

Generations

SPECIAL EXPANDED EDITION



The Official Publication of the National Ataxia Foundation

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National Ataxia Foundation Annual Membership Drive Begins in May

Why a National Ataxia Foundation (NAF) Membership? Membership is a partnership between you and the NAF. As a member you are a stakeholder in the organization, investing in the NAF's capacity to provide important programs and services.

As a member you are strengthening the organization's ability to provide important ataxia publications, maintaining a current web site, and creating ataxia awareness.

Membership support brings world-class researchers together through programs such as

the NAF Ataxia Investigators Meeting (AIM) and offering a multi-day ataxia conference through the NAF Annual Membership Meeting. Membership support also helps in the printing and distribution of *Generations*, development of local support groups, and the expansion of ataxia social networking sites.

Please support the 2015 NAF Annual Membership Drive and please ask others to also become an NAF member.

There are various NAF membership levels to choose from: Individual, Household, Patron, Professional and Lifetime. Recently added in 2014 is a Recurring Gift Membership, where you can pledge a monthly or quarterly gift (see pages 38-39).

Please visit our website, www.ataxia.org. The "Membership" link is on the top right (in the blue cloud "Act" box). When you have opened the membership link, click on the drop-down box to select the membership level, then you can sign up via the web, or please feel free to call us at (763) 553-0020 to sign up over the phone. If you prefer to use U.S. mail, please use the form on the back page of your *Generations* newsletter. Thank you!



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National Ataxia Foundation 58th Annual Membership Meeting

“Soaring Mile High for a Cure”

The 2015 National Ataxia Foundation's Annual Membership Meeting (AMM) was hosted by the NAF's North Central Region. The Foundation would like to congratulate the North Central Region on hosting such a successful meeting! More than 375 attendees came for the three-day event. Attendees came from 42 U.S. states and Washington DC and from four international countries including Canada, Denmark, United Kingdom, and India.

The National Ataxia Foundation would like to extend a special thank you to all the attendees, speakers, facilitators, exhibitors and the outstanding volunteers of the 2015 “Soaring Mile High for a Cure” NAF AMM held in Denver, CO. The NAF recognizes the resources, sacrifices, and challenges that many attendees face to attend an AMM. Your attendance is valued and truly appreciated. This conference would not have been possible without the time, contributions, and efforts given by so many.

Thank you much for the wealth of information and knowledge that was brought to the meeting by all the speakers, facilitators and exhibitors. The information and skills taken away from this meeting by the attendees is invaluable and worth more than any words can say.

It was so wonderful working with the North Central Region Leadership. Their commitment and dedication toward the successful execution of this meeting was truly exceptional.

Thank you to Lora Morn for volunteering as our on-site nurse at the meeting.

We would also like to thank David Garcia for taking such memorable pictures of the event and John Mauro for doing the videography.

There were several new elements to this year's

AMM program that were exciting to introduce and were well received. The format of the program changed so that General Sessions were scheduled in the mornings and Birds of a Feather Sessions were divided and offered either Friday or Saturday afternoon. This potentially left many attendees with an afternoon free to visit the exhibitor booths, check out the Activity Room, stroll around downtown Denver, and visit with other attendees.



Volunteers at the T-shirt table. More pictures from the AMM are on pages 32-33.

For the first time, attendees had access to an app for the meeting that allowed them to view the meeting schedule and session description, select sessions they wanted to attend and create their own schedule and reminders, interact with other attendees, access exhibitor information, post pictures, and view maps of the meeting space and local area. Approximately 40% of the meeting attendees used the app and found it a great tool. The NAF was able to broadcast the General Sessions on Sunday “live” through a

Continued on page 4

Annual Meeting Recap

Continued from page 3

free webcast. The webcast was viewed 292 times and received great reviews from viewers that appreciated having access to these presentations. All General Session presentations are available on DCP's website as audio-synched videos. Several sessions are available to view for free at www.dcpvidersonline.com/naf/. The DCP order form can be found in this issue of *Generations* on page 44.

At this year's AMM the Foundation recognized the numerous fundraising events that were conducted in 2014. "I Am The Strength Behind Ataxia" awards were presented to Dr. Brent Fogel, the DeMint Family, and Chadapangu Chandu Prasad George. Dr. Susan Perlman received an Outstanding Achievement award for her exceptional care to ataxia patients over the last 35 years, and Dr. Lawrence Schut received a Lifetime Achievement Award for his exceptional care to ataxia patients for more than 50 years.

Considerable appreciation and gratitude goes out to this year's sponsors Athena Diagnostics,

the FA Project, MetLife Center for Special Needs Planning, HB Cares, and Dunkin Donuts. Thank you to the Denver Convention and Visitors Bureau for the local information provided for this year's meeting. Thank you to the Sheraton Downtown Denver Hotel for their service and hospitality throughout this event. ❖



Mike Parent presents the Lifetime Achievement Award to Dr. Lawrence Schut



Left to right: Dr. Brent Fogel, Dr. Susan Perlman, and Gerry and Cindy DeMint with their awards



Chadapangu Chandu Prasad George with his award

Thank you to everyone who made the 2015 Annual Membership Meeting such a resounding success. We look forward to seeing you in Orlando in 2016!

*The NAF Board of Directors along with the
NAF Southeast Region would like to invite you to attend the*

National Ataxia Foundation 59th Annual Membership Meeting April 1-3, 2016



Join us in Orlando for the Annual Membership Meeting!

— RESERVATION INFORMATION WILL BE ANNOUNCED SOON —

For the latest information on conference registration, program schedule, and area information, keep checking the National Ataxia Foundation website, www.ataxia.org.

2016 NAF AMM “Support Our Conference” Campaign

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

For more information on Orlando, visit www.visitorlando.com.



Share Your AMM Stories & Photos

Personal stories and photos from our readers are a valuable part of *Generations*.

Do you have a story or photo from the 2015 AMM that you would like to share?

Please submit them to joan@ataxia.org to be considered for publication. The deadline for the upcoming summer issue is May 15.

From the Desk of the Executive Director

We were pleased that you were able to join us at the 2015 NAF 58th Annual Membership Meeting (AMM) in Denver, Colorado on March 6-8. Hosted by the North Central Region, this year's conference attendees included nearly 50% who were first timers. We hope that the meeting met your expectations and you found the conference informative and had the opportunity to network and meet new friends.

A special thank you to all the members of the North Central Region and to the AMM North Central Planning Committee who participated in the planning for this important meeting. A very special thank you to our amazing volunteers at the meeting and to the organizers, participants, donors, and sponsors of Walk'n Rolls for Ataxia and other events who helped raise funds for the meeting. The NAF is also grateful to our AMM sponsors: Athena Diagnostics, Dunkin' Donuts, The FA Project, HB Cares, and MetLife Center for Special Needs Planning.

Plans have already begun for the 2016 NAF AMM, which will be held on April 1-3, 2016 in Orlando, Florida. The 2016 AMM, hosted by the Southeast Region, will be in conjunction with the NAF's Sixth International Ataxia Investigators Meeting (AIM). As in previous AIM years, you will have the opportunity to meet with world-leading ataxia investigators through an afternoon poster session on Thursday, March 31. Please plan your travels accordingly to make sure you do not miss this opportunity to meet with the researchers. More information about the 2016 AMM will soon be available on the NAF's web site, social media, and future issues of *Generations*. We look forward in seeing you in

sunny Orlando, Florida.

The National Ataxia Foundation is a membership supported nonprofit organization which offers its members a discounted registration fee in attending the annual membership meeting. A NAF Membership also provides you with a subscription to the NAF quarterly newsletter, *Generations*. As a NAF member, your support significantly helps in providing important programs and services for the ataxia community.



Michael Parent

Membership support allows representation at various medical/research conferences, community information tables, CFC events and Abilities Expos. Membership helps in the development, printing, and distribution of ataxia publications and in providing current and accurate information through print, in-office and electronic media. Your membership support is far reaching in support group development and in creating greater ataxia awareness.

The NAF Annual Membership Drive will begin in May. We ask that you please renew your membership and invite a friend, co-worker, or relative to also become a NAF Member. If each of us would ask one other person to join...think of what we could accomplish for the ataxia community. Please look for the 2015 NAF Annual Membership Drive letter in the mail in May. You may also renew your membership on the back page of this issue of *Generations*. Membership expiration dates are shown on the address label. Thank you for your continued support through membership.

International Ataxia Awareness Day (IAAD) is September 25. The NAF has available on its web site, www.ataxia.org, an IAAD Kit on how you can get involved in creating ataxia awareness in your area. It is never too early to begin ►►

planning to create ataxia awareness and in recognizing IAAD.

This issue of *Generations* provides a listing and summaries beginning on page 8 of the research studies funded in late December 2014 for fiscal year 2015. Three of these studies were through a partnership with the Bob Allison Ataxia Research Center (BAARC). Also funded in 2014 was a Clinical Research Training Fellowship in Ataxia Award in partnership with the American

Academy of Neurology's American Brain Foundation (Summer 2014 *Generations*, page 17). Through your support and our partners, the NAF was able to support 25 promising ataxia research studies in 2014, totaling nearly \$1,000,000. The impact that each research donation made is profound and enabled the NAF to fund the best science in the world. Your research gifts are far reaching and give hope to all of us. Thank you! ❖

Thank you MetLife Center for Special Needs PlanningSM



Thank you MetLife Center for Special Needs PlanningSM for supporting the 2015 National Ataxia Foundation's 58th Annual Membership Meeting. MetLife Center for Special Needs PlanningSM is dedicated to helping families secure both lifetime care and quality of life for their dependents with special needs.

Their mission is to help families plan for the future of their dependents with special needs, including preserving government benefits and

providing insurance and other financial solutions which can help provide lifetime quality care.

MetLife's Special Needs Planners can help you determine your dependent's needs and funding options to address those needs. MetLife does not provide tax or legal advice. They will work with your tax and legal advisors regarding your specific situation. To learn more about MetLife Center for Special Needs PlanningSM please call 1-877-638-3375. ❖

Research Summary Primer

This issue of *Generations* includes summaries of recently funded ataxia research. Research grants made by the National Ataxia Foundation fall into several categories, as follows:

Research Seed-Money Grants: One-year grants that provide seed monies in early or pilot phases of studies that may attract future funding from other sources.

Young Investigator Awards for SCA Research: One-year grants of \$50,000 awarded to encourage the young investigators to pursue a career in spinocerebellar ataxia research.

Pioneer SCA Translational Research Awards: One-year grants of \$100,000 awarded that will

facilitate the development of treatments for the spinocerebellar ataxias.

Young Investigator Award: One-year grants awarded to encourage young investigators to pursue a career in the field of ataxia research.

Post-Doc Fellowship Awards: One-year grants intended for researchers to spend a third year in a post-doc position to increase their chance of establishing an independent ataxia research program.

Other Research Grant: The Foundation continues to support the National Ataxia Database, an important tool for clinical research.

Research Seed Money Grant

Glutamate Decarboxylase in Cerebellar Ataxia

By Christiane Hampe, PhD

University of Washington, Seattle, WA



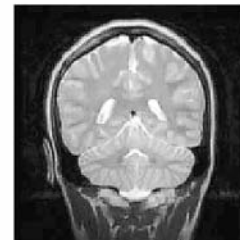
Dr. Christiane Hampe

The pathogenesis of cerebellar ataxias is only poorly understood, obstructing the design of effective therapies. Some patients with cerebellar ataxia show markers of autoimmunity, such as antibodies directed against the patient's own proteins. The antibodies may interfere with neurotransmission and therefore be part of the disease process. One of the targets of these antibodies is the enzyme glutamate decarboxylase (GAD). This enzyme is critical for neurotransmission and lack of its expression has been linked to neurological symptoms such as epileptic seizures, gait abnormalities and anxiety. Our goal is to assess the role of GAD in cerebellar ataxias. Central to the role of GAD are two different functions; its enzymatic activity, resulting in the production of the inhibitory neurotransmitter GABA, and its function in the delivery of the neurotransmitter to the nerve endings. It is unclear which of these functions is impaired in patients with cerebellar ataxia. We will use a mouse model that lacks expression of GAD. These mice show ataxia-associated symptoms. We will first re-instate normal GAD function by expression of normal GAD in the animals' brain. Our second aim is to express a mutated form of GAD. This mutation lacks the ability to deliver the neurotransmitter to the nerve endings but retains full enzymatic activity. In our third aim we will use a different mutant of GAD. This mutant lacks GAD enzymatic activity, but can still deliver the neurotransmitter to the nerve endings. The animals will be tested for their behavior with several tests designed to evaluate cerebellar ataxia-associated symptoms. These experiments will allow us to understand which function of GAD is impaired in cerebellar ataxia and aid in the design of a targeted therapy. ❖



**PATIENTS with
SCA1, SCA2, SCA3, SCA6 and
MSA-C
needed for an MRI study
at the University of Minnesota, Minneapolis**

Travel expenses reimbursed.
Contact: Diane Hutter
(612) 625-2350
hutte019@umn.edu



Research Seed Money Grant

Pathological and Therapeutic Roles of Immunoproteasomes in SCA1

By **Do-Hyung Kim, PhD**

University of Minnesota, Minneapolis, MN (in partnership with the Bob Allison Ataxia Research Center)

The ubiquitin proteasome pathway has been implicated in SCA1 pathogenesis. Inhibition of the proteasome increased ataxin1 nuclear inclusion formation. The mutant ataxin-1 nuclear inclusion was found to contain the 20S proteasome. While this has led to a suggestion that impairment of the proteasomal functions might be important for SCA1, the exact roles of proteasomes in SCA1 have been lacking. This project is focused on immunoproteasomes, a special type of proteasomes expressed in immune cells and induced in non-immune cells by cytokines, inflammation and oxidative stress. Most of constitutively expressed standard proteasomes are replaced with immunoproteasomes under stress or infection. Immunoproteasomes play a crucial role in antigen presentation, but it has an emerging role in clearing oxidized, aberrant proteins that accumulate in stress. They also play crucial roles positively or sometimes negatively in inflammatory responses through poorly-understood mechanisms. The proposed research is to define the roles of immunoproteasomes in SCA1. As a first step, we propose to establish neuronal cellular systems and demonstrate a proof of concept regarding the roles of immunoproteasomes in SCA1. Based on the status quo knowledge, there are two possible functions of immunoproteasomes. In early state of onset of the disease, immunoproteasomes might play a protective role in preventing the aggregation of misfolded mutant ataxin-1. In late state after progression of the disease or the aggregates formed, immunoproteasomes might contribute to persistent, inflammatory effects increasing cellular toxicity. A beneficial effect would be expected from their role in clearing aberrant proteins. It is known that immunoproteasomes have a higher catalytic power than standard proteasomes in clearing aberrant proteins. Thus, in early stage of SCA1 when the mutant ataxin1 starts to be expressed, immunoproteasomes would play a role in clearing misfolded proteins that might stay temporally as aberrant states. However, exaggerative expression or mutation or phosphorylation of S776 of ataxin-1 may overcome the capability of immunoproteasomes to alleviate misfolded proteins. Other possible deleterious effect might be associated with a change in MHC-I antigen presentation. MHC-I participates in neuronal plasticity, and neuronal induction of MHC-I has been shown to happen only in electrically silent neurons, thus suggesting a possible implication in immunosurveillance on functionally impaired neurons. To study these implicative functions of immunoproteasomes in SCA1, it is essential to establish neuronal cellular systems in which we could control the expression of ataxin1 constructs and immunoproteasomal proteins in an inducible manner. Using the established cellular systems, we will be able to clarify how ataxin1 mutant expression affects the induction of immunoproteasomes. Inversely, we will be able to clarify how immunoproteasomal induction or suppressed expression at different stages of ataxin1 expression could affect ataxin1 aggregate formation and cellular toxicity.



Dr. Do-Hyung Kim



Research Seed Money Grant

Molecular Pathogenesis Studies of Spinocerebellar Ataxia Type 1

By Janghoo Lim, PhD

Yale University, New Haven, CT



Dr. Janghoo Lim

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, and cerebellar Purkinje cell (PC) 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 glutamine expansion in the Ataxin-1 (ATXN1) protein. Building on our studies of SCA1 and ATXN1, we have recently found that the level of Wnt- β -catenin signaling activation is significantly upregulated within both the PCs and non-PCs of a SCA1 mouse model that expresses the mutant ATXN1 only in PCs. This suggests that the mutant protein is able to activate Wnt- β -catenin signaling in neighboring cells, and that this activation may be relevant to the pathogenesis of SCA1. In this proposal, we will test the hypothesis that Wnt signaling activation in non-PCs can cause or contribute to PC dysfunction or degeneration in SCA1. To test this idea, will perform a combination of molecular and cell biological studies, as well as genetic studies in mice. We believe that this study will lead us to better understand the pathogenic mechanisms of SCA1 and several other inherited ataxias, which we hope will open the possibility of future therapies. ❖



SEEKING PATIENTS WITH SCA (ANY TYPE)

FOR A CLINICAL TRIAL USING TRANSCRANIAL MAGNETIC STIMULATION TO IMPROVE GAIT, POSTURE, AND MOBILITY

at the Berenson-Allen Center for Non-invasive Brain Stimulation at

Beth Israel Deaconess Medical Center, Boston MA

You will be asked to come in for daily treatments (M-F) for 4 weeks, 30 minutes a session.

You will be compensated for your time.

If you are interested or would like more information, please contact

Seth Wakefield at 617-667-0209 or email swakefie@bidmc.harvard.edu



Research Seed Money Grant

Functions of Senataxin, Product of the AOA2 Target Gene SETX, in Autophagy and Lysosome Function

By **James L. Manley, PhD**
Columbia University, New York, NY

Ataxias constitute a family of neurological disorders that prevent affected patients from coordinating their movements. Ataxia with Oculomotor Apraxia 2 (AOA2) is a form of ataxia that has an early onset, occurring between age three and 30 years. The rate of progression and severity are variable with some patients needing wheelchairs in their second decade and others still capable of some walking into their fourth decade. AOA2 is an inherited disease caused by mutations in the senataxin (SETX) gene. Despite recent studies implicating SETX as a protector of the genome, its function in the brain remains largely unknown. In order to bring more insights into SETX function, we are particularly interested in understanding how disease-associated mutations can lead to AOA2. By using powerful cellular, molecular and biochemical approaches, we have obtained preliminary data implicating SETX in an unanticipated cellular pathway called autophagy. Autophagy is involved in clearing unnecessary or defective cellular components, and is known to be altered in a wide range of neurological disorders. We will investigate how SETX functions in this pathway in normal cells and how this function is disturbed by AOA2 mutations. A better understanding of the functions of SETX will lead to increased understanding of ataxia and ultimately to novel therapeutic approaches to stop or retard the disease. ❖

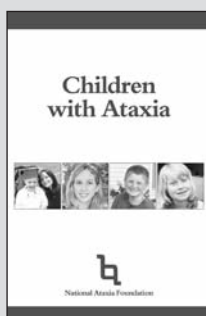


Dr. James L. Manley

NAF to Update “Children with Ataxia” Booklet

We are seeking stories of the courage and the challenges that a child living with ataxia faces for a second edition of the booklet “Children with Ataxia.” The first edition shared the stories of five children as well as stories in memory of three children who had lost their struggle with ataxia.

To submit a story for possible inclusion in the booklet, please send the



article to susan@ataxia.org. Stories should be no longer than 600 words and may be edited for the publication. Stories can be written by a parent, grandparent, teacher or anyone who knows and cares for a child, under 18 years old, with ataxia.

A PDF version of the current booklet is available at www.ataxia.org/pdf/Children_with_Ataxia.pdf.

Research Seed Money Grant

Generation and Characterization of Spinocerebellar Ataxia 36 Patient Stem Cell-derived Neurons to Study Disease Mechanisms and Develop Novel Therapeutic Strategies

By Wilfried Rossoll, PhD

Emory University School of Medicine, Atlanta, GA

Spinocerebellar ataxia 36 (SCA 36) is an inherited progressive neurodegenerative disorder, which has been diagnosed so far mainly in Japan and Spain. Affected patients develop gait ataxia, eye movement abnormalities, hearing loss, and specific motor symptoms similar to amyotrophic lateral sclerosis (ALS) or Lou Gehrig's disease.



Dr. Wilfried Rossoll

SCA 36 is caused by a large repeat expansions in a specific genetic region, leading to abnormal RNA and proteins that affect nerve cells, primarily in the cerebellum and the spinal cord. This disease is inherited in an autosomal dominant fashion, meaning that each child of an affected parent has a 50% chance to inherit the ataxia gene.

As a first step in an effort to find the cause, treatment, and cure for this ataxia, we will generate “induced pluripotent stem cells” (iPSCs) from patient skin cells. These stem cells will then be differentiated into nerve cells similar to the cells known to function poorly and ultimately degenerate in SCA36 patients.

This new “disease in a dish” cell culture disease model will allow us and other ataxia researchers to 1) answer important questions about the disease mechanism, and 2) enable us to test the efficacy of potential therapies for SC36 and potentially other ataxias caused by genomic repeats. ♦

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 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 or call (605) 312-6413. Thank you for participating in this important research tool.

Research Seed Money Grant

The Nature and Impact of Sleep Dysfunction in Cerebellar Ataxias

By Jeremy D. Schmahmann, MD

Massachusetts General Hospital, Boston, MA

Cerebellar ataxias comprise a large group of disorders caused by damage to the cerebellum, a region of the brain known to play an important role in motor control. These disorders typically manifest with gait and balance difficulties, slurred speech, and impaired control of hand dexterity and eye movements. People with cerebellar ataxia may also experience cognitive deficits such as poor memory, multitasking, difficulties in learning, attentional problems, and depression. In addition, ataxia patients often report poor sleep and fatigue. This can be troublesome, because healthy sleep enhances learning, memory, emotional processing and positive mood, whereas poor sleep diminishes quality of life. Sleep research is an important avenue to explore because if sleep disturbances are indeed regularly seen in patients with ataxia, then measures can be taken to improve sleep and consequently, other aspects of daily life.

The goal of the proposed research study is to understand the nature of sleep disturbances associated with cerebellar ataxias. Specifically, we will look at several aspects of sleep quality and determine the prevalence of sleep disorders, such as those characterized by breathing difficulties or excessive movements during sleep. These sleep disturbances reduce the efficiency of sleep, resulting in the individual feeling fatigued, exhausted and making it hard to carry out daily activities. We aim to define the pattern of sleep disorders that occur in patients with cerebellar ataxia, and investigate whether these sleep disturbances influence cognition and mood, particularly depression. This is the first study to systematically assess the quality of sleep in cerebellar ataxias, and we expect that this will contribute to the development of treatments to improve health and enhance quality of life of patients and families dealing with ataxia. ❖



Dr. Jeremy Schmahmann

E-mail Blasts

E-mail blasts from the National Ataxia Foundation are sent out periodically covering ataxia research, events and other timely issues of interest to those with ataxia, their families and caregivers, as well as doctors and those doing ataxia research.

Please send your e-mail address to joan@ataxia.org so you don't miss out on important information.

Share Your Story

Generations is published quarterly by the National Ataxia Foundation and reports on topics related to ataxia.

Personal stories from our members are an important part of the publication. Stories submitted should be no longer than 1,200 words. Please include a picture. Submit stories to joan@ataxia.org to be considered for publication.

Research Seed Money Grant

Determinants of Neuron-specific Pathogenesis: Study in a *C. Elegans* Model of SCA3

By **Andreia Teixeira-Castro, PhD**

University of Minho, Braga, Portugal



Dr. Andreia Teixeira-Castro

Spinocerebellar ataxia type 3 (SCA3), also known as Machado-Joseph disease (MJD), is caused by mutations in the protein ataxin-3 that make this protein prone to aggregate and toxic to specific groups of neurons. This leads to the progressive neurodegeneration and to the typical symptoms of SCA3: ataxia and severe limitations in eye movements and swallowing among others. Currently there is no effective treatment for this disorder. In this project, we are interested in understanding why mutant ataxin-3 protein, despite being present nearly in all regions of the human body including the brain, seems to affect and cause death of specific cells of the brains (neurons) and not to all. For this, we will use a model of the disease in the worm *C. elegans*, which in spite of being a very simple animal, possesses a very well characterized nervous system of 302 neurons, is quite well characterized at the genetic and molecular level, is transparent – allowing monitorization of events within the neurons in the live animal, and, unlike mouse models, is amenable to large scale studies. This model, which has been generated in our lab, expresses the mutant human protein in its nervous system and replicates important features of the disease, such as the aggregation of ataxin-3 and a neurological impairment of the animals (including abnormal movement). We will use it to analyze each one of the 302 neurons and to determine which neuron-subtypes are affected by the expression mutant human ataxin-3 (by identifying neurons containing ataxin-3 aggregates/inclusions). Next, we will isolate those neurons and also others resistant to the presence of mutant ataxin-3 and we will analyze all the molecules (RNA profiling) that are present in affected versus resistant neurons in the SCA3 worm. From this work, we hope to identify new players, which will help us to better understand the intriguing pattern of neurodegeneration and we believe that those molecules may constitute new cellular targets for the development of new therapies for SCA3. ❖

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iSearchiGive.com is a search engine powered by Yahoo! Search and *iGive.com* and is the Internet's first online shopping mall where a portion of each purchase is donated to a charity of your choice.

Sign up today and indicate that the National Ataxia Foundation is your favorite cause.

Vehicle Donation

The donation of your vehicle to the National Ataxia Foundation will help support the important work being done on behalf of all who are affected by ataxia. To donate your car, truck, boat or motor home, visit www.donateacar.com or call 1-800-240-0160. Your vehicle will be picked up at your home, office or other place that you designate.

Research Seed Money Grant

Molecular Mechanism of Autosomal Dominant Sensory Ataxia

By Richard Wojcikiewicz, PhD

The Research Foundation for SUNY, Syracuse, NY

Autosomal Dominant Sensory Ataxia (ADSA) is a novel neurodegenerative disease caused by a point mutation in a protein called RNF170. Afflicted individuals exhibit an ataxic gait and loss of sensory perception, particularly in the extremities, and this appears to result from degeneration of neurons in the posterior columns of the spinal cord. However, the molecular mechanism by which the mutation to RNF170 causes the disease is completely unknown. In the proposal, I plan to apply my laboratory's expertise in biochemistry and cell biology to the molecular mechanism of ADSA, focusing on how the mutation affects the biochemical and cell biological properties of RNF170. This should reveal how the mutation disrupts cells, should help us understand the reason why neurodegeneration occurs, and may point towards therapeutic strategies for ADSA and perhaps other ataxias.



❖ **Dr. Richard Wojcikiewicz**

Young Investigator Award for SCA Research

Role of Microglia in SCA1 Pathogenesis

By Marija Cvetanovic, PhD

*Institute for Translational Neuroscience, University of Minnesota, Minneapolis, MN
(in partnership with the Bob Allison Ataxia Research Center)*

Microglia are the brain cells charged with responding and repairing injury. However, reports of their role in neurodegenerative diseases have been conflicting – in some cases they ameliorate while in others they promote pathology. One possible explanation is that microglia play different roles depending on the stage of disease: early in disease they may be beneficial, while later they become detrimental. Indeed our preliminary data using mouse models suggest that this may be the case in SCA1.

We will use pharmacological approach and new drug PLX3397 to remove microglia from the brain without any adverse effects. We will examine how removing microglia early and late in disease affects SCA1 pathogenesis. Importantly these experiments will identify therapeutic window for PLX3397 treatment.



❖ **Dr. Marija Cvetanovic**

Young Investigator Award for SCA Research

Defining Pathways that Regulate Levels of Polyglutamine Protein in MJD/SCA3

By **Maria do Carmo Pereira da Costa, PhD**

University of Michigan, Ann Arbor, MI

While many advances have been made toward understanding polyglutamine (polyQ) diseases, no preventive treatment is yet available for this group of fatal neurodegenerative disorders which include Machado-Joseph disease (MJD), also known as Spinocerebellar Ataxia type 3 (SCA3). In MJD and other polyQ diseases the toxic mutant protein accumulates. Thus, a simple therapeutic strategy is to reduce levels of the mutant gene or encoded protein.



**Dr. Maria do Carmo
Pereira da Costa**

The goal of this proposal is to identify molecular pathways that modulate levels of expanded-polyQ ATXN3, the toxic protein causing MJD. I seek to understand ATXN3 biology, in particular its cellular stability and clearance, with the long-term objective of manipulating specific cellular pathways to reduce levels of toxic ATXN3 as potential therapy for MJD. I have recently screened the full human genome (18,110 genes) for genes modulating mutant ATXN3 abundance in cells. Building on this genome-wide data and using bioinformatics I propose to select a group of candidate genes for further validation in an independent cell model of MJD. I will then use pharmacological and/or genetic approaches to further validate novel molecular pathways that regulate mutant ATXN3 abundance in the

brain using mice that are modified to express the full human mutant gene. The proposed studies will advance knowledge about how cells handle this important ataxia disease protein and identify novel cellular targets for potential therapy of MJD patients. ♦

Young Investigator Award for SCA Research

Structural Insights for Drug Discovery Targeting SK2/3 Channels for SCA

By **Miao Zhang, PhD**

Chapman University School of Pharmacy, Irvine, CA

SK channels play important roles in physiological and pathophysiological conditions. These channels have been linked with the symptom of spinocerebellar ataxia. A tremendous amount of effort has been devoted to developing drugs targeting SK channels. In 2012, we discovered the binding pocket of the non-selective modulators in SK channels. However, the subtype nonselective ►►

modulators can potentiate all of the four SK channel subtypes, which might cause side effects. This year, we identified the binding pocket for the subtype selective modulators of SK2/SK3 channels. With this discovery, the computer based drug discovery targeting SK2/SK3 channels has become possible, which will inevitably facilitate drug discovery targeting SK2/SK3 channels. Motivated by the binding pocket we identified, we are now aiming at the discovery of the new generation of compounds targeting SK2/SK3 channels selectively. We will combine computer based approaches and experimental techniques to work towards this goal.

Our study will lead to new subtype selective compounds for modulation of SK2/SK3 channels. These new compounds themselves can serve as the candidates in preclinical and clinical researches for new therapeutic approaches towards spinocerebellar ataxia. These compounds can also serve as pharmacological tools for studying of SK channels in Purkinje cells during ataxia development. ❖



Dr. Miao Zhang

Pioneer SCA Translational Research Award

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

By Beverly Davidson, PhD

*Children's Hospital of Philadelphia Research Institute, Philadelphia, PA
(in partnership with the Bob Allison Ataxia Research Center)*

There are currently no therapies that delay onset or progression of spinocerebellar ataxia. In earlier work, we showed that gene silencing approaches had a profound positive impact on disease readouts in two animals models of spinocerebellar ataxia type 1 (SCA1). We have also completed initial pilot studies in monkeys to determine if the delivery paradigm we use for mice can be translated into a primate brain. Importantly, our delivery approach is scalable from mice to primates, and in these initial monkey studies we found efficient gene silencing of the target ataxin-1 gene in critical brain areas affected by disease. Additionally, we have rebuilt the silencing construct for human use. In this study, we will perform dosing studies in SCA1 mice to determine the lowest effective dose. We will also test if delivery to SCA1 mice later during the disease course can reverse some or all of the clinical readouts. Finally, we will perform studies in nonhuman primates using doses that bracket our proposed effective dose for humans. These studies are an important step to moving this work towards a SCA1 therapy for patients. ❖



Dr. Beverly Davidson

Pioneer SCA Translational Research Award

Identification of Druggable Targets that Modulate the Levels of SCA-causing Proteins in Vivo

By **Ismael Al-Ramahi, PhD**

Baylor College of Medicine, Houston TX

The ultimate goal of this proposal is to identify druggable gene networks whose modulation leads to reduced steady-state levels of SCA (SCA1, SCA2 and SCA7) causing proteins. Six SCAs are caused by expansion of polyglutamine tracts leading to aberrant conformation and oligomerization, impaired degradation and increased accumulation of the corresponding proteins.



Dr. Ismael Al-Ramahi

With time, the polyQ-expanded proteins can trigger a variety of neuronal insults including transcriptional alterations, abnormal Ca²⁺ homeostasis, impaired vesicle transport, etc. Besides targeting anyone of these downstream path-

ogenic mechanisms, an attractive alternative for developing SCA therapeutic approaches is to reduce the levels of the disease causing protein.

Studies in animal models of SCA1 and Huntington's have shown that decreasing the levels of the mutant proteins by genetic manipulation can ameliorate disease phenotypes, sometimes even after symptoms have already manifested (1-5 for examples). Based on this potential to not only delay but also reverse neurodegeneration, we set out to identify "druggable" targets that modulate

the levels of polyQ-expanded ATXN1, the SCA1-causing protein. As a proof of principle, we screened the "kinome" using a complementary forward genetic screen that targeted the levels of human ATXN1[82Q] in a *Drosophila* model and in a human cell model for SCA1. This approach revealed that knocking down multiple components of the RAS-MAPK- MSK1 pathway reduces ATXN1 levels in *Drosophila* and human cells. We then validated these results using SCA1 mouse models, and we also showed that pharmacological inhibition of this pathway reduces ATXN1 levels (Park, J and Al-Ramahi, I et.al. 6).

Given these encouraging results, now we intend to expand this approach to additional "druggable" candidates. Using inducible shRNAs we will screen the homologs of 3048 human "druggable" genes belonging to the groups of non-olfactory GPCRs, ion channels, membrane transporters, protein quality control and recycling (ubiquitination, proteasome and autophagy) and "druggable" transcription factors, for their ability to suppress ATXN1[82Q]-induced neurodegeneration in *Drosophila*.

Next, we will ascertain which suppressor genes exert their effect via modulating ATXN1[82Q] levels. First, using siRNAs targeting the human homologs of the *Drosophila* hits, we will perform a FACS based-screen to identify modulators of ATXN1[82Q] levels in human cells. FACS hits will then be validated for their ability to modulate endogenous ATXN1 in human cells as well as ATXN1[82Q] in *Drosophila*. Mechanisms ►►

regulating protein levels, often show broad applicability across neurodegenerative diseases; e.g. mTOR inhibition (rev. 11) or CHIP activation (rev. 10). In addition, experimental evidence indicates that SCA-causing proteins may be functionally or pathologically linked among each other⁷⁻⁹. Hence, the modifiers obtained in the proposed ATXN1 screen should have a high

potential to suppress other SCAs. To capitalize on this, I will test the FACS hits from the ATXN1 screen for their ability to suppress the toxicity and decrease protein levels of expanded ATXN2 and ATXN7 in *Drosophila* and cells respectively. The result of this project will be a number of druggable targets with very high translational value for the treatment of SCAs. ❖

Pioneer SCA Translational Research Award

ASO Targeting of Bidirectional Transcripts and RAN Translation in SCA8

By **Laura Ranum, PhD**

University of Florida, Gainesville, FL

The spinocerebellar ataxias are often caused by repeat expansion mutations in which repetitive stretches of three or more letters of the genetic code are repeated extra times. The genetic mutation is found in families with a dominant history of disease but also frequently appears in individuals with no family history as a “sporadic” form of ataxia. Through our work on SCA8, we have discovered that expansion mutations can be expressed in both directions and that the resulting CUG and CAG expansion RNAs can direct the production of an unexpected category of mutant proteins without the normal regulatory signals. Our goal is to understand how these mutant RNAs and proteins contribute to disease and to develop therapeutic strategies to block their effects.



Dr. Laura Ranum

Study Participants Needed in Pittsburgh

A research team affiliated with Carnegie Mellon University and the University of Pittsburgh is looking for participants for a study investigating the role of the cerebellum in auditory and speech learning. The study will take one to two hours, and will primarily involve computer-based tasks involving auditory and visual stimulus materials. Participants must be located within 180

miles of Pittsburgh, 18 years or older, and able to hear words spoken at a typical conversational level.

Interested participants should call Corrine Durisko, Study Coordinator, at (412) 624-7475 or cgaglia@pitt.edu. The testing location is flexible and will be determined based on the preference of each study participant.

Pioneer SCA Translational Research Award

Targeting the Intracellular Localization of Ataxin-3 as Novel Treatment Strategy for Spinocerebellar Ataxia Type 3 (SCA3)

By **Thorsten Schmidt, PhD**

University of Tübingen, Tübingen, Germany

Spinocerebellar ataxia type 3 (SCA3), which is also known as Machado-Joseph disease (MJD) is caused by the expansion of a tandem repeat of the three DNA elements C, A, and G within the so called ataxin-3 gene. The ataxin-3 gene serves



Dr. Thorsten Schmidt

as blueprint of the ataxin-3 protein. In SCA3 patients, protein molecules aggregate in characteristic subpopulations of the 100 billion cells of the human brain. These protein aggregates are typically found within the cellular nucleus although ataxin-3 usually resides in the cytoplasm. This means that in SCA3 “something” impacts the localization of ataxin-3, moves it from the cytoplasm to the nucleus and lets it aggregate there. In the recent years, we extensively studied this move of ataxin-3 within the cell. Importantly, we observed that specific mouse models

develop symptoms of SCA3 only, if ataxin-3 indeed moves to the nucleus. In other words: Keeping ataxin-3 in the cytoplasm protected our mice from the disease! We, therefore, anticipated this transport process as a novel treatment target or treatment strategy for SCA3. But which drug is able to keep ataxin-3 in the cytoplasm? The development of a novel drug may take years or even decades as extensive studies on its function and safety are required until it will be approved by the FDA (Food and Drug Administration) for use in humans. We, therefore, asked ourselves whether drugs which are already FDA approved and on the market (but for a different indication) may impact the localization of ataxin-3. In order to identify such drugs, we generated an assay which allows us to evaluate whether a certain compound or drug is able to withhold ataxin-3 in the cytoplasm. We recently used this assay to test a collection of FDA-approved drugs and indeed identified two drugs which not only keep ataxin-3 in the cytoplasm but also even prevent its aggregation. The identified drugs are (for their respective indication) already on the market for decades and used by millions of patients. In order to find out whether these drugs could also be used for the treatment of SCA3, we aim to confirm within this project whether any of the two drugs is effective in mammals i.e. in our mouse model of SCA3. A positive confirmation would not mean that this drug could immediately be given to human SCA3 patients but would be a critical next step towards the development of a treatment for SCA3.

Deadline

The deadline to submit materials for the summer issue of *Generations* is May 15 and August 7 for the fall issue. Please submit content by e-mail to joan@ataxia.org.



Young Investigator Award

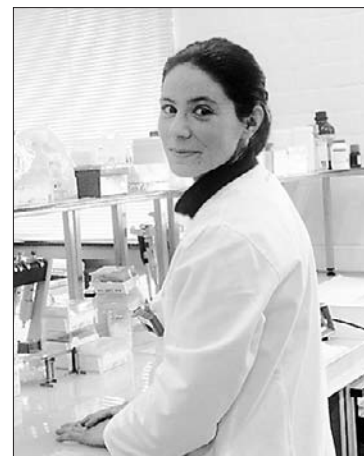
The Role of mTOR in Friedreich's Ataxia and Identification of New Pathways for Therapeutic Intervention

By **Simona Donatello, PhD**

Université Libre de Bruxelles, Brussels, Belgium

Friedreich's ataxia (FRDA) is the most predominant and incurable inherited form of ataxia, caused by deficiency of Frataxin (Fxn), a mitochondrial protein involved in important metabolic pathways, including the respiratory chain. To date several evidences have shown a possible involvement in the pathogenesis of FRDA, of the mechanistic Target Of Rapamycin (mTOR), a protein that regulates essential cellular functions such as cell growth, cell proliferation, cell survival, cell motility, protein synthesis and translation. Up to now, a systematic study of this pathway in FRDA is still missing and the mechanisms connecting Fxn to mTOR are still unclear and debated in literature. Moreover, it appears that the role of mTOR in FRDA may be very different in different cellular contexts (astrocytes and neurons). Therefore we believe that a better understanding of the role played by mTOR in Fxn function will contribute to find novel targets for therapeutic intervention in FRDA.

We seek to do so by using an *in vitro* cell model based on glial and neuronal cells obtained from differentiation of pluripotent stem cells generated from fibroblasts of controls and FRDA patients. In particular, by modulating the expression of Fxn and mTOR, we would like also to study how they interconnect and affect each other and how the cellular context is important in modulating the disease. Furthermore, to investigate new possible therapeutic approaches we will study the effect of rapamycin, a commonly used drug that inhibits mTOR, in the modulation of Fxn expression and cellular oxidation in affected cells. Altogether, we think that these novel investigations will contribute to shed new light on the still unclear mechanisms that regulate Fxn physiology by possibly identifying new targets, such as those in the mTOR pathway, for FRDA treatment and cure.



Dr. Simona Donatello

Weill Cornell Medical College Study

A new 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 Denesy Mancenido at (646) 962-4537 or dem2026@med.cornell.edu.

Post-Doc Fellowship Award

Neural Mechanisms of Cerebellar Function in Ataxia

By **Marife Arancillo, PhD**

Baylor College of Medicine, Houston, TX



Dr. Marife Arancillo

Ataxia is a debilitating brain disease that obstructs movement – the most fundamental human behavior. It deprives affected individuals of their coordination and mobility, and as a consequence performing even the most basic and essential daily tasks, such as walking and eating, becomes near impossible. Defects in the cerebellum are the most common causes of ataxia. The cerebellum is a

primary brain center for controlling movement. Each and every motion is critically dependent on the activity of the cerebellum. Intriguingly, ataxia arises when there is either too much or too little activity in the cerebellum. But how these two seemingly opposite states can cause the same disease is a mystery. This problem has remained unsolved because the actual neural signals that trigger ataxia have not been identified. My goal in this proposal is to define the defective signals that are initiated in the cerebellum of ataxic mice and to determine how these signals travel through the circuit to obstruct movement. To achieve this goal, I developed a genetic toolkit that enables me to selectively block certain signals in the mouse cerebellum. In doing so, I am able to flood the system with too many signals or eliminate signals; both conditions cause ataxia. A major advantage of my strategy is that after interfering with cerebellar signal communication, I am able to use our

brain recording methods to track how the remaining signals disrupt ongoing movement. The ability to track the signals “on-line” as the mice are making ataxic movements is a significant technical advance. This is because the cell death that is usually observed in the existing models of ataxia has occluded the possibility of pinpointing exactly how brain processing occurs in ataxia. This is not a problem in my model, as I have not found any indication of cell loss. The experiments that I am proposing will deepen our knowledge of brain function in ataxia and provide new opportunities for developing effective therapies to treat the disease. ❖

CFC Number

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

Matching Gifts

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

Post-Doc Fellowship Award

Defining the Role of Mitochondrial DNA Mutations in the Neuronal Degeneration of Friedreich's Ataxia

By **Angela Bhalla, PhD**

University of Alabama, Birmingham, AL

Friedreich's ataxia (FA), the most common inherited neurodegenerative ataxia, affects 1–2 in 50,000 individuals. Affected individuals possess an expanded repeat of GAA, three specific nucleotides, or DNA building blocks, within the frataxin gene (6–34 GAA repeats in unaffected individuals, 66–2,000 GAA repeats in FA). While the GAA repeat expansion changes the DNA sequence of the frataxin gene, it does not mutate the frataxin protein, but instead hinders the production of the frataxin protein, ultimately leading to insufficient levels of frataxin protein. The frataxin protein resides in the mitochondria, the energy producers of the cell, which interestingly also contain their own DNA, or genetic material. Low levels of frataxin cause impaired mitochondrial function and increased levels of DNA-damaging molecules called reactive oxygen species (ROS). Increased ROS can damage mitochondrial DNA, creating mutations that could impede mitochondrial function and cause the degeneration of neuronal (brain) cells observed in FA affected individuals. This study aims to determine the relationship between mitochondrial DNA damage, mitochondrial function, and neurodegeneration in FA. We will measure i) the number of mitochondrial DNA mutations, and ii) mitochondrial function, in affected individuals' cells and tissues as well as in neuronal cells derived from affected individuals' skin cells (induced pluripotent stem cell-derived neuronal cells). The results of this study will provide insights into the contribution of mitochondrial DNA damage and mitochondrial function to the neurodegeneration of FA. ❖



Dr. Angela Bhalla

IAAD Apparel

International Ataxia Awareness Day (IAAD), September 25, is just around the corner. Create ataxia awareness by wearing an "I am the Strength behind ataxia" T-shirt or other ataxia awareness apparel. You can order ataxia awareness apparel online by visiting NAF's web site, www.ataxia.org, and clicking on "Store" or by using the order form on page 45 of this issue.

GoodSearch

Did you know that donating money to the National Ataxia Foundation is as easy as changing your Internet search engine?

GoodSearch.com donates 50 percent of its revenue to the charities designated by its users. Simply go to the site and follow the easy steps to make the NAF your charity of choice. Then use GoodSearch as you would any other search engine. Thank you.

Post-Doc Fellowship Award

Developing the Novel microRNA-mediated Therapeutic Approach for Spinocerebellar Ataxia Type 6

By Yu Miyazaki, MD, PhD

University of Chicago, Chicago, IL

Spinocerebellar ataxia type 6 (SCA6) is one of the most common forms of autosomal dominant SCA, representing 10-20% of patients with dominantly-inherited ataxia and approximately 5/100,000. Patients with SCA6 develop slowly progressive cerebellar ataxia usually beginning age 40-50 years associated with extensive selective degeneration Purkinje cells, neurons in the cerebellum.



Dr. Yu Miyazaki

SCA6 is a member of trinucleotide repeat disorders. Trinucleotide repeat disorders, also known as trinucleotide repeat expansion disorders, are a set of genetic disorders caused by trinucleotide repeat expansion, a kind of mutation

in which DNA trinucleotide repeats in certain disease genes exceed the normal, stable threshold, which differs for each gene. SCA6 is associated with triplet nucleotide of CAG repeat expansions in the gene, *CACNA1A*. The expanded CAG repeats are translated into a tract of uninterrupted glutamine residues forming what is known as a polyglutamine tract "polyQ." No preventive treatment exists for the numerous polyQ diseases including SCA1, 2, 6,

Huntington disease, spinal and bulbar muscular atrophy. Although *CACNA1A* is known to encode the $\alpha 1A$ subunit of the neuronal Ca^{2+} channel, numerous efforts have failed to implicate expanded polyQ tracts and altered Ca^{2+} channel function in SCA6. However, we recently discovered that the disease is attributable to expression of a polyQ repeat expansion within a second *CACNA1A* gene product, $\alpha 1ACT$, that normally serves as a transcription factor critical for cerebellar cortical development. Generally, each protein is translated from an mRNA that is transcribed from its gene, however, *CACNA1A* gene encodes two proteins of in case of a Ca^{2+} channel and a transcription factor. Although previous investigators mainly focused on the former, a Ca^{2+} channel in the pathogenesis of SCA6, we showed that the latter of a transcription factor, $\alpha 1ACT$ bearing the polyQ expansion is pathogenic in SCA6.

MicroRNAs (miRNAs) are a diverse class of highly conserved small RNA molecules that function as crucial regulators of gene expression in animals and plants. Recent functional studies have shown the potent activity of specific miRNAs as disease modifiers in human. Thus, potential therapeutic approaches that target the miRNA processing pathway have recently attracted attention. Over the last several years, an important role of miRNAs in the pathogenesis of SCA, Parkinson disease, Alzheimer disease, and other neurodegenerative disorders has been reported. Our proposal will address two ►►

hypotheses that are fundamental to the understanding of the miRNAs involved in the pathogenesis of SCA6 and the development of the miRNA mediated therapeutic approach for SCA6, 1) that miRNAs regulate the second *CACNA1A* gene product, $\alpha 1$ ACT; 2) that the delivery of a disease specific miRNA for SCA6

will be therapeutic. Thus, this study will provide insights from the pathways of miRNAs that play an important role in the $\alpha 1$ ACT metabolism. These insights will help the development of future novel therapies directed at the core part in pathogenesis of SCA6. ❖

Post-Doc Fellowship Award

Longitudinal Study of Neuropathology of Spinocerebellar Ataxia Type 7

By Carlos Roberto Hernandez-Castillo, PhD

Universidad Nacional Autonoma de Mexico, Coyoacan, Mexico

Spinocerebellar ataxia type 7 (SCA7) is considered one of the rarest autosomal dominant cerebellar ataxias. Early postmortem studies have shown degeneration mainly in olivopontocerebellar regions. Recent imaging studies carried out in our lab have expanded the knowledge of the pathological changes resulting from the SCA7 degenerative process, including white matter reduction, grey matter atrophy and functional connectivity abnormalities. However, all those reports have been performed in cross-sectional studies.

To investigate the advance of the degenerative process over time, we propose to carry out a longitudinal study in a relatively large cohort of SCA7 patients during two years. To this end, twenty-six genetically confirmed patients have accepted to participate in this study. Magnetic resonance imaging will be used to acquire multimodal images including: high resolution anatomical, diffusion tensor and resting state functional. The scale for the assessment and rating of ataxia (SARA) will be used to evaluate the patient's motor impairment. Cognitive deficits will be evaluated by means of different standardized tests specifically selected taking into account the visual impairment produced by the SCA7 mutation.

The patients' group includes participants with different disease durations (from 2 to 20 years), as well as CAG expansions (41 to 71). This variability will allow an in-depth analysis of the advance of the degenerative process at different stages of the disease. At the same time, it would allow a longitudinal exploration of the relationships between the different variables, including CAG expansion, SARA score and the cognitive results. Moreover, some studies have suggested that functional connectivity abnormalities precede anatomical degeneration. The proposed analysis might help understand what are the most early observable changes that may be useful as biomarkers to be used along specific therapies or treatments in the early stages of the disease. ❖



**Dr. Carlos Roberto
Hernandez-Castillo**

Post-Doc Fellowship Award

Antisense Oligonucleotide (ASO) Treatment for Spinocerebellar Ataxia 3 (SCA3)

By **Gautam Rajpal, PhD**

University of Michigan, Ann Arbor, MI



Dr. Gautam Rajpal

Spinocerebellar Ataxia 3 (SCA3) is a common and ultimately fatal form of ataxia with no known disease-slowng treatment. The production of the mutant disease protein is known to cause the disease, and our goal is to target the disease protein and prevent it from causing SCA3. We will do this by using an antisense molecule that reduces expression of the disease protein in brain cells that are crucial in the development of the disease. ❖

Post-Doc Fellowship Award

Understanding Disease Development in Friedreich's Ataxia in a Time-resolved Way: a New Cellular Model

By **Tommaso Vannocci, PhD**

King's College, London, England



Dr. Tommaso Vannocci

Friedreich's ataxia (FRDA) is a relentless neurodegenerative disease which affects approximately one individual in 50,000 with a carrier in 120 people. The genetic cause of FRDA was finally found in 1996. It is caused by reduce levels of a specific protein, called frataxin. Although we now know that frataxin is an essential component of the human body, its specific role is still unclear. An important limitation encountered in most of the studies published so far is that, as in many other diseases, it is difficult to distinguish the primary causes of the disease and therefore of the partial absence of frataxin from consequences. A way to clarify this point is to be able to switch off/on at once the frataxin production or modulating it in a cellular model which would allow us to closely follow the temporal progression of the effects. This is now possible thanks to genetic tools

developed only relatively recently in gene therapy. The applicant has already partially set up this system in the group of Prof. Pastore. Our preliminary data appear very promising and interesting but, in order to complete the initial phase of this project, we need to find financial support to pay the applicant's salary for five additional months. Further support will be sought from other sources after. ❖

Research Grant Award

Web-based National Ataxia Database

By **Susan Perlman, MD**

University of California – Los Angeles

Five prior National Ataxia Foundation grants were used to develop and maintain the web-based National Ataxia Database. It is currently housed on the UCLA computer servers, and over the years since its development, has provided natural history database support to the UCLA Ataxia Clinic, as well as to the Ataxia Clinic at Johns Hopkins University. Other “ataxologists” in California, Arizona, Nevada, and Colorado have expressed interest in using it as well. It has begun to provide a platform to support and join specialists in clinical care and clinical research of ataxia. It will ultimately assist all members of the Ataxia Clinical Research Consortium in future collaborative endeavors in clinical research and in setting standards for clinical care.

The templates for the Rare Disease Network-supported CRC-SCA natural history study are now part of The National Ataxia Database. Following the end of funding of that project, with the help of the NAF “bridge” grant for the web-based National Ataxia Database, we were able to continue to import the existing coded data of the natural history study into the National Ataxia Database, to enable continued enrollment and follow-up of subjects in this important study of SCA 1, 2, 3, and 6. There are now 13 registered sites contributing to this project. Over 300 subjects have been enrolled and are pursuing serial examinations and banking of specimens.

The National Ataxia Database will also be open for ataxia researchers to “bank” other clinical data collected, either in the individual researcher’s private data docks (not accessible to other ataxia researchers) or in data docks shared by several researchers (e.g., a proposed project to look at coded clinical data on people with sporadic ataxia). ❖



Dr. Susan Perlman

Individuals with SCA 1, 2, 3, 6, 8 Needed

Adults with SCA1, SCA2, SCA3, SCA6, and SCA8 are needed to participate in a research study of cerebellar function. Testing will involve a 90-minute MRI of the brain, neurological testing, and cognitive (thinking and mood) testing.

The cerebellum is an integral part of the brain that controls balance, coordination, and eye movements among other vital functions.

However, many questions about its structure and function in cerebellar syndromes remain unanswered. Through our studies, we hope to

gain a better understanding of the normal functions of the cerebellum as well as its contribution to ataxia. Your participation in this research will help build our understanding of ataxia and cerebellar function. Thank you for the gift of your time.

Subjects will be paid \$25 for MRI scan and \$25 for cognitive testing.

Contact Ann Fishman (Research Coordinator) at (410) 502-5816 or ataxiaresearch@jhu.edu for more information.

Research Grant Award

Diagnosing the Cerebellar Cognitive Affective Syndrome (CCAS)

By **Jeremy D. Schmahmann, MD**

Massachusetts General Hospital, Harvard University, Boston, MA

The following is the final research summary of a grant funded by NAF for Fiscal Year 2013

Background: Cerebellar Ataxia results from damage to the cerebellum caused by genetic disorders, or acquired problems such as infections, stroke, and tumor. Cerebellar injury can also impair the way we think and respond emotionally, producing the Cerebellar Cognitive Affective Syndrome (CCAS; Schmahmann and Sherman, 1998).



Dr. Jeremy Schmahmann

The cognitive symptoms of the CCAS comprise difficulties with executive function, language, visual spatial skills, memory and attention. Executive function (also known as cognitive control and the supervisory

attentional system) is an umbrella term for the management (regulation, control) of cognitive processes, including working memory, reasoning, multitasking, and problem solving as well as planning and execution. Language impairments include problems with verbal fluency, grammar, syntax and reasoning as well as recognition of metaphors or figurative speech. Visual spatial deficits include difficulties recognizing and remembering complex shapes and figures or planning visual spatial concepts. In daily life, patients may struggle with reading street maps or parking the car in a narrow parking lot.

Strategies for verbal learning and memory retrieval are involved, and short term memory may be impaired. The affective symptoms of the CCAS include emotional dysregulation, behavioral changes and apathy. The dysmetria of thought theory (Schmahmann, 1991, 2010) states that the cerebellum regulates thoughts and emotions in the same way as it coordinates movement. Cerebellar ataxia, or dysmetria (the Greek term used to mean disordered control of timing, rhythm and appropriate movement), is matched in the realms of intellect and emotion by overshoot and undershoot of cognitive and affective skills, manifesting as the CCAS. This is a dramatic new understanding of the role of the cerebellum and it has implications not only for people with known cerebellar damage but also for other patient populations whose main problems are in the behavioral realm, and in whom a disordered cerebellum may be playing an important role.

The problem to be solved: A difficulty in diagnosing the CCAS is that its defining features – deficits in executive function, visual spatial processing, linguistic skills, and emotional dysregulation, are not adequately assessed in routine tests of cognition function such as the Mini Mental State Examination (MMSE) or the Montreal Cognitive Assessment (MoCA). It is therefore likely that the CCAS is missed in patients who have cerebellar lesions. Further, the CCAS was defined in patients with disease confined to the cerebellum, but many inherited cerebellar ataxias also involve other areas of ►►

the brain and it is not yet known how to distinguish what nonmotor features result from cerebellar injury versus damage to other brain regions.

The aims of the study: This study had two major major aims.

- To develop a diagnostic test battery that could be used to detect the CCAS in patients with cerebellar disease.

- To determine whether the impairments in patients with isolated cerebellar disease were the same or different than those in patients whose problems are not only in the cerebellum but also in the cerebral hemispheres.

Methods used: We evaluated groups of patients with conditions that affect the cerebellum only (patients with genetic disease and acquired disorders such as infection or stroke known to be confined to the cerebellum), and those that affect cerebellum as well as other brains areas (e.g., SCAs 1, 2 and 3). A total of 79 patients with cerebellar diseases were examined. We used a comprehensive array of tests of cognitive function able to evaluate the CCAS as well as other deficits not usually seen following cerebellar lesions.

Our results: As predicted, brief neuropsychological tests (MMSE and MoCA) designed to detect cognitive impairment in patients with cerebral cortical dysfunction such as Alzheimer's disease, were not significantly abnormal in cerebellar patients.

In contrast, more searching neuropsychological tests confirmed the existence and the nature of the CCAS.

All cerebellar patients had the syndrome to varying degrees.

This included significant difficulties in the previously identified domains of the CCAS, namely, executive function including working memory, multitasking, planning, abstract reasoning, and attention, language and visual-spatial function, verbal memory, social cognition and neuropsychiatric features.

There was no significant difference in the performance of patients who had isolated cerebellar diseases compared to patients with complex cerebrotocerebellar diseases. Cerebellar damage alone was sufficient to account for most of the cognitive findings.

Some aspects of cognitive performance were entirely or relatively spared in patients with cerebellar disease, consistent with the original notion that the CCAS is neither a confusional state, nor a global dementia. Notably, declarative memory was spared in patients with cerebellar disease. Declarative memory ("knowing what") is memory of facts and events, and refers to those memories that can be consciously recalled (or "declared"). It is sometimes called explicit memory, since it consists of information that is explicitly stored and retrieved. Cerebellar patients had difficulty with verbal learning that depends on successful strategies of encoding in order to be able to recall information later, and consequently they had trouble with long term retrieval of previously learned verbal information.

Conclusions of the study: The currently constructed brief tests of those aspects of mental function that are under the control of the cerebral hemispheres are not adequate for the detection of the CCAS.

When the appropriate tests of cognition and emotion are used, the CCAS can be identified in a wide range of inherited and acquired cerebellar disorders. These tests make it possible to determine which cognitive problems are related to the cerebellar injury, and which arise from damage to non-cerebellar areas.

The cerebellum is essential for many cognitive processes and emotional-relevant behaviors as defined in the CCAS. Cerebellar damage itself, regardless of the presence of additional cerebral hemisphere damage, is sufficient to degrade the cognitive and affective circuits that underlie the CCAS.

Diagnosing the CCAS
Continued from page 29

There is a subset of tests within our larger battery of studies that detect the CCAS. We are currently adapting these to develop a brief battery of cognitive tasks, the Cerebellar Cognitive Affective Syndrome Rating Scale – (CCAS-RS). This will be an essential tool going forwards for the evaluation of cognition and emotion in patients with cerebellar dysfunction.

The implications of these results for ataxia patients: The ability to diagnose the CCAS with a brief battery of tests (the CCAS-Rating Scale) will improve the diagnosis and management of the nonmotor manifestations of cerebellar disease. This will translate to improved care for patients with cerebellar dysfunction and allow clinicians to recognize these nonmotor disorders, grade them on a scale of severity, and institute treatments aimed at improving patients' quality of life. ♦

Pioneer SCA Translational Grant Award

Natural History of and Genetic Modifiers in Spinocerebellar Ataxias

By Tetsuo Ashizawa, MD

University of Florida, Gainesville, FL

The following is the final research summary of a grant funded by NAF for Fiscal Year 2013

The goal of this project was to establish an optimal infrastructure which allows for scientifically sound clinical trials of treatments for SCAs 1, 2, 3 and 6.



Dr. Tetsuo Ashizawa

To accomplish this goal the Clinical Research Consortium for Studies of Cerebellar Ataxias (CRC-SCA) has set three specific objectives in our proposal. The first objective (**Objective #1**) was to prospectively obtain natural history

data in a well-orchestrated longitudinal study at participating sites in the US. The second objective (**Objective #2**) was to identify genetic modifiers of the SCAs 1, 2, 3 and 6. The third

objective (**Objective #3**) was to collect DNA, body fluids, cells and tissues, and establish iPS cell (adult-tissue-derived stem cell) lines from patients with SCAs 1, 2, 3 and 6.

For **Objective #1** it was essential to establish a database where the clinical data obtained under the NIH grant NS68897 and new data obtained under this NAF Pioneer grant can be stored. The data collected under the NIH grant had been stored at the NIH Data Management Coordinating Center (DMCC) until the grant expired. The transfer of the data from the DMCC database to the CRC-SCA database at UCLA was completed under the NAF Pioneer grant, and we now can store additional data in this new database and retrieve the data for analyses. We had a face-to-face meeting of the CRC-SCA as a satellite meeting of the NAF Ataxia Investigator Meeting (AIM) in Las Vegas on March 17, 2014. The CRC-SCA members discussed the logistics of the natural history study and the use of the CRC-SCA database. ▶▶

The natural history database now includes clinical and genetic data of 66 patients with SCA1, 83 with SCA2, 148 with SCA3, 91 with SCA6 and 14 with genotype undetermined by DNA testing (a total of 402 subjects, up from 347 subjects at the beginning of the Pioneer grant funding). The number of subjects is still increasing although at a slow rate. With addition of a few new centers, the CRC-SCA continues to cover the entire US coast to coast (see map).



Based on our well-characterized patient populations, participants planned for two studies of brain magnetic resonance imaging of patients with SCAs; one is for advanced multi-modal MRI in SCAs (Dr. Gulin Oz, University of Minnesota) and the other is for functional MRI in patients with SCA6 (Dr. David Vaillancourt, University of Florida). The proposal for these projects were submitted to the NIH as grant applications for R01 (by Dr. Oz) and R21 (by Dr. Vaillancourt) funding. Although these applications did not receive fundable scores on the first round, they will be revised and resubmitted as A1 applications. Additionally, Dr. Christophe Lenglet, University of Minnesota, is about to submit a U01 NIH grant on brain connectivity and gene networks in SCAs for the November 5th deadline this year. These projects are important for **Objective #3** whose major goal is to develop clinically and pathogenically relevant biomarkers.

Investigators from Columbia University have planned new studies based on the natural history data in our new database housed at UCLA. Dr. Sheng-Han Kuo conducted analyses of the relationship between the use of Coenzyme Q10 and clinical severity in spinocerebellar ataxias. He

found that use of Coenzyme Q10 is associated with better clinical outcome in SCA1, 2, and 3. Dr. Kuo recently published the result (Lo et al. Coenzyme Q10 and Spinocerebellar Ataxias. Movement Disorders, in press). He has also completed the study of vascular burden in SCAs for which he is preparing a manuscript entitled “Vascular Burden and Clinical Progression in Spinocerebellar Ataxias”. Dr. S.H. Subramony of the University of Florida analyzed ocular movements of SCA patients. He found distinct eye movement abnormalities that are useful in identifying the genotype and understanding the disease process. He also recently published the result (Moscovich et al. Clinical Evaluation of Eye Movements in Spinocerebellar Ataxias: A Prospective Multicenter Study. J Neuroophthalmol. 2014 Sep 25. [Epub ahead of print]).

As for clinical trials, Dr. Guangbin Xia of the University of Florida reported the result of a randomized, double-blind, placebo-controlled, cross-over trial of dalfampridine (a drug that blocks potassium channel and has been approved by the Food & Drug Administration (FDA) for treatment of multiple sclerosis), demonstrating good safety and tolerability of the drug in patients with SCAs 1, 2, 3 and 6. The study was too small to demonstrate statistically significant efficacy of the drug. The result of this study is in preparation for publication. Dr. Shoji Tsuji of Tokyo University has asked the CRC-SCA to participate in preparing for a clinical trial for treatment of multisystem atrophy (MSA), in which he found mutations in the *COQ2* gene. Furthermore, Ataxion, Inc. and Steminent BioTherapeutics, Inc. showed their interests in clinical trials for ataxias, focusing on SK channel modulators and mesenchymal stem cells, respectively.

For **Objective #2**, Drs. Stefan Pulst and Pattie Figueroa of the University of Utah and the CRC-SCA investigators collaborated with the European group for a genetic modifier study. Data suggesting the existence of modifier genes

Continued on page 34

THE NATIONAL ATAXIA FOUNDATION
58th Annual Membership Meeting

“Soaring Mile High”

— Denver, Colorado —



2015 AMM logo
designed by
Bridget Sweeney

Alice Lee



Angela Li



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

Mike
Cammer
and
Karen
Leader



(Front) Jerree
Holmes; (back)
Dee Dorsey



(Back, left to right) Sam
Kirtton and Chris Tippett;
(front) Cathy DeCrescenzo
and Joe DeCrescenzo



Marilyn Schut-Lee
and Dr. Larry Schut



(Back, left to right) Pat Nac
Yeoman, Keri Naccarato, K
(front) Sam Nacca



Hot Hula Gr



Denver Ataxia Support Group

AXIA FOUNDATION Membership Meeting "High for a Cure"

— March 6-8, 2015 —



der



Friday morning speakers



Nacarrato, Rebecca
Kelly Nacarrato;
Nacarrato



Dr. Terry Fife
and Bonnie Sills



Debbie Crystal,
Charlotte DePew,
and Trish Hysong

More photos
are available
on the
NAF's website,
www.ataxia.org

Donovan
and
Debra
Simpson



Saturday morning
speakers



Dr. Abigail
Collins and
Cathy
DeCrescenzo
dancing
at the
Banquet



Group – Friday Session



Healing through Writing session

Natural History of...
Continued from page 31

for SCAs were presented in the publication (du Montcel et al. Modulation of the age at onset in spinocerebellar ataxia by CAG tracts in various genes. *Brain*. 2014 Sep;137:2444-55). In a separate study, we collaborate with Dr. Martin Delatycki's group at Murdoch Institute, Melbourne, Australia for development of epigenetic biomarkers of SCAs. Meanwhile, the University of Utah continues to collect DNA samples.

For **Objective #3**, Serum, cerebrospinal fluid (CSF) and fibroblast samples are collected, stored and cataloged at individual centers. It became apparent that substantial funding would be necessary to expand this program of biological sample repository. For autopsy brain collection Dr. Ranum has spearheaded the effort to establish the system through which patients and families can arrange donation of the brain. The logistics of brain autopsy is complex and still needs further education of patients, families, caregivers, medical professionals and even researchers. The

number of samples in these programs has been small. For establishment of iPS cells from SCA patients, Dr. Xia has been collecting skin biopsies from which he has obtained fibroblasts in early passages. In collaboration with Dr. Zbigniew K. Wszolek of Mayo Clinic Jacksonville, we established access to additional fibroblasts from SCA patients. To date we have established readiness for deriving iPS cells from these fibroblasts (Xia et al. Generation of human-induced pluripotent stem cells to model spinocerebellar ataxia type 2 in vitro. *J Mol Neurosci*. 2013 Oct;51(2):237-48). However, making iPS cells from fibroblasts is expensive and further funding will be necessary to develop a substantial SCA iPS cell repository.

In summary, the NAF Pioneer grant has helped the CRC-SCA further advance the existing infrastructure toward readiness for clinical trials. The data and track record we acquired under the Pioneer grant will be highly valuable in the current and future applications for NIH funding with a larger budget to firmly establish the clinical trial readiness. ❖

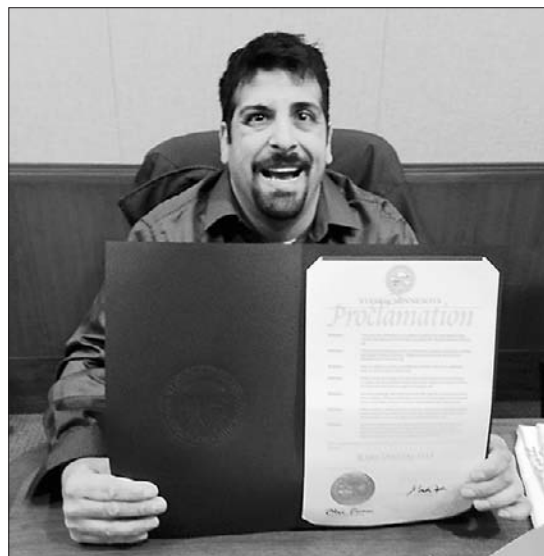
Rare Disease Day

In recognition of Rare Disease Day, the National Ataxia Foundation participated at the Minnesota State Government House Event to help raise awareness of rare disease issues that are relevant at the state level.

With the support of the National Organization of Rare Disorders (NORD), state events were held in 31 states. In attendance at the Minnesota event on February 24, were medical professionals, rare disease researchers, legislators and individuals and families affected by rare diseases.

Eric Pogulis, who is active in the Twin Cities Ataxia Social Group, was an invited speaker at the event. He shared his very moving personal story of living with ataxia himself and caring for his mom who also has ataxia.

Thank you, Eric, for helping raise awareness of ataxia at the Minnesota state level. ❖



Eric Pogulis with the State of Minnesota's Rare Disease Day Proclamation

Meet the Newly Elected NAF President – William Sweeney

William (Bill) Sweeney is a member of a SCA1 family. Bill's family story is like that of many hereditary ataxia families. His father, John, began to develop balance and speech issues in his early 60's. At his retirement physical in 1975, he was referred to a neurologist and diagnosed with ALS (Lou Gehrig's disease). John eventually sought a confirming diagnosis from the Mayo Clinic – and was told he did not have ALS – but that the cause of his symptoms could not be identified. It was not until 1996, when Bill's brother, Mike, was genetically tested after experiencing similar symptoms to those of his father that his family learned what afflicted his father.

Bill has two sisters and four brothers. Three of his brothers have been diagnosed with SCA1. Bill commented, "Like all individuals, caregivers, and families affected by ataxia, we learn more about this disease every day. A primary lesson learned is that this is a family disease – and that the ramifications of ataxia are best confronted with openness rather than in an atmosphere of denial. Attending the NAF annual meetings and Twin City Ataxia Support Group meetings has helped my family see how our experiences, challenges and frustrations parallel those of all families affected by ataxia."

Bill graduated from St. John's University (Minnesota) and did graduate work in Business Finance at the Universities of Montana and Colorado. He began a banking career in 1976 in Arizona, where he spent 14 years split between Phoenix and Tucson working in commercial lending. Bill returned to Minnesota in the

mid-1990's where he joined US Bank at their headquarters office in Minneapolis. He retired in 2010 after working with distressed business loans and lending to nonprofit organizations.

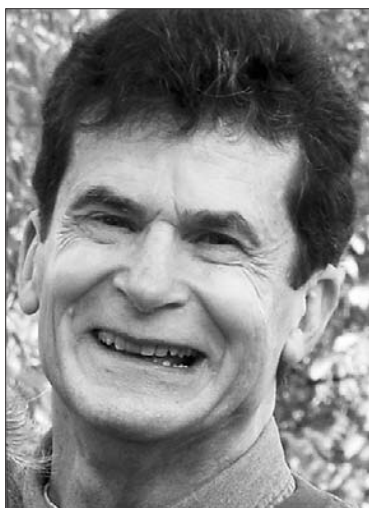
While in Tucson, Arizona, Bill served on the Boards of Directors for the Boy Scouts and Big Brothers/Big Sisters and served on the Finance Committee for the Catholic Diocese of Tucson. For the past 10 years, he has served on the Board of Guild Incorporated – a St. Paul, MN nonprofit – and chaired that Board for six years.

He joined the NAF Board of Directors in 2007, has been a member of the Executive Committee since 2009 and served as Treasurer from 2012-15. He has been active in the Twin Cities Support Group and helped start the Twin Cities Walk, Stroll n' Roll in 2010. Over the past five years, that event has raised more than \$250,000 in support of the Foundation. In March 2015, Bill was elected President of the

National Ataxia Foundation.

Bill noted, "I am divorced with no children – but have 13 nieces and nephews, several of whom have started their own families. Nine of my nieces and nephews are offspring of my brothers with ataxia. It is my family's hope that research will uncover a cure for ataxia or way to significantly ameliorate ataxia symptoms so that all my nieces and nephews generation can live normal lives."

The National Ataxia Foundation welcomes Bill Sweeney as the newly elected President of the National Ataxia Foundation. ❖



William Sweeney

Walk n' Roll for Ataxia

The ultimate finish line ... a cure for ataxia

What is Walk n' Roll for Ataxia?

The Walk n' Roll for Ataxia program is the National Ataxia Foundation's largest national grassroots fundraising event. Since its inception in 2007, Walk n' Roll for Ataxia currently takes place in cities across the U.S. Since its inception in 2007, Walk n' Roll for Ataxia has raised more than \$1,200,000 thanks to the support and tireless commitment from walkers, rollers, runners, volunteers, donors, and sponsors.

Why Walk or Roll?

Thousands of families, friends, co-workers, neighbors, and communities come together each year to support NAF's fight to improve the lives of people affected by ataxia and their families.

How Can I Participate?

For more information, or to start a Walk n' Roll in your community, please contact Lori Shogren, NAF Special Projects Coordinator, at (763) 553-0020 or lori@ataxia.org.

— 2015 Walk n' Roll Events and Contact Information —

Walk for Dave

Liverpool, NY – TBD

Marc Alessi pianoman345@hotmail.com

Concord Walk n' Roll

Concord, CA – September TBD

Brian Petersen smileypetersen@yahoo.com

New York Walk n' Roll

New York, NY – September TBD

Kathy Gingerelli kgingerelli@msn.com

Minnesota Walk, Stroll n' Roll

St. Louis Park, MN – September 12

Terry Sweeney mnataxiawalk@yahoo.com

Denver Run, Walk n' Roll

Denver, CO – September 13

Charlotte DePew cldepew77@comcast.net

Atlanta Walk n' Roll

Duluth, GA – September 19

Greg Rooks atlantaataxia@gmail.com

New England Walk n' Roll

Auburn, MA – September 26

John Mauro johnmauro62@me.com

OC/LA Walk n' Roll

Orange County, CA – September 26

Daniel Navar danieln27@gmail.com

Utah Walk n' Roll

Layton, UT – September 26

Jenny Durran jenny@utahataxia.org

Michigan Walk n' Roll

Ann Arbor, MI – October TBD

Elizabeth Sullivan elizsull@umich.edu ❖



For more information, please visit www.ataxia.org/events/walk_n_roll.aspx.

Raising Ataxia Awareness Is a Key Goal of the NAF

Ataxia affects many lives and yet is it still a relatively unknown disease. One challenge that the National Ataxia Foundation faces is generating awareness in the medical community and the general public. The NAF is fortunate to have John Mauro, NAF Board Member, work with his wife Dana to raise awareness.

John is an experienced marketing person with the ability to be creative in finding ways to bring about greater awareness of ataxia. One of his efforts included a “What is Ataxia?” video which you are invited to view at <http://tinyurl.com/nhholv9>.

Raising ataxia awareness does not need to be complex. John provided these suggestions: “Simple short videos can be effective. Create something that is memorable, inspiