbiology in the College of Medicine at the University of Florida. Dr. Ranum's group has focused on the identification and characterization of genes that cause ataxia and muscular dystrophy

*Continued on page 34*

*Ataxia Researches Honored...*  
*Continued from page 33*

and has mapped and identified the genes for SCA5, SCA8 and myotonic dystrophy type 2. Dr. Ranum's work on SCA8 has led to two surprising discoveries: 1) expansion mutations in which the letters of the genetic code (e.g. CAG CAG CAG CAG) are repeated too many times, are often expressed in two directions; and 2) a cellular traffic light that scientists thought provided a critical signal required for cells to make proteins does not apply to SCA8 and a number of other expansion mutations. In other words, these repeat expansions cause the protein-making machinery of the cell to run molecular "red lights," producing up to six unexpected proteins which accumulate in patient brains. The technical term for these proteins is repeat associated non-ATG (RAN) proteins. Current efforts are focused on understanding the impact of these proteins in SCA8 and other repeat diseases and to develop therapeutic strategies to reverse disease.

Dr. Ranum is a member of NAF's Board of Directors and Medical Research Advisory Board and serves as a reviewer for numerous scientific journals and funding agencies including the National Institutes of Health.

"Funding from the NAF has been critical and I am grateful for the support. Early in my career

seed grants from the NAF allowed me to generate preliminary data and to obtain larger grants from the NIH to study both SCA5 and SCA8. Recently, a larger Pioneer Grant from the NAF has allowed us to ramp up our efforts and use our SCA8 mice to develop therapeutic strategies to reverse disease. I am grateful to the many SCA families I have met through the NAF and worked with over the years. I have also been fortunate to work with great students and postdocs. It takes a large effort and many people to battle these diseases and I am so pleased that our SCA8 work will be supported by a seven-year Javits award from the NIH." said Dr. Ranum.

"The National Ataxia Foundation congratulates Huda Zoghbi, MD and Laura Ranum, PhD in receiving the distinguished Javits Neuroscience Investigator Award in recognition of their extensive body of work in ataxia research. Their crucial research efforts truly offer tangible hope for a much brighter future. We are also very thankful to our donors who enabled NAF to support their early and crucial research efforts." said Michael Parent, NAF Executive Director.

#### **Additional Information**

<https://www.bcm.edu/news/awards-honors-faculty-staff/zoghbi-javits-award-ataxia-research>

<http://news.ufl.edu/archive/2015/08/prominent-award-goes-to-uf-researcher-laura-pw-ranum-.html> ❖

## **Have You Remembered the NAF in Your Estate Planning?**

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

The use of the following language ensures that your gift is directed appropriately:

"I bequeath \_\_\_% of my estate (or fund) to the National Ataxia Foundation, a 501(c)(3) non-

profit organization located at 2600 Fernbrook Lane, Suite 119, Minneapolis, MN 55447-4752. Federal Tax ID# 41-0832903."

For further information about naming the National Ataxia Foundation as a beneficiary, please contact Mike Parent at [mike@ataxia.org](mailto:mike@ataxia.org) or (763) 553-0020.

Thank you for your support of the important work of the Foundation.

# Writing ‘Necklace of Stones’

By Alice Lee

It was a healing experience writing the book *Necklace of Stones*. I’m very glad I wrote it. At age 63, I proved to myself that I am able to finish a project.

When you have a chronic, progressive illness such as ataxia, it is often hard to feel good about yourself. Completing this book helped me and gave me the chance, through my readings, to reach out and make a difference again in other people’s lives. When I was working as a teacher, I felt I had a purpose. After I medically retired at age 55, I volunteered in the schools until I could no longer do this due to fatigue and the progression of my disease.

As I wrote *Necklace of Stone*, I enjoyed the revising process, trying to improve the text, sentence by sentence, phrase by phrase, word by word. The first part was already written, and then it took about two years to complete the rest of the book. My editor, Lisa, told me to make snapshots; what she was telling me is a basic rule, “Show, don’t tell.”

I am a poet. I studied poetry and poets by

myself from the mid-1970s for about 35 years, so prose was a new thing for me, filling in the details. I enjoy reading historical fiction, memoirs, and mysteries and some of my favorite writers use prose like poetry; each word matters. They grew up not using English as their first language, so their works became very good writing.

My editor and audiences have asked such questions as: What are some of the challenges that you have had to deal with because of ataxia? Is it long distances, wheelchair access, steps, fatigue? The main thing I’ve had to deal with is lack of energy and fatigue; I tend to go and go and go and then collapse in a heap with no energy left. I also have chronic insomnia. That doesn’t help at all.

The best thing about the book tours is seeing dear friends and family, and even a former

teacher. To be effective, I have to be part entertainer as well as imparting knowledge. I’m a ham; I love to perform. My voice is not as strong as it used to be, but I have my husband in the wings to take over if I’m especially sick or tired. I also have more trouble using my keyboard now than last year. Organization is a skill that teachers and writers need; however with age and this disease, I am losing that. It is much harder to write a long piece.

A friend I made at the last National Ataxia Foundation convention in Denver in March 2015 gave me a piece of advice I use: “Try to do as much for yourself for as long as you can.” I am



Alice Lee reading from “Necklace of Stones” at Village Books in Bellingham, WA

## Friedreich Ataxia Tissue Donation

If you have Friedreich Ataxia and you are interested in the Tissue Donation Program, please contact Dr. Arnulf Koeppen at (518) 626-6377 or [arnulf.koeppen@va.gov](mailto:arnulf.koeppen@va.gov).

Continued on page 36

Writing 'Necklace of Stone'...  
Continued from page 35

very independent. Not being able to drive has been a big blow. Yes, there are losses, grief, and sadness, but I don't dwell on the losses. It is what it is, and everyone has something to deal with.

If you too are dealing with something, don't give in to self-pity. It doesn't help. Write your story down. Use a tape recorder if you can no longer use a keyboard, and have a friend or relative transcribe it, but get it down. Read, read, read others' memoirs for how they do it. Read books written about how to write memoirs. Take a class. If you can no longer read, books on tape are available. I really encourage you to "Just do it!"

*Necklace of Stones: a memoir of poetry and place* by Alice Lee (Barranca Press 2015) is available through your local bookstore and online venues.

Missed your chance to hear Alice read? Visit <https://youtu.be/wV4vetptVSw> for a snippet of her reading at Bookworks in Albuquerque, NM.

### 2015 Book Tour Events to Date

- February 12, Milwaukie Ledding Library, OR
- March 7, Healing through Writing at the National Ataxia Foundation's 58th AMM, Denver, CO
- May 3, NM Launch at Teatro Paraguas, Santa Fe, NM
- May 7, Reading at Bookworks, Albuquerque, NM
- May 9, Reading at Moby Dickens, Taos, NM
- June 16, Reading at Third Place Books, Lake Forest Park, WA
- June 17, Reading at Village Books, Bellingham, WA
- August 4, Reading at Jacobsen's Bookstore, Hillsboro, OR
- October 6, at the Public Library, Anacortes, OR



## More Pearls of Wisdom

Submitted by Peter Meyerhoff

I fell out of my wheelchair while seated. I didn't think this was possible. Pitched forward and fell on my head. Fortunately, the thick carpet kept injuries to a minimum.

First order of business: stay on the floor and get the heart rate down. Allow about five minutes. Next, figure out how you are going to get back in the wheelchair. My wife helped there. She put a waist belt on me while I was still on the floor and rolled me sideways onto my knees. Now my butt was a lot closer to the seat level of the chair. Next she maneuvered the wheelchair and locked it to make the final transfer as easy as possible. Final transfer was with help of my arms pushing up on nearby furniture.

How did it happen in the first place? I was reaching forward to get something. Don't reach forward; sidle up next to the thing you want to get, then reach sideways to get what you want. The sides of the wheelchair will keep you safe.

If you would like to contact Peter, please e-mail him at [hpmeyerhoff@gmail.com](mailto:hpmeyerhoff@gmail.com).

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Share your *Pearls of Wisdom* in a future issue of *Generations*. Please e-mail yours to Joan at [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.

# Ataxia and Distance Couldn't Stop Our Love

By Katherine Dzieszkowski

I am writing as a thank you for all the HOPE that your Foundation provides and to share a love story that was started due to your support groups.

In August of 2013 I was diagnosed with an unknown form of spinocerebellar ataxia. I see a wonderful neurologist who not only treats my illness but encourages me to live life to the fullest.

In 2014 I traveled to Chicago for a second opinion with a neurologist who agreed with my treatment plan.

I joined five ataxia support groups and started to chat with many who were young and affected with all different types ataxia. I created a "bucket list" for myself as the prognosis for ataxia seemed grim. I had been through many changes, not only physical but emotional. I lost my year-long relationship; I had to move closer to my family for safety reasons and my depression hit a high as I had to quit working and apply for disability.

I started to become more involved in the support group as I found myself relating to others in so many ways. I was changing, there was no denying that. My speech was slurred and garbled, my walking was starting to be compromised, and several people actually referred to me as drunk. I shared these experiences with my new found friends and started to feel much better emotionally.

This is where my love story begins. I have never been the kind of girl who wanted to get

married or have children. In my eyes, at 35 years old, that time had passed me by. And after a break-up, due to my diagnosis, I was anti-love. I saw no need to get my heart broken on top of my ataxia diagnosis.

One day, as I was scrolling the posts on the National Ataxia Foundation support group and feeling quite lonely, I actually posted about an ataxia dating site. To my knowledge there wasn't one. I received a message though, that was pretty forward, and asked me if I wanted to date. Being apprehensive I said, "I don't know. I was just curious if others gave up on love as I had." Little did I know that message would lead to an intense relationship and a proposal almost a year later.

Now, I'm not opposed to online dating, but international online dating was something I wasn't too fond of. I heard the stories of green

cards, but I also believe that God places people in your life for a reason, and who am I to question that. Yuba was that person and I decided I wasn't going to stand in my own way of happiness.

We started talking pretty much all day long from the beginning. First we talked about our journeys with ataxia, but soon we started to get more personal in our conversations. Before long we knew each other's family lives and each



**Katherine and Yuba on the beach  
in Agadir, Morocco**

*Continued on page 38*

*Ataxia and Distance Couldn't Stop Our Love*  
Continued from page 37

other's fears and dreams. We became each other's best friend, separated by an ocean. A day after my birthday on October 20, 2014, we started our relationship which became Facebook official.

Our relationship grew and after a while, we started talking about me traveling there and even marriage. As I stated before I wasn't engulfed with the idea of marriage, but I found myself wanting to marry him. This was both exciting and weird to me. I was in the deepest, most intense love I have ever been in, and I welcomed it!

In January 2015, I began planning my trip to visit him. Part of my bucket list included international travel, so my trip would be fulfilling two of my wishes.

My first time flying with ataxia, my first time flying internationally and I was doing it alone! I arrived in Agadir, Morocco after three flights, long layovers and a time change that was unbearable. Due to the country's laws, Yuba and I were not allowed to kiss or hug at the airport, but this American broke the law and hugged her sweetheart upon meeting. Besides Yuba, his mother and aunt met me at the airport.

Yuba has Friedreich ataxia (FRDA). As others with FRDA, he began noticing symptoms at a

young age and was officially diagnosed in 2011 at 25 years old.

After spending almost two weeks in Morocco, I knew he was perfect. Yuba proposed to me on the beach on June 3. It was magical. Because I never pictured this moment in my head there were no expectations. I was engulfed in the moment and it was perfect.

I returned home June 7. I told my mother, my siblings and my father of my engagement. We posted our engagement on Facebook and the good news was well received by our friends and extended family.

We are planning our wedding for September 25, 2016. We chose that day to honor ataxia since it is International Ataxia Awareness Day, and without the support group sponsored by your Foundation we never would have met. We will have a special table dedicated to the National Ataxia Foundation at our wedding.

There are several things that having ataxia has taught me: the greatest of those being NOT to GIVE UP! The future may not be what we expect but that doesn't mean it's not going to be worth it.

Thank you to the National Ataxia Foundation for all the hope and research you are providing.

If you are interested in contacting Katherine please e-mail her at [rine19@hotmail.com](mailto:rine19@hotmail.com). ❖

## Share Your Story

*Generations* is published quarterly by the National Ataxia Foundation and reports on research, chapters and support group activities, events and other topics related to ataxia. Personal stories from those affected by ataxia are an important part of the publication. Stories submitted should be no longer than 1,200 words. If possible, tell how NAF has made an impact in your life or situation. Submit stories to [joan@ataxia.org](mailto:joan@ataxia.org) to be considered for publication.

## \$200,000 Research Match Challenge

Your donation to the 2015 NAF Annual Ataxia Research Drive will be matched dollar for dollar up to \$200,000 by an anonymous donor. Please help us reach this match by giving to the NAF Annual Ataxia Research Drive beginning October 15 through December 15. Thank you.

# My Mantra: 'Use It or Lose It'

By Joanne Loveland

I have been dealing with noticeable symptoms of Spinocerebellar Ataxia (SCA6) since I was 55 years old. For most of my life, I have enjoyed outdoor activities. Although never a super athlete, I love swimming, hiking, camping, boating, tennis, and ballroom dancing. I did play competitive and social tennis.

It was on the tennis court that I noticed my first symptoms. First my "hand-eye coordination" began to be affected. I couldn't hit the "sweet spot" on my racquet strings. I also began to "see double" sometimes. It was very disconcerting to see two tennis balls coming my way. I was sure this was all related to the Lasik surgery I had in 2000 to improve my distance vision. However, I could also tell my speed on the tennis court was declining.

My next noticeable challenge was stairs. I no longer felt secure descending down a flight of stairs without holding on to the railing. Stepping off curbs made me feel uneasy.

I began to look seriously at our family history. My Grandmother (my Dad's Mom) began to have balance problems in her early 60's. She was told she had late onset MS. My Dad also began to notice coordination issues in his early 60's. The progression of motor loss is slow and gradual. In his late 60's he went to see a neurologist. He was eventually diagnosed with Spinocerebellar Ataxia – not MS. It was revealed that he had inherited his condition from his mother. About the same time, his sister was also diagnosed with

SCA6. The family history was taking shape.

This form of ataxia is dominant. Every sibling has a 50:50 chance to inherit the mutant gene. My brother and I both have the condition. We experienced symptoms earlier than both Grandmother and Dad.

We all are hearing from physicians and neurologists that exercise is a good way to slow down the progression of any neuro-degenerative condition, whether it is MS, Parkinson's or ataxia.

Exercise is so individual. Some like to take a class, some go to a gym and work out on machines, while others prefer a video at home. Whether it is individually or with others, do something everyday. Often it is more motivating to do different types of exercise. Try something new. Stimulate your brain cells and fire up your neurons. It is important not to overdo when you are dealing with a neurological condition. Yoga and chair yoga

are great for stretching. A strength and toning class at a senior center can be a great class to try.

I am easily bored by doing the same things everyday, so I mix it up. I have tried many things. I stick with activities I feel are pushing my comfort zone. Do exercises to improve your balance, use your less dominant side, do motor sequencing, cross the mid-line, stretch and work on flexibility.

Over the last 11 years, I have tried many ways



Joanne Loveland

*My Mantra: 'Use It or Lose It'*  
Continued from page 39

to stimulate my central nervous system and my motor/musculature system. I, by no means, have done it all, but here are things I have tried in my journey to stay emotionally and physically fit:

- Massage
- Acupuncture
- Aero-pilates machine
- Treadmill
- Yoga
- Swimming
- Laser Light Stimulation
- Quantum Neurology
- Strength class with weights, bands, and balls
- Dashaway Walker – use for long-distance walking exercise

Another symptom I deal with regularly is double vision. It isn't all the time, but I wear prism glasses when driving or when I am in a room with a lot of movement or activity like a

movie or a museum. The glasses make everything clear and remove the double vision. For that, I am very grateful. I recommend seeing (pardon the pun) an ophthalmologist who sees patients with brain disorders. Prism glasses look no different than regular glasses.

I am an adventurous person, and stay active and enjoy life. Family and friends give me incredible support. My faith gives me courage and strength. One of my greatest joys is to encourage and share my journey with others so we all can enjoy a good quality of life. Focus every day on what you can do.

Having ataxia has taught me many things: patience, compassion, gratitude, and love of myself first and then others.

Please don't hesitate to contact me if you have any questions.

Joanne B. Loveland  
Northern California Support Group Leader  
[joaneloveland@gmail.com](mailto:joaneloveland@gmail.com)



## Weill Cornell Medical College FRDA Study

A new Institutional Review Board (IRB)-approved study at Weill Cornell Medical College on Friedreich Ataxia (FRDA) is recruiting patients between 18 and 30 years old.

The purpose of the study is to compare different tests and procedures and to evaluate their usefulness in assessing the cardiac manifestations of FRDA. The study requires a two-day, overnight stay in New York City.

For more information, please contact Gerardine Rodriguez by phone at (646) 962-4537 or by e-mail at [ger3001@med.cornell.edu](mailto:ger3001@med.cornell.edu).

## Donate a Vehicle to Benefit NAF

Do you have a spare car, truck, or motor home sitting around unused, or know someone who does?

Donating a vehicle to the National Ataxia Foundation helps support the important work that is being done on behalf of all who are affected by ataxia and their families.

In addition to helping others, you can also help yourself by donating a vehicle, as you may qualify for a tax deduction. Please consult your tax advisor for more information about this benefit.

To donate your car, truck or motor home, call 1-800-240-0160 or visit [www.donateacar.com](http://www.donateacar.com). Your vehicle will be picked up at the location you designate. Please have the certificate of title with the vehicle.

THE NAF BOARD OF DIRECTORS ALONG WITH THE NAF  
SOUTHEAST REGION WOULD LIKE TO INVITE YOU TO ATTEND

# THE MAGIC OF A CURE

DREAM IT.  
HOPE IT.

**National Ataxia Foundation**  
Annual Ataxia Conference  
April 1-3, 2016 ★ Orlando, Florida  
Hosted by the Southeast Region



*The Caribe Royale Orlando is pleased to provide the facilities for the 2016 Annual Ataxia Conference (AAC)*

Note: Name change from Annual Membership Meeting (AMM) to Annual Ataxia Conference (AAC)

## Room Reservations – Begins November 4

**Standard room reservations** at the Caribe Royale can be made starting November 4 at <https://bookings.ihotelier.com/bookings.jsp?groupID=1477001&hotelID=5636>. For guests who prefer to phone in their reservation, call Hotel Reservations at 800-537-7737 and ask for the National Ataxia Foundation's group rate which is under the group name, "National Ataxia Foundation."

**ADA room reservations** must be reserved through the NAF office starting on **November 4 at noon CST** by contacting (763) 553-0020 or [lori@ataxia.org](mailto:lori@ataxia.org). Calls or e-mails prior to noon CST on November 4 to reserve an ADA room cannot be honored.

*Reservations at group rate will be available until February 27, 2016.*

*The NAF group rate starts at only \$149 +tax for Standard Rooms.*

*See Room Type Guide on pages 48-50 for additional details.*

## Meeting Registration – Begins November 4

Registration for the 2016 NAF AAC will open on November 4. You are encouraged to register before February 12, 2016 to receive the early registration discount rate. In addition, members of the NAF pay a lower registration fee to attend the Annual Ataxia Conference. 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. For the latest information on conference registration, program schedule, and area information keep checking the NAF's website [www.ataxia.org](http://www.ataxia.org).

## 2016 NAF Annual Ataxia Conference "Support Our Conference" Campaign

Help support the 2016 AAC by donating online. <https://naf.myetap.org/fundraiser/16AMM/>

For more information on Orlando visit <http://www.visitorlando.com/>

VisitOrlando.



THE MAGIC OF A CURE

DREAM IT.  
HOPE IT.

**National Ataxia Foundation**  
Annual Ataxia Conference  
April 1-3, 2016 ★ Orlando, Florida  
Hosted by the Southeast Region

The National Ataxia Foundation (NAF) Board of Directors and the National Ataxia Foundation Southeast Region invite you to attend the **59th Annual Ataxia Conference (AAC)**. Please join us at the Caribe Royale in Orlando, FL to learn, share, network, have fun, and enjoy the sites.

The 2016 AAC will bring together the ataxia community to not only meet and learn from world-leading ataxia researchers and clinicians, but also to build new friendships and reunite with old friends. Come and be part of the largest ataxia gathering in the world!

When registration opens on November 4, you are encouraged to take advantage of the early registration discount rate. In addition, members of the National Ataxia Foundation pay a lower registration fee to attend the Annual Ataxia Conference.

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 to call or e-mail Joan Jensen at [joan@ataxia.org](mailto:joan@ataxia.org) or (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 2016 Annual Ataxia Conference. The meeting registration fee includes attendance at all the sessions, light appetizers at the Welcome Reception and a delicious plated meal at the Banquet.

The National Ataxia Foundation is offering a limited number of 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 [lori@ataxia.org](mailto:lori@ataxia.org) or (763) 553-0020 to request an application by mail.

The complete meeting schedule, events and registration forms will be listed in the winter 2015-16 issue of *Generations* and on the NAF's website when available. The following is a brief program overview. Additional information can be found on the NAF website, [www.ataxia.org](http://www.ataxia.org).

### Pre-Meeting Activities

#### Thursday, March 31

- Registration Opens: 9 a.m. – 5 p.m.
- Silent Auction Item Drop-off: 9 a.m. – 5 p.m.
- Exhibitors: Noon – 5 p.m.
- Set-up available: 10 a.m. Exhibitors will be present from Thursday afternoon through Sunday morning as their schedules permit.
- Leadership Meeting: 1 – 3 p.m. ▶▶

- Fundraising Meeting: 4 – 5 p.m.
- AIM Posters: 5:15 – 6:15 p.m.

## Tentative Program Overview

### Friday, April 1

- Registration: 8 a.m. – 5 p.m.
- General Sessions: 9 a.m. – 12:30 p.m.
- Exhibitors: 8 a.m. – 5 p.m.
- Silent Auction Bidding: 8:30 a.m.–5 p.m. All items being donated for the Silent Auction are due in the Silent Auction room by Friday, April 1 at 4 p.m.
  - Activity Room: 10 a.m. – 5 p.m. The activity room is open to all ages. Persons under the age of 12 must be accompanied by a parent or guardian who is age 18 or older.
  - Birds of a Feather (Group A): 2 – 5 p.m. This year the Birds of a Feather will be offered again on Friday and Saturday afternoon. The schedule will be available in the winter issue of *Generations*. Please review the schedule for your specific session.
  - Meet & Greet Reception: 5 p.m. (new time) featuring light appetizers.

### Saturday, April 2

- Registration: 8 a.m. – 5 p.m.
- Exhibitors: 8 a.m. – 5 p.m.
- General Sessions: 9 a.m. – noon
- Silent Auction Bidding: 8:30 a.m. – 12:30 p.m. Winners must pick-up and pay for their

items from 4 – 7 p.m. on Saturday.

- Activity Room: 10 a.m. – 5 p.m. The activity room is open to all ages. Persons under the age of 12 must be accompanied by a parent or guardian who is age 18 or older.
- Birds of a Feather (Group B): 2 – 5 p.m. This year the Birds of a Feather will be offered again on Friday and Saturday afternoon. The schedule will be available in the winter issue of *Generations*. Please review the schedule for your specific session.
- Saturday Evening Banquet: 7 p.m. featuring a delicious plated meal and entertainment.

### Sunday, April 3

- Registration: 9 – 11 a.m.
- Exhibitors: 9 – 11 a.m.
- General Sessions: 9 a.m. – 12:30 p.m.

## About Orlando

A world-renowned destination, Orlando is the place to make all of your vacation dreams come true. Of course, it is beloved for its theme parks: Walt Disney World, Universal Orlando® Resort, SeaWorld Orlando and many others. With seven of the world's top 20 theme parks in one destination, not to mention nearly 100 other attractions, Orlando certainly knows how to entertain. Discounted Disney theme park tickets can be found at [www.mydisneymeetings.com/59aac/](http://www.mydisneymeetings.com/59aac/). Orlando also beckons with world-class resorts, shopping opportunities for every budget, all-season golf courses, and some of the most enticing dining opportunities on the planet. Less known but equally inviting are the downtown sections of Orlando itself and many nearby towns in Central Florida – places that celebrate public art and take pride in offering a myriad of cultural opportunities.

**Transportation** – Mears Transportation Group ([www.mearstransportation.com/global/orlando](http://www.mearstransportation.com/global/orlando)) runs lift-equipped shuttle service between hotels, attractions and Orlando International Airport, but 24-hour advance reservations

## Trip Planning Kit

Request a free Orlando Vacation Planning Kit today at [www.visitorlando.com/vacation-planning-kit](http://www.visitorlando.com/vacation-planning-kit). Your free kit is provided by Visit Orlando, the official source for Orlando travel planning, and will include the *Official Visitor Guide* which includes information on hotels, attractions, events and Orlando maps.

To find out more about the NAF Annual Ataxia Conference (AAC), visit the NAF's website, [www.ataxia.org](http://www.ataxia.org).

### Annual Ataxia Conference Overview Continued from page 43

are required. The I-Ride Trolley is the best way to see International Drive. The trolleys, featuring lifts and lock-downs, operate daily from 8 a.m. to 10:30 p.m. with service every 20 minutes.

Please visit [www.visitorlando.com](http://www.visitorlando.com), for a complete list of attractions, planning, and transportation information.



**The Caribe Royale is the office hotel of the 2015 NAF Annual Ataxia Conference**

### Caribe Royale

The Caribe Royale is the official conference hotel of the 2016 NAF Annual Ataxia Conference. The Caribe Royale is located on World Center Drive and is 15.5 miles from the Orlando International Airport at 8101 World Center Drive, Orlando, FL 32821.

For your stay and planning purposes at the Caribe, the following information is provided. Additional details will be listed in the winter issue of *Generations* and on the NAF website.

- The meeting space being held for the NAF is in the Grand Sierra Ballroom area of the Grand Caribe Convention Center.

- Room reservations open on November 4. The \$19.95 per night resort fee is waived for attendees booked inside the NAF room block. For more room reservation information please refer to the AAC announcement on page 41.

All ADA rooms must be reserved through the NAF office starting on November 4 at noon CST. Availability of ADA room types are limited. Please have alternative room types in mind when requesting a reservation for an ADA room. For more detailed information about the room types available refer to the Room Type Guide found on pages 48-50.

- If you need ADA equipment you are encouraged to bring those items with you or make arrangements to rent equipment locally. The NAF is unable to provide ADA equipment however the Caribe Royale may have a limited number of shower chairs, grab bars, or detachable shower heads available. Be sure and request these items when making your reservation if needed. ▶▶

## Silent Auction

The Silent Auction held during the National Ataxia Foundation Annual Ataxia Conference (AAC) is a fun way to support the NAF and for you to bid on quality items from various states and countries. This long-standing NAF tradition begins Friday April 1 at 8:30 a.m., with final bidding ending on Saturday at 12:30 p.m. Winners must pick up and pay for their items from 4-7 p.m. on Saturday.

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

crafted items, hotel stays and weekend get-aways. Items being donated should be dropped off at the registration area on Friday, April 1 at 4 p.m. Please complete and include the form at left with your items.

If you are not able to attend the conference, but have a quality item that you would like to donate, please call (763) 553-0020 or e-mail Joan at [joan@ataxia.org](mailto:joan@ataxia.org) for details on where to ship your item. Donate an item and then have fun bidding on the items of your choice!

Thank you for supporting this event.

- Parking at the Caribe Royale – Self-parking is complimentary. Valet parking is available at Caribe Royale. The costs are as follows: \$9 plus tax Day Guest Valet (per day) and \$12 plus tax Overnight Valet (per night). Visit their restaurant/bar and get your ticket validated (three-hour max). There is ample parking available in the open lot surrounding the resort and convention center. If you are planning on using a handicap parking space bring your out-of-state or international disabled parking permit with you. It should be prominently displayed in the windshield of the car when you are parked in designated public handicapped parking spots. Temporary permits are not available.

- Service Dog Information – The service dog relief area at the Caribe Royale will be designated near the Convention Center and Tower II.

Transportation Options – Guests staying at Caribe Royale and Buena Vista Suites can easily enjoy much that Orlando has to offer with a variety of discounted and complimentary transportation options. Complimentary schedule shuttle transportation to all four Walt Disney Parks as well as Disney Springs (formally known as Downtown Disney) in the evening for dining

and entertainment options is available. Shuttle reservations can be made up to 30 days in advance. **Lift-equipped shuttle service reservations are required at least 24-hours in advance.** All other reservations must be made at least one hour prior to departure, first come, first served. It is requested that attendees be at the bus stop 10 minutes early. Shuttle reservations can be made by contacting at Guest Services at (407) 238-8010 prior to arrival or in the main lobby seven days a week 7 a.m. to 10 p.m. or at Ext. 8010 when you are on-site. Please note there are some shuttle service changes. See the Caribe Royale website, [www.thecaribehotelsorlando.com/transportation](http://www.thecaribehotelsorlando.com/transportation), for more information.

- A standard Wi-Fi package (Basic Plan) for up to two devices is complimentary in guest rooms for AAC attendees. The price is currently \$4.99 per day to upgrade your plan to four devices per suite. Upon check in you can access the internet by entering the suite number and last name of the individual listed on the room reservation.

- Please visit the Caribe Royale website, [www.cariberoyale.com](http://www.cariberoyale.com), for more information.

Continued on page 46

**Don't forget about your SILENT AUCTION item Donation!!**

Please have card filled out and attached to your item prior to bringing it into the registration room. Thank you!

*Item Description* \_\_\_\_\_

*Minimum bid (if Any) \$* \_\_\_\_\_

*Name* \_\_\_\_\_

*Name of Group* \_\_\_\_\_

*Address* \_\_\_\_\_

*City* \_\_\_\_\_ *State* \_\_\_\_\_ *Zip* \_\_\_\_\_

*Phone Number* \_\_\_\_\_ 2016

*Email Address* \_\_\_\_\_

*Item Number* \_\_\_\_\_  
Office Use only

*Annual Ataxia Conference Overview*  
Continued from page 45

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

### Transportation and Getting There

Orlando International Airport Ground Transportation – Information Booths are located on Level 3 (Departures) of Terminal A at the West end (gates 1-59) near Sea World and at the East end (gates 70-129) near Sea World. Note: Information Booths are open from 6 a.m. to 8 p.m. Visit [www.orlandoairports.net/transport/local\\_transport.htm](http://www.orlandoairports.net/transport/local_transport.htm) or [www.orlandoairports.net/ops/disabled.htm](http://www.orlandoairports.net/ops/disabled.htm) or call (407) 825-8463 for a complete listing of accessible services and ground transportation options to and from the Orlando International Airport.

#### Shuttle Vans

- Located in Terminal A on the Ground Transportation Level (Level 1) at the Commercial Lane parking spaces: A9-A10 and A36-A37.
- Located in Terminal B, on the Ground Transportation Level (Level 1), at the Commercial Lane parking spaces: B9-B10 and B40-B41.
- Mears Transportation Group – (407) 423-5566 or [www.mearstransportation.com](http://www.mearstransportation.com). Mears Transportation Group runs lift-equipped shuttle service between hotels, attractions and Orlando International Airport, but **24-hour advance reservations are required.**

#### Taxi Cabs

- Located in Terminal A, on the Ground Transportation Level (Level 1), at Commercial Lane parking spaces: A5-A8 and A22-A25.
- Located in Terminal B, on the Ground Transportation Level (Level 1), at Commercial

Lane parking spaces: B5-B8 and B30-B34.

- Ace Metro/Luxury Cab – (407) 855-1111
- Diamond Cab Company – (407) 523-3333
- Quick Cab – (407) 447-1444
- Star Taxi – (407) 857-9999
- Town & Country Transport – (407) 828-3035
- Yellow/City Cab – (407) 422-2222

#### Rental Cars

If you are planning to rent a car in Orlando, be sure to call ahead to reserve vehicles with hand controls. Several rental companies—including Alamo, Avis, Dollar, Hertz and Enterprise—have these models available for rent.

### Orlando Area Services and Resources

#### Personal Care Attendants (PCA)

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 Orlando. 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.

- Firstlight Home Care – (407) 434-0675 or [www.firstlighthomecare.com/home-healthcare-winter-park-orlando](http://www.firstlighthomecare.com/home-healthcare-winter-park-orlando)
- Sunshine In Home Care, LLC – (407) 992-6670 or [www.sunshineinhomecare.com](http://www.sunshineinhomecare.com)

#### Childcare

If you need childcare, please make arrangements prior to attending the meeting. Please note that the NAF is unable to provide childcare services. Due to liabilities and health concerns, NAF staff or volunteers and hotel employees are not able to provide childcare services.

- Super Sitters, Inc. – (407) 382-2558 or <http://super-sitters.com/>

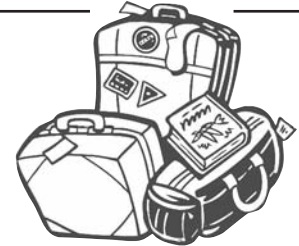
#### Accessible Equipment, Wheelchair, and Scooter Rentals

- K&M Rentals – (407) 363-7388 or [www.km-rentals.com](http://www.km-rentals.com)

• ScootaRama – (407) 897-6839 or [www.scootarama.com](http://www.scootarama.com)  
 • Scootaround Inc. – 1-888-441-7575  
<http://scootaround.com>

• ScooterBug – 800-726-8284 or [www.scooterbug.com](http://www.scooterbug.com)  
 • Walker Mobility – (407) 518-6000, 1-888-SCOOTER or [www.walkermobility.com](http://www.walkermobility.com) ❖

## NAF Travel Grant Program Needs Your Support



*“Being around other people with ataxia at the meeting helps me feel less alone.”*

The National Ataxia Foundation’s Annual Ataxia Conference (AAC) connects the ataxia community. The meeting program is designed to foster learning and understanding by providing informative presentations about ataxia research and on living with ataxia. Connecting with those who understand and face the same challenges is also an important component in which individuals with ataxia, their family members, and caregivers have the opportunity to share and network.

Traveling to an Annual Ataxia Conference can be financially difficult. To help those with ataxia who are unable to financially attend the AAC, the NAF established an AAC Travel Grant Program to help with some of the costs associated with attending the AAC.

You can help someone with ataxia attend the

AAC by making a donation to the NAF AAC Travel Grant Program. Your gift will make an immense difference in someone’s life. Thank you for your support and for making the AAC experience possible for an individual affected by ataxia who would not have been able to attend without your help.

### Applying for a Travel Grant

Visit the NAF website, [www.ataxia.org](http://www.ataxia.org), to download the application. If you would like an application sent to you in the mail, contact Lori Shogren at (763) 553-0020 or by e-mail at [lori@ataxia.org](mailto:lori@ataxia.org) to request one. Applications will be accepted until January 15, 2016. Travel Grant applicants will be notified of the status of their application after the application deadline and after all applications have been reviewed. ❖

## AAC Exhibitors and Sponsors Wanted

The National Ataxia Foundation invites companies or individuals who have products or services that would be helpful for those with ataxia to submit an exhibitor application to exhibit at the National Ataxia Foundation’s 59th Annual Ataxia Conference (AAC), “The Magic of a Cure. Dream it. Hope it.”

The 2016 AAC will be held in Orlando, FL on April 1-3, 2016. Please contact Joan at [joan@ataxia.org](mailto:joan@ataxia.org) for an exhibitor application.

The NAF is grateful to those organizations that

have provided generous support of the Annual Ataxia Conference.

Please consider being a sponsor of the 2016 Annual Ataxia Conference. For more information on becoming a sponsor please contact Mike Parent at [mike@ataxia.org](mailto:mike@ataxia.org).

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

# 2016 Annual Ataxia Conference Room Type Guide

## Caribe Royale Orlando

The Caribe Royale is a resort property on 53 acres just minutes from Orlando's world famous theme parks and attractions at 1818 World Center Dr, Orlando, FL 32821. The Caribe Royale has 1,218



spacious, well-appointed one-bedroom suites, 120 luxurious two-bedroom lakeside villas, and expansive state-of-the-art meeting and event facilities, along with a variety of dining options. All rooms come with a pull-out sofa bed. The bed height in all rooms is 27". Self-parking and in-room Internet are both complimentary for NAF attendees at the Caribe Royale.

## Buena Vista Suites Orlando

On the Caribe Royale property is their sister property the Buena Vista Suites. Both properties will provide attendees easy access to the Caribe Convention Center also located on the property. Parking

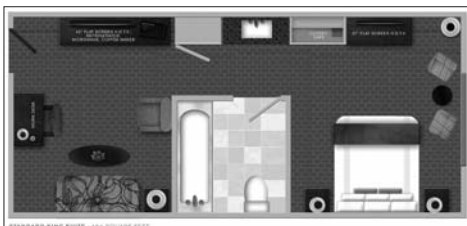


and in-room Internet are both complimentary for NAF attendees at the Buena Vista Suites. The Buena Vista Suites has 279 one-bedroom suites. All rooms come with a pull-out sofa bed. The bed height in all rooms is 27". Standard Suite layouts at the Buena Vista Suites is the same as the Standard Suite layout at the Caribe Royale.

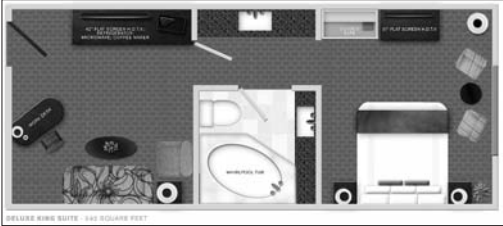
## Room Type Chart

Visit the Caribe Royale website for additional details: [www.cariberoyale.com](http://www.cariberoyale.com).

| Room Type  | Rate        | Description  |
|--|-------------|--|
| Caribe Standard Suites<br>King/Double Queen – 494 sq. ft.<br>Smoking/Non-Smoking | \$149 + tax | A limited number of ADA rooms with Roll-in Showers or Step-in Tubs are available in the Standard King One-Bedroom Suites (smoking and non-smoking). These room types are located within the three towers on the resort property. The bathroom door width in ADA Suites is 33 7/8". The step-in tub height is 13.5". The bathroom door width in non-accessible Suites is 29 7/8". |

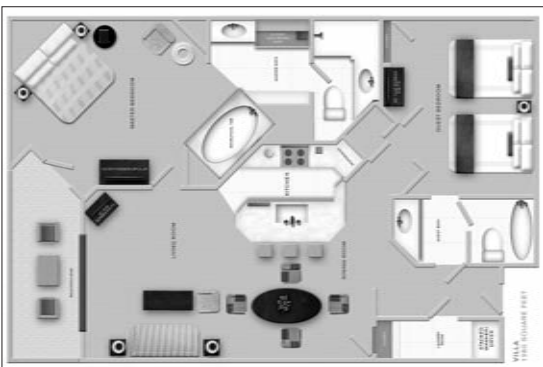


| <i>Room Type</i>  | <i>Rate</i> | <i>Description</i>  |
|---|-------------|---|
| Caribe Deluxe King Suites –<br>592 sq. ft.<br>Non-Smoking | \$169 + tax | A limited number of ADA rooms with Step-in❖<br>Tubs are available in the larger Deluxe King<br>One-Bedroom Suite format. These room types<br>are located within the three towers on the resort<br>property. The bathroom door width in ADA<br>Suites is 33 7/8". The step-in tub height is<br>13.5". The bathroom door width in non-<br>accessible Suites is 29 7/8". |



| <i>Room Type</i>                       | <i>Rate</i> | <i>Description</i>   |
|--|-------------|--|
| Caribe Executive Suites<br>Non-Smoking | \$299 + tax | A limited number of ADA rooms with Step-in<br>Tubs are available in the Two Bedroom Execu-<br>tive Suite format. These room types are located<br>within the three towers on the resort property.<br>The bathroom door width in ADA Suites is<br>33 7/8". The Step-in Tub height is 13.5". The<br>bathroom door width in non-accessible Suites<br>is 29 7/8". |

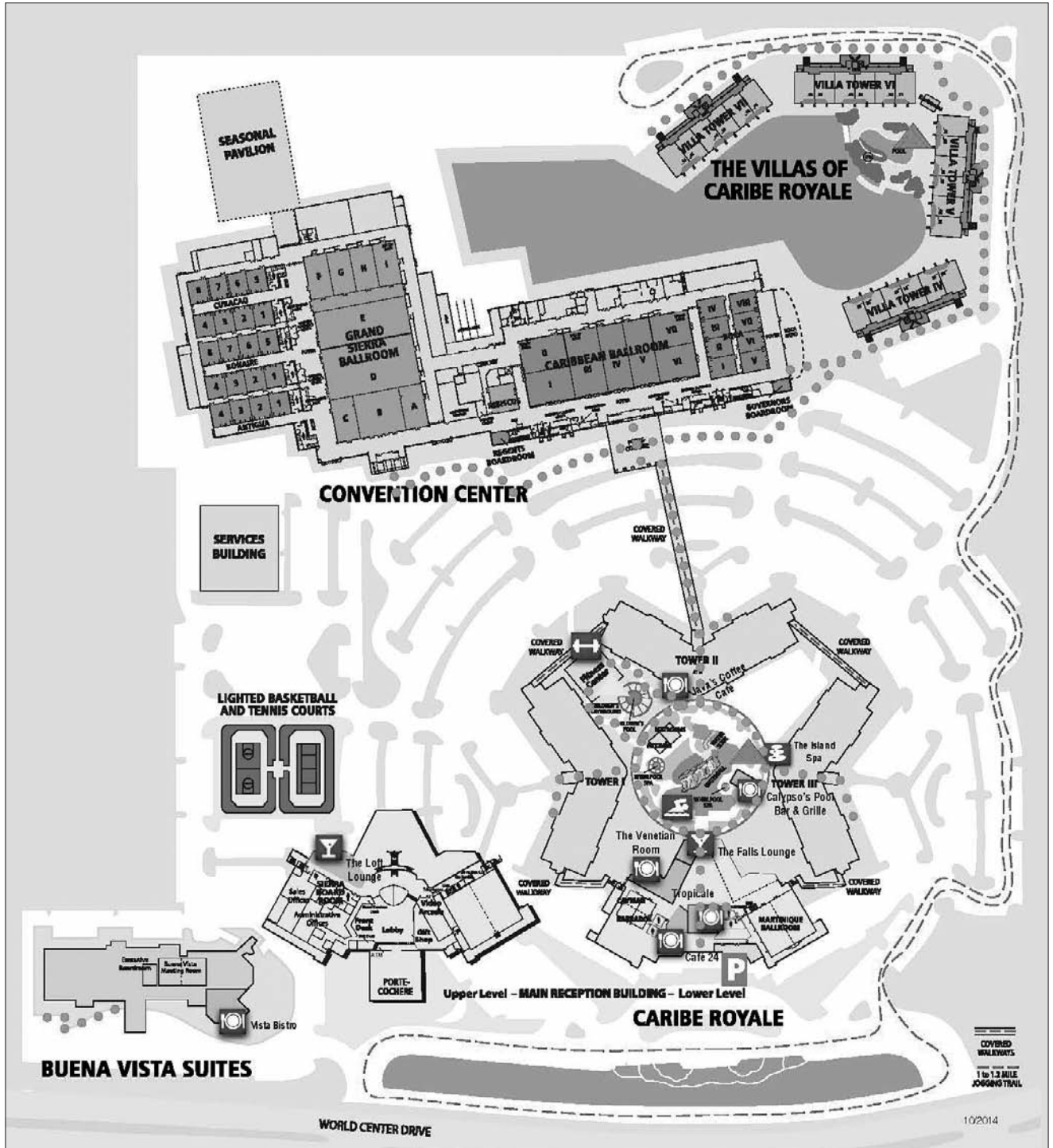
| <i>Room Type</i>                                     | <i>Rate</i> | <i>Description</i>   |
|--|-------------|--|
| Caribe Villas – 1,260 sq. ft.<br>Smoking/Non-Smoking | \$229 + tax | A limited number of ADA rooms with Roll-in<br>Showers or Step-in Tubs are available in the<br>two-bedroom villa (smoking and non-smoking)<br>format. Villas are located in four, four-story<br>towers surrounding a private villa pool and set<br>slightly apart from the rest of the hotel. How-<br>ever, you're just a short stroll away from dining<br>options located in the main reception building<br>and central area of the hotel. All villas come<br>with a queen-sized, pull-out sofa bed in addi-<br>tion to the king master bedroom and double<br>queen bedroom. The bathroom door width in<br>all villas is 33". The step-in tub height is 13.5". |



| <i>Room Type</i>   | <i>Rate</i> | <i>Description</i>  |
|--|-------------|---|
| Buena Vista Standard King<br>Suites – 460 sq. ft.<br>Smoking/Non-Smoking | \$149 + tax | A limited number of ADA rooms with Roll-in<br>Showers and Step-in Showers are available in<br>the King Suite (smoking and non-smoking)<br>formats. The step-in tub height is 13.5".<br>Standard Suite layout at the Buena Vista Suites<br>is the same as at the at the Caribe Royale. |

### Resort Property Map

Visit [www.cariberoyale.com](http://www.cariberoyale.com) for additional resort information.



Are you a member of the National Ataxia Foundation? Become an NAF member or renew your membership online today at [www.ataxia.org](http://www.ataxia.org). YOUR MEMBERSHIP MATTERS!



# Chapter and Support Group News *from Around the Country*

## **Tri-State Ataxia Support Group**

*Submitted by Kathy Gingerelli*

Our May meeting featured a nice showing of a variety of people including a few new shows, our steadfast members and it was the night for some members who were not seen in a while. The welcome/introduction part was done quickly so we could follow the agenda for the night.

The Abilities Expo held May 1-3 at the Convention Center in Edison, NJ was a huge success. The NAF booth manned by Kathy Gingerelli (Tri-State Ataxia Support Group) and John Mauro (Central Massachusetts Ataxia Support Group) was busy all weekend. We had so many people stop by to ask questions and be educated about ataxia.

Since there was not enough time for our group to book a venue for a Walk n' Roll event to promote IAAD, our group will piggyback onto John's walk.

I spoke about the First Annual Disability Pride Parade and Festival to be held on July 7 in New York City. Please visit [www.DisabilityPrideNYC.com](http://www.DisabilityPrideNYC.com) or see the article on page 29.

## **Maine Ataxia Support Group**

*Submitted by Kelley Rollins*

My dear friends involved in the Maine Ataxia Support Group, December 31 will be the last day I will be the leader/president of the group. I have enjoyed being friends with you all and meeting others through e-mail and learning about their ataxia. I hope we can find a replacement and the transition will be smooth beginning 2016. Please, everyone, give this some thought about picking up this rewarding position.

## **Greater Atlanta Ataxia Support Group**

*Submitted by Dave, Greg and Lealan*

We had a great meeting on Saturday July 18, with 34 members participating. Our guest speaker was Beverly Stegman, owner and manager of the Foundation Therapy Centers. She discussed simple yoga techniques for breathing and improving posture and balance. We also discussed the CoRDs Registry and that the registration process has been simplified.

*Continued on page 52*



**Members of the Greater Atlanta Ataxia Support Group**

Chapter and Support Group News  
Continued from page 51

**Albany Ataxia Support Group**

Submitted by Jason Wolfer

On Friday night, July 17, the Albany Support Group met in the backyard of one of the group members for a potluck-style picnic. The group has an annual picnic every summer, and it is more of a social setting that everyone enjoys. Unfortunately, this year there were several members missing.



Members of the Albany Ataxia Support Group

**Portland Ataxia Support Group**

Submitted by Jason Wolfer

On Sunday afternoon, July 19, the Portland Support Group met at a local hamburger restaurant for a casual lunch together. Our group has



Members of the Portland Ataxia Support Group

only been meeting for nine months, but we have been discussing for several months the idea of meeting for a meal together. This was our first attempt and unfortunately most of the members that wanted this to happen were not present. We ended up with only five of us, but had an enjoyable time.

**Northern California Ataxia Support Group**

Submitted by Joanne Loveland

NCASG held its summer meeting on Saturday, July 11. We welcomed five new couples and a total of 11 new guests with 43 attending the meeting.

During our business meeting, Jen Buehler, this year's Walk n' Roll organizer, announced we will recognize International Ataxia Awareness Day on Sunday, October 4. This year's event will include a picnic and new NAF President Bill Sweeney will be our guest speaker. Brian Petersen announced that he is organizing his own Walk n' Roll on September 19 in Concord. All donations will go to the NAF for research at both events.

Sacramento has started their own group headed by Teresa Bredberg and Donna Hogue, both of whom have husbands with ataxia. They are meeting monthly for now, and have more people attending at each meeting. We are so grateful for the effort they are making to help others in their area.

Our quarterly newsletter has a new format thanks to Dawn Ngo. Special thanks to Alan Acacia who launched our first newsletter a year ago. Our state-of-the-art website, <https://norcalataxia.org>, continues to be a great on line resource for Northern California. We encourage everyone to use it as a place to get useful information about NCASG.

We broke into three small groups: men, women and spouses/caregivers for our "Living with Ataxia" program. For an hour everyone shared personal challenges; what some are ►►

doing for exercise and other topics of choice. This small group environment has proved to be very helpful to those participating.

We plan on wearing ataxia t-shirts at our next meeting and taking a group photo.

**Denver Area Ataxia Support Group**

*Submitted by Charlotte DePew*

The Denver Support Group met July 18 and three new members attended. After the usual potluck lunch social, we listened to Naomi S. Hubert, M.Ed., Housing Rehabilitation and Accessibility Specialist from the Colorado Division of Housing. Naomi gave a talk on adaptive home modification very similar to the one she gave at the AMM in Denver in March. We had a lively question, answer, and sharing presentation and all appreciated Naomi's information. Some of her adaptations are inexpensive and do-it-yourself projects if you do not have ataxia.

An update was given on our planned September 13 Run, Walk 'n Roll in Honor of Karen Coquet. Several volunteered to help and donate a basket for our drawing.

**Greater Houston Ataxia Support Group**

The Senior Expo was held at the Pasadena Convention Center on August 12. It was an event where local resources in the area for seniors were represented. The GHASG represented



**Kirby Cardenas (left), Head of Park & Rec for the City of Pasadena, and Bonnie Sills at the Senior Expo in Pasadena**

NAF at the resource table for ataxia and helped with "Ataxia 101."

**India Ataxia Support Group**

*Submitted by Chandu Prasad George*

"An Ataxic's Story - The Hindu," published in local media in India, is about Zoyeb Zia. He has SCA and is very enthusiastic and passionate about spreading awareness on ataxia. It lets people know about ataxia. He hopes it will provide some ataxia awareness. You can find the article here: <http://m.thehindu.com/features/magazine/zara-khan-profiles-an-ataxic/article7540615.ece>.

**New Hampshire Ataxia Support Group**

*Submitted by Jill Porter*

We held our meeting on Saturday, August 22. The meeting consisted of sharing time, an exchange of where everyone is with their diagnosis and how they are presently functioning.

We encourage everyone to join the NH Team online at <http://ataxia.donorpages.com/2015NewEnglandWnR/NewHampshireSupportGroup> and to register to attend the walk on October 3 at Lamansky Field: Rocketland in Auburn, MA. Please join us in raising funds in recognition of Ataxia Awareness Day on September 25. We have set a goal of \$7,500. All proceeds benefit the National Ataxia Foundation, a 501(C)(3) organization.

Chiropractor Dr. Adam Burch and his wife joined us midway through our meeting and he engaged the group explaining his philosophy on how he treats individuals to increase mobility by stimulating the areas of the body that are not working well. His approach is simple, easy, inexpensive and involves repetition on the part of the individual. His information and demonstrations of various stretches brought forth many questions and conversation. He plans to attend the Walk n' Roll so for those of you who were not able to attend you will get an opportunity to meet him there. ❖

# NAF Directory of Chapters, Support Groups, Social Networks 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, joining a chapter or support group without the NAF's written permission is strictly prohibited.*

## 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=hmum](http://www.youtube.com/user/NatlAtaxiaFound?feature=hmum)

**Please note:** The hometown of each Support Group Leader or Ambassador is noted below. For group meeting locations please refer to the Calendar of Events.

## Chapters, Support Groups and Ambassadors

### – ALABAMA –

#### ALABAMA SUPPORT GROUP LEADER

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### – ARIZONA –

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**Mary Fuchs** – Sun Lakes, AZ

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

<https://www.facebook.com/groups/arizonaataxia/>

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

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*NAF Directory**Continued from page 55*[www.ataxia.org/chapters/Chesapeake/default.aspx](http://www.ataxia.org/chapters/Chesapeake/default.aspx)**MID-ATLANTIC SOCIAL SUPPORT GROUP LEADER****Bailey Vernon, Health Educator**

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(507) 282-7127

E-mail: [logoetz@gmail.com](mailto:logoetz@gmail.com)[www.ataxia.org/chapters/LoriGoetzman/default.aspx](http://www.ataxia.org/chapters/LoriGoetzman/default.aspx)**– MISSISSIPPI –****MISSISSIPPI CHAPTER PRESIDENT****Camille Daglio** – Hattiesburg, MSE-mail: [daglio1@bellsouth.net](mailto:daglio1@bellsouth.net)[www.ataxia.org/chapters/Mississippi/default.aspx](http://www.ataxia.org/chapters/Mississippi/default.aspx)**– MISSOURI –****KANSAS CITY SUPPORT GROUP LEADERS****Jim Clark** – Gladstone, MO

(816) 468-7260

**Lois Goodman** – Independence, MO

(816) 257-2428

[www.ataxia.org/chapters/KansasCity/default.aspx](http://www.ataxia.org/chapters/KansasCity/default.aspx)**ST. LOUIS AREA SUPPORT GROUP LEADER****Sarah “Janeen” Rheinecker** – St. Louis, MO

(417) 379-3799

Email: [sjrheinecker@gmail.com](mailto:sjrheinecker@gmail.com)[www.ataxia.org/chapters/StLouis/default.aspx](http://www.ataxia.org/chapters/StLouis/default.aspx)**AMBASSADOR****Roger Cooley** – Columbia, MO

(573) 474-7232 before noon

E-mail: [rogercooley@mediacommbb.net](mailto:rogercooley@mediacommbb.net)[www.ataxia.org/chapters/RogerCooley/default.aspx](http://www.ataxia.org/chapters/RogerCooley/default.aspx)**– NEW HAMPSHIRE –****NEW HAMPSHIRE SUPPORT GROUP LEADER****Jill Porter** – Manchester, NH

(603) 626-0129

E-mail: [jilleporter@comcast.net](mailto:jilleporter@comcast.net)[www.ataxia.org/chapters/Bedford/default.aspx](http://www.ataxia.org/chapters/Bedford/default.aspx)**– NEW JERSEY –****NEW JERSEY SUPPORT GROUP LEADER****Priya Mansukhani** – Bridgewater, NJ

(908) 685-8805

E-mail: [priyamans@gmail.com](mailto:priyamans@gmail.com)[www.ataxia.org/chapters/NewJersey/default.aspx](http://www.ataxia.org/chapters/NewJersey/default.aspx)**TRI-STATE SUPPORT GROUP LEADERS****Denise Mitchell** – Bronxville, NYE-mail: [markmeghan2@gmail.com](mailto:markmeghan2@gmail.com)

## CFC Number

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

**Kathy Gingerelli** – Parsippany, NJ  
(973) 334-2242  
E-mail: kgingerelli@msn.com  
[www.ataxia.org/chapters/Tri-State/default.aspx](http://www.ataxia.org/chapters/Tri-State/default.aspx)

– **NEW YORK** –

**CENTRAL NEW YORK SUPPORT GROUP LEADER**

**Mary Jane Damiano** – N. Syracuse, NY

**Judy Tarrants** – Fabius, NY

(315) 683-9486

E-mail: jtarrants@aol.com

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

**TRI-STATE SUPPORT GROUP LEADERS**

**Denise Mitchell** – Bronxville, NY

E-mail: markmeghan2@gmail.com

**Kathy Gingerelli** – Parsippany, NJ

(973) 334-2242

E-mail: kgingerelli@msn.com

[www.ataxia.org/chapters/Tri-State/default.aspx](http://www.ataxia.org/chapters/Tri-State/default.aspx)

– **NORTH CAROLINA** –

**TARHEEL SUPPORT GROUP LEADERS**

**Jerry and Tammy Hauser** – Advance, NC

(336) 998-2942

E-mail: deaconwfu@msn.com

**Norma Bryant** – Cary, NC

(513) 417-9289

E-mail: normabryant1@gmail.com

**Ron and Donna Smith** – Garner, NC

(919) 779-0414

E-mail: rsmith@sacherokee.com

E-mail: dsmith@sa-pr.com

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

– **OHIO** –

**GREATER CINCINNATI AREA SUPPORT GROUP LEADERS**

**Jennifer Mueller** – Lexington, KY

(513) 284-2865

E-mail: jenmu@yahoo.com

**Julia Soriano** – Cincinnati, OH

(513) 899-1195

E-mail: julia@epivision.com

Group Blog: <http://ataxiafoundationcleveland.blogspot.com/>

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

**CLEVELAND AREA SUPPORT GROUP LEADER**

**Carmen Pieragastini** – Willowick, OH

(216) 272-5588

E-mail: willowpier@roadrunner.com

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

– **OREGON** –

**WILLAMETTE VALLEY SUPPORT GROUP LEADER**

**Jason Wolfer** – Gervais, OR

(503) 502-2633

E-mail: wolfer.jason@gmail.com

**Facebook Group:**

<https://www.facebook.com/groups/388993597939205/>

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

– **PENNSYLVANIA** –

**CENTRAL PA SUPPORT GROUP LEADER**

**Christina Rakshys** – Allentown, PA

(610) 395-6905

E-mail: cpa.ataxia@rcn.com

**Michael Cammer** – Downingtown, PA

(610) 873-1852

E-mail: michael.cammer62@hotmail.com

**Facebook Group:**

<https://www.facebook.com/groups/1475283086068548/>

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

**WESTERN PA SUPPORT GROUP LEADER**

**Donna Eiben** – South Park, PA

(412) 655-4091

E-mail: dawn.eiben@verizon.net

S.G. Website:

<http://nafwesternpasupportchapter.weebly.com/>

**Facebook Group:** <https://www.facebook.com/wpaataxia>

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

– **RHODE ISLAND** –

**RHODE ISLAND SUPPORT GROUP LEADER**

**Anabela Azevedo** – Bristol, RI

(401) 297-8627

E-mail: azevedo70anabela@gmail.com

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

– **SOUTH CAROLINA** –

**AMBASSADOR**

**Brad Forth** – Greenville, SC

(864) 415-8147

E-mail: bradf@photoforth.com

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

– **TENNESSEE** –

**MIDDLE TN AREA SUPPORT GROUP LEADER**

**Alex Cohn** – Nashville, TN

(256) 504-0240

E-mail: alex.j.cohn@us.pwc.com

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

– **TEXAS** –

**GREATER HOUSTON AREA SUPPORT GROUP LEADER**

**David Brunnert** – Cypress, TX

(713) 578-0607

E-mail: david.brunnert@sbcglobal.net

**Facebook Group:**

<https://www.facebook.com/groups/ataxia.houston/>

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

**NORTH TEXAS SUPPORT GROUP LEADER**

**David Henry Jr.** – Trophy Club, TX

(817) 739-2886 (contact by e-mail preferred)

E-mail: cheve11e@sbcglobal.net

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

**AMBASSADORS**

**Dana LeBlanc** – Orange, TX

(409) 883-5570

E-mail: tilessal@yahoo.com

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

**Debra Whitcomb** – El Paso, TX

(915) 329-0721

E-mail: debrawhitcomb@hotmail.com

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

## NAF Directory

Continued from page 57

## – UTAH –

## UTAH SUPPORT GROUP LEADERS

**Grant Beutler** – Salt Lake City, UT

E-mail: grant.beutler@gmail.com

**Jenny Durrant** – North Ogden, UT

E-mail: jenny@utahataxia.org

**Lisa Ord, PhD, LCSW** – Salt Lake City, UT

(801) 587-3020

E-mail: lisa.ord@hsc.utah.edu

**Facebook Page:** [www.facebook.com/utahataxia](http://www.facebook.com/utahataxia)S.G. Website: [www.utahataxia.org](http://www.utahataxia.org)[www.ataxia.org/chapters/Utah/default.aspx](http://www.ataxia.org/chapters/Utah/default.aspx)

## – VIRGINIA –

## CHESAPEAKE CHAPTER PRESIDENT

**Carolyn Davis** – Vienna, VA

(703) 759-2008

E-mail: ccnafpres@gmail.com

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

## – WASHINGTON –

## OLYMPIC AREA SUPPORT GROUP LEADER

**Sherry McLaughlin**

(360) 344-2445

E-mail: ccherilynmc@yahoo.com

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

## SEATTLE AREA SUPPORT GROUP LEADER

**Milly Lewendon** – Kirkland, WA

(425) 823-6239

E-mail: ataxiaseattle@comcast.net

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

## AMBASSADOR

**Linda Jacoy** – Spokane, WA

(509) 482-8501

E-mail: linda4727@hotmail.com

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

## – WISCONSIN –

## WISCONSIN SUPPORT GROUP LEADER

**Jenny Mathison** – Madison, WI

(608) 285-5285

E-mail: mjmathison@att.net

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

## International Support Groups & Ambassadors

## – CANADA –

## OTTAWA SUPPORT GROUP LEADER

**Prentis Clairmont** – Ottawa, Ontario

(613) 864-8545

E-mail: prentis.clairmont@gmail.com **Facebook Group:**<https://www.facebook.com/groups/1468963499991380/>[www.ataxia.org/chapters/Ottawa/default.aspx](http://www.ataxia.org/chapters/Ottawa/default.aspx)

## – INDIA –

## INDIA SUPPORT GROUP LEADER

**“Seek a Miracle Ataxia Group” (SAMAG)****Chandu Prasad George**

Hyderabad, Secunderabad, India

Mobile: 0091-9989899919, 0091-9885199918

E-mail: sam\_ataxiaindia@yahoo.com

S.G. E-mail: india.ataxiagroup@gmail.com

**Facebook Group:** <https://www.facebook.com/ataxiain>S.G. Website: [www.ataxia.in](http://www.ataxia.in)[www.ataxia.org/chapters/Chandu/default.aspx](http://www.ataxia.org/chapters/Chandu/default.aspx)

## – PAKISTAN –

## AMBASSADOR

**Sajjad Jaider** – Sindh, Pakistan

0092-(300) 8221850

E-mail: sajjadhaiderb@hotmail.com



### PATIENTS with EARLY SYMPTOMS of FRIEDREICH'S ATAXIA

age 10 and above needed for an MRI study to  
evaluate the chemistry and connectivity of the  
brain and spinal cord in Friedreich's ataxia

at the Center for Magnetic Resonance Research  
at University of Minnesota

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

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

If you are interested or have questions, please call

Diane Hutter @ (612) 625-2350 or e-mail [hutte019@umn.edu](mailto:hutte019@umn.edu).



# Calendar of Events

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

## SUPPORT GROUP MEETINGS

– **Thursday, October 8, 2015** –

### St. Louis Area Ataxia Support Group Meeting

**Time:** 5:30 – 7:30 p.m. Meetings will be held at on the second Thursday of every month.

**Location:** Washington University Medical Center, 4444 Forest Park Ave., Rm. 509, St. Louis, MO 63108

**Details:** For additional information contact Janeen Rheinecker at (417) 379-3799 or [stlataxia@gmail.com](mailto:stlataxia@gmail.com).

– **Saturday, October 10, 2015** –

### Central Minnesota Ataxia Support Group Meeting

**Time:** 9:45 – 11:45 a.m.

**Location:** Harvest Bank Branch, 24952 County Road 7, St. Augusta, MN 56301

**Details:** For additional information contact Marsha Binnebose at (320) 248-9851 or [mbinnebose@hotmail.com](mailto:mbinnebose@hotmail.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:** Ben Washington Baptist Church, 615 Davis St., Irving, TX 75061

**Details:** The meeting room is in a separate building from the church. For more information contact David Henry at [cheve11e@sbcglobal.net](mailto:cheve11e@sbcglobal.net).

### Northern California Ataxia Support Group Meeting

**Time:** 11:30 a.m. – 2 p.m.

**Location:** Our Savior's Lutheran Church, 1035 Carol Ln., Lafayette, CA

**Details:** For more information or to RSVP contact Joanne Loveland at (952) 323-6895 or [joanneloveland@gmail.com](mailto:joanneloveland@gmail.com).

### Tampa Bay Ataxia Support Group Meeting

**Time:** 12:30 – 3 p.m.

**Location:** Morsani Center, 13330 USF Laurel Dr., #1013, Tampa, FL 33612

**Details:** Please note that meeting dates can and

do change. For more information contact Nygel Lenz at (727) 451-9165 or [nygellenz@gmail.com](mailto:nygellenz@gmail.com).

– **Wednesday, October 14, 2015** –

### Willamette Valley Ataxia Support Group Meeting – Albany

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

**Location:** 400 NW Hickory, Albany, OR 97321

**Details:** For more information contact Jason Wolfer at (503) 502-2633 or [wolfer.jason@gmail.com](mailto:wolfer.jason@gmail.com).

– **Saturday, October 17, 2015** –

### Denver Area Ataxia Support Group Meeting

**Time:** 1 – 4 p.m.

**Location:** Swedish Medical Center, Second Floor Conference Center (meeting room TBD), 501 E. Hampden Ave., Englewood, CO 80113.

**Details:** For more information contact Charlotte DePew at (720) 379-6887 or [cldepwe77@comcast.net](mailto:cldepwe77@comcast.net).

### Orange County Ataxia Support Group Meeting

**Time:** 2 – 4 p.m. on the third Saturday of every other month

**Location:** Orange Coast Memorial Medical Center (room TBD), 9900 Talbert Ave., Foundation Valley, CA 92708

**Details:** For more information contact Daniel Navar at (323) 788-7751 or [danieln27@gmail.com](mailto:danieln27@gmail.com) or Cindy DeMint at (714) 970-1191 or [cindyocataxia@gmail.com](mailto:cindyocataxia@gmail.com).

### Twin Cities Ataxia Social Group Meeting

**Time:** 10 a.m. on the third Saturday of every month (approximately two hours)

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

**Details:** For additional information contact Lenore Healey Schultz at (612) 724-3784 or [schultz.lenore@yahoo.com](mailto:schultz.lenore@yahoo.com).

– **Saturday, October 24, 2015** –

### Alabama Ataxia Support Group Meeting

**Time:** 10 a.m. – 1:30 p.m.

**Location:** Covenant Presbyterian Church, Home-wood, AL

**Details:** For more information contact Becky

*Continued on page 60*

*Calendar of Events**Continued from page 59*

Donnelly at (205) 987-2883 or [donnely6132@aol.com](mailto:donnely6132@aol.com).

**New Hampshire Ataxia Support Group Meeting****Time:** 10 a.m. – noon**Location:** Hannaford Market, 5 Colby Ct., Bedford, NH**Details:** For more information or to RSVP contact Jill Porter at (603) 626-0129 or [jilleporter@comcast.net](mailto:jilleporter@comcast.net).

– **Saturday, November 7, 2015** –

**Greater Atlanta Ataxia Support Group Meeting****Time:** 1 p.m.**Location:** Emory Center for Rehabilitation Medicine, 1441 Clifton Rd. NE, Rm. 101, Atlanta, GA 30322**Details:** For more information call (404) 822-7451 or [atlantaataxia@gmail.com](mailto:atlantaataxia@gmail.com).

– **Wednesday, November 11, 2015** –

**Willamette Valley Ataxia Support Group Meeting – Albany****Time:** 11:30 a.m. – 1 p.m. on the second Wednesday of every month**Location:** 400 NW Hickory, Albany, OR 97321**Details:** For more information contact Jason Wolfer at (503) 502-2633 or [wolfer.jason@gmail.com](mailto:wolfer.jason@gmail.com).

– **Thursday, November 12, 2015** –

**St. Louis Area Ataxia Support Group Meeting****Time:** 5:30 – 7:30 p.m. Meetings will be held at on the second Thursday of every month.**Location:** Washington University Medical Center, 4444 Forest Park Ave., Rm. 509, St. Louis, MO 63108**Details:** For additional information contact Janeen Rheinecker at (417) 379-3799 or [stlataxia@gmail.com](mailto:stlataxia@gmail.com).**Tri-State Ataxia Support Group Potluck Meeting****Time:** 6:30 – 8:30 p.m.**Location:** Bethel Israel Medical Center, Phillips Ambulatory Care Center (PACC), Second Floor Conference Room, 10 Union Square East, New York, NY**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 14, 2015** –

**Central Minnesota Ataxia Support Group Meeting****Time:** 9:45 – 11:45 a.m.**Location:** Harvest Bank Branch, 24952 County Road 7, St. Augusta, MN 56301**Details:** For additional information contact Marsha Binnebose at (320) 248-9851 or [mbinnebose@hotmail.com](mailto:mbinnebose@hotmail.com).**North Texas Ataxia Support Group Meeting****Time:** 10 a.m. – noon**Location:** Ben Washington Baptist Church, 615 Davis St., Irving, TX 75061**Details:** The meeting room is in a separate building from the church. For more information contact David Henry at [cheve11e@sbcglobal.net](mailto:cheve11e@sbcglobal.net).

– **Sunday, November 15, 2015** –

**Chi-town Ataxia Friendship Group Meeting****Time:** 1 p.m. on the third Sunday of odd-numbered months.**Location:** Good Samaritan Hospital (White/Blue Oak Rm.), 3815 Highland Ave., Downers Grove, IL 60515**Details:** For additional information contact Jonas Cepkauskas at (708) 381-5555 or [jonas@chitownataxia.org](mailto:jonas@chitownataxia.org).

– **Saturday, November 21, 2015** –

**Twin Cities Ataxia Social Group Meeting****Time:** 10 a.m. on the third Saturday of every month (approximately two hours)**Location:** Langton Place in Roseville at 1910 W. County Rd. D, Roseville, MN 55112**Details:** For additional information contact Lenore Healey Schultz at (612) 724-3784 or [schultz.lenore@yahoo.com](mailto:schultz.lenore@yahoo.com).

– **Saturday, December 5, 2015** –

**Greater Atlanta Ataxia Support Group Holiday Party****Time:** 1 p.m.**Location:** Grace Life Church, 655 Molly Ln., Ste. 150, Woodstock, GA 30189**Details:** For more information call (404) 822-7451 or [atlantaataxia@gmail.com](mailto:atlantaataxia@gmail.com).**New Hampshire Ataxia Support Group Meeting****Time:** 10 a.m. – noon**Location:** Hannaford Market, 5 Colby Ct., Bedford, NH**Details:** For more information or to RSVP contact Jill Porter at (603) 626-0129 or [jilleporter@comcast.net](mailto:jilleporter@comcast.net).**Orange County Ataxia Support Group Meeting****Time:** 2 – 4 p.m. on the third Saturday of every month ▶▶

other month.

**Location:** TBD

**Details:** For more information contact Daniel Navar at (323) 788-7751 or [danieln27@gmail.com](mailto:danieln27@gmail.com) or Cindy DeMint at (714) 970-1191 or [cindyocataxia@gmail.com](mailto:cindyocataxia@gmail.com).

– **Wednesday, December 9, 2015** –

**Willamette Valley Ataxia Support Group Meeting – Albany**

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

**Location:** 400 NW Hickory, Albany, OR 97321

**Details:** For more information contact Jason Wolfer at (503) 502-2633 or [wolfer.jason@gmail.com](mailto:wolfer.jason@gmail.com).

– **Thursday, December 10, 2015** –

**St. Louis Area Ataxia Support Group Meeting**

**Time:** 5:30 – 7:30 p.m. Meetings will be held at on the second Thursday of every month.

**Location:** Washington University Medical Center, 4444 Forest Park Ave., Rm. 509, St. Louis, MO 63108

**Details:** For additional information contact Janeen Rheinecker at (417) 379-3799 or [stlataxia@gmail.com](mailto:stlataxia@gmail.com).

– **Saturday, December 12, 2015** –

**Alabama Ataxia Support Group Christmas Social**

**Time:** TBD

**Location:** B & A Warehouse, Birmingham, AL

**Details:** For more information contact Becky Donnelly at (205) 987-2883 or [donnelly6132@aol.com](mailto:donnelly6132@aol.com).

**Central Minnesota Ataxia Support Group Meeting**

**Time:** 9:45 – 11:45 a.m.

**Location:** Harvest Bank Branch, 24952 County Road 7, St. Augusta, MN 56301

**Details:** For additional information contact Marsha Binnebose at (320) 248-9851 or [mbinnebose@hotmail.com](mailto:mbinnebose@hotmail.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:** Ben Washington Baptist Church, 615

Davis St., Irving, TX 75061

**Details:** The meeting room is in a separate building from the church. For more information contact David Henry at [cheve11e@sbcglobal.net](mailto:cheve11e@sbcglobal.net).

– **Saturday, December 19, 2015** –

**Twin Cities Ataxia Social Group Meeting**

**Time:** 10 a.m. on the third Saturday of every month (approximately two hours)

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

**Details:** For additional information contact Lenore Healey Schultz at (612) 724-3784 or [schultz.lenore@yahoo.com](mailto:schultz.lenore@yahoo.com).

**INFORMATIONAL, AWARENESS, AND IAAD EVENTS AND FUNDRAISERS**

**International Ataxia Walk n' Roll for Ataxia IAAD Event and Fundraiser**

**Time:** Going on now through the end of 2015!

**Details:** Join the NAF International Ataxia Walk n' Roll for Ataxia! In Recognition of International Ataxia Awareness Day (IAAD) Dust off your walking shoes, bikes, trikes ... and join us as we extend an invitation to one and all! Join us in raising ataxia awareness and funds to help support the important work of the National Ataxia Foundation! All proceeds benefit the National Ataxia Foundation for more information contact [naf@ataxia.org](mailto:naf@ataxia.org).

<http://ataxia.donorpages.com/2015GlobalWnR/>

– **Saturday, October 3, 2015** –

**AZ Shop 'til you Drop Craft and Vendor Fair**

**Time:** 9 a.m. – 12:30 p.m.

**Location:** Disability Empowerment Center, 5025 W. Washington, Phoenix, AZ 85034

**Details:** You will find Health and Wellness vendors, a Chinese Auction, 50/50 raffle and kids games and prizes. This is a free event, donations accepted. All proceeds benefit the National Ataxia Foundation. For more information about attending contact Angela Li at (847) 505-4325 or [angelali1010@gmail.com](mailto:angelali1010@gmail.com) or Mary Fuchs at (480) 212-6425 or [mary11115@msn.com](mailto:mary11115@msn.com).

<http://ataxia.donorpages.com/2015AZShop/>

**New England Walk n' Roll for Ataxia IAAD Event and Fundraiser**

**Time:** 9 a.m. – noon

**Location:** Rocketland, Auburn, MA. All proceeds

*Calendar of Events*  
Continued from page 61

benefit the National Ataxia Foundation.

**Details:** For more information about the event, contact John Mauro at (508) 736-6084 or [john@ataxia.org](mailto:john@ataxia.org).

[www.facebook.com/events/786303194810958/](http://www.facebook.com/events/786303194810958/)  
[www.ataxia.org/walk/auburn](http://www.ataxia.org/walk/auburn)

– **Sunday, October 4, 2015** –

**Northern CA Walk n' Roll for Ataxia  
IAAD Event and Fundraiser**

**Details:** Picnic to follow the Walk n' Roll. For more information about the event, contact Jen Buehler at (510) 468-6474 or [jenbuehler@aol.com](mailto:jenbuehler@aol.com).

– **Saturday, October 10, 2015** –

**Tea Time for Ataxia**

**Time:** Choice of sitting at 11:00 a.m. – 1:00 p.m. or 1:30 – 3:30 p.m.

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

**Details:** 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).

– **Tuesday, October 20, 2015** –

**Boscov's Friends Helping Friends**

**Details:** Boscov's Department Store will again be hosting the popular Friends Helping Friends special shopping day. 25% discount shopping passes are available for \$5 to use on this special shopping day. The \$5 from your shopping pass purchase goes to benefit the National Ataxia Foundation. To purchase your shopping pass contact Mike Cammer at (610) 996-5814 or [michael.cammer62@hotmail.com](mailto:michael.cammer62@hotmail.com).

– **Saturday, October 31, 2015** –

**Michigan Walk n' Roll for Ataxia  
IAAD Event and Fundraiser**

**Time:** TBD

**Location:** University of Michigan Biomedical Science Research Building (BSRB), 109 Zina Pl, 5031 BSRB, Ann Arbor, MI 48109.

**Details:** There is no registration fee. All donations are welcome and benefit the National Ataxia Foundation. For additional information please contact Elizabeth Sullivan at (734) 232-6247 or [elizsull@umich.edu](mailto:elizsull@umich.edu) or Tanya Tunstull at (313) 736-2827 or [tinyt48221@yahoo.com](mailto:tinyt48221@yahoo.com).

[www.ataxia.org/walk/michigan](http://www.ataxia.org/walk/michigan)

– **Thursday, December 3, 2015** –

**International Day of Persons with Disabilities**

**Details:** Today, the world population is over 7 billion people. More than one billion people, or approximately 15 percent of the world's population, live with some form of disability. 80 percent live in developing countries. Evidence and experience shows that when barriers to their inclusion are removed and persons with disabilities are empowered to participate fully in societal life, their entire community benefits. Barriers faced by persons with disabilities are, therefore, a detriment to society as a whole, and accessibility is necessary to achieve progress and development for all.

[www.un.org/en/events/disabilitiesday/background.shtml](http://www.un.org/en/events/disabilitiesday/background.shtml)

– **Friday, December 4-6, 2015** –

**DC Metro – Abilities Expo**

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

**Location:** Dulles Expo Center, 4320 Chantilly Shopping Center, Chantilly, VA 20154

**Details:** Admission is free.

[www.abilities.com/dcmetro/](http://www.abilities.com/dcmetro/)

– **April 1-3, 2016** –

**59th NAF Annual Ataxia Conference (AAC)**

**Location:** Caribe Royale, Orlando, FL

**Details:** Registration fee required to attend. See page 41 for more information, or visit [www.ataxia.org/events/2016\\_AAC/2016\\_AAC\\_Announcement.pdf](http://www.ataxia.org/events/2016_AAC/2016_AAC_Announcement.pdf)

<https://naf.myetap.org/fundraiser/16AMM/> ❖

**Thank you NAF Chapters, Support Group Leaders,  
and Ambassadors for all your hard work!**

Please help us keep your information up-to-date  
by mailing updates to [lori@ataxia.org](mailto:lori@ataxia.org).

# 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 2015. 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.

|                     |                   |                      |                  |                     |
|---------------------|-------------------|----------------------|------------------|---------------------|
| David Alessi        | Doug Flynn        | Michael Leader       | Amanda Renneberg | Henry Skala         |
| Crystal Allsopp     | Cindy Fondulis    | Madelyn Leake        | Norma Rice       | Kathryn Smithers    |
| Wayne Anderson      | George Fowler     | Tony Lewendon        | Jim Richards     | Marilyn Stevens     |
| David Ashley        | Chie Franklin     | Lisa Lingard         | Laura Riermaier  | Clinton Stewart     |
| Bruce Ayres         | Jerry Frey        | Joanne Loveland      | Elizabeth Riley  | Janette St. George  |
| Sharon Baggett      | John Frey Jr.     | Kathleen Lowry       | Janet Riley      | Robert St. George   |
| William Bassett     | Mary Fuchs        | Amy Maranowicz       | Raymond Rogers   | Linda Strum         |
| M.A. Bengard        | Helen Fulghum     | David Mason          | Ellen Rogers     | Ernest Talarico Jr. |
| Leonie Birch        | Katelyn Fuller    | Massanova Family     | Mary Romero      | Joseph Thell        |
| Fred Blasberg       | Jonathan Fuller   | Jeremy Masserant     | Margaret Russo   | Alan Tindall        |
| Ruth Buckley        | Gregson Gann      | Masserant Family     | William Sander   | Patricia Tobias     |
| Dennis Burdett      | Melvin Goodman    | Jane Massmann        | Cindy            | Dr. Aymee           |
| Kyle Bussas         | Brenda Graner     | Jimmy Mathis         | Santa Croce      | Torres-Michels      |
| Mike Cammer         | Lawrence Graner   | David Matley         | Roberta          | Phil Turnbull       |
| Paul Canfield       | Teresita Guerrero | John Mauro           | Santa Croce      | Jacob Van Buren     |
| Kenny Canter        | Ricardo Guerrero  | Gloria McConville    | Donald           | Anna Vibberts       |
| Phyllis Celio       | John Gulick       | Frank McConville     | Santa Croce      | Eleanor Vibberts    |
| Ching Family        | Sarah Hale        | Alisa McFarland      | Dom Santa Croce  | Joseph Villa        |
| Bob Clausen         | Patricia Hamilton | Mike McLain          | Fred Santa Croce | Barry Washburn      |
| Joe Coffey          | Mary Hartmann     | Robert McMurtry      | Leonard Schless  | Donna Weaver        |
| Coffey Family       | Helen Henry       | Linda Meier          | Lazarus Schless  | Daniel West         |
| Tiffinay Compiano   | David Henry Jr.   | Debra Michael        | Linda & Ed       | Dan West            |
| Roger Cooley        | Raymond Hesser    | Vicki Miller         | Schwartz         | David Westrick      |
| Hal Crawford        | Patricia Hogan    | Carol Miller         | (anniversary)    | Whipple Family      |
| Russell Crystal     | Johnny Hogan      | Mary Mueller         | Aaron Scott      | Anna Widing         |
| Mary Danson         | Krista Humes      | Carol Mullen         | Derek Semler     | Mike Widing         |
| Page Davis          | Jerry Hunt        | Keri Naccarato       | Cheryl Serge     | Jackie Widing       |
| Kennon Davis        | Marilyn Hunt      | Gerry Neugebauer     | Stephen Shears   | Steve Widing        |
| Cathy DeCrescenzo   | Bonnie Huston     | Matt Oetting         | Veronica Silva   | Christopher Wier    |
| Maria DeJaco        | Kerry Johnson     | C.J. O'Neal          | Peggy Simmang    | Jon Zilles          |
| Bernadette DeLuca   | Terry Johnson     | Peter Ostrowski      |                  | ❖                   |
| Olive Derrington    | Barbara Jones     | Richard Ostrowski    |                  |                     |
| Angelo Dios         | Anne Kaiser       | Byron Parker         |                  |                     |
| Dawn Dizon          | Barry Karas       | Robert Pecora        |                  |                     |
| Randy Dombrowski    | Dru Keene         | John Pellegrino      |                  |                     |
| Fred Donnelly       | Denis Kelly       | Kay Pogulis          |                  |                     |
| Rick Donnelly       | Ercel Kern        | Jennifer Powell      |                  |                     |
| Teresa Drakos       | Anne Killan       | Rita Powell-         |                  |                     |
| Naomi Droz          | Young Kim         | Lobascio             |                  |                     |
| Bonne Dunkelberg    | Jamie Kosieraki   | Ernest Prince        |                  |                     |
| John Dunn           | Julie Lahey       | Robert Quick         |                  |                     |
| Daniel Eustache     | Gerald Laukhuf    | Ron Randol           |                  |                     |
| Bill & Leslie Evens | Lorrie Laukhuf    | Annie Reed           |                  |                     |
| (anniversary)       | Jennifer Leader   | Shirley Reifenberger |                  |                     |

## Deadline

The deadline to submit materials for upcoming winter edition of *Generations* is Friday, October 30.

Please 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.



## National Ataxia Foundation

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

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### 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 \_\_\_\_\_

**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).**

### MEMBERSHIP

Yes, I want to help fight ataxia! Enclosed is my membership donation. (*Gifts in U.S. 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

*Recurring Gift Membership Program:*

If you wish to contribute monthly or quarterly, please consider the Recurring Gift Membership Program.

For more information contact the NAF office or visit [www.ataxia.org/giving/default.aspx](http://www.ataxia.org/giving/default.aspx).

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 NAF.

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

Credit Card:  Visa  MasterCard  Discover

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

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

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

Signature \_\_\_\_\_

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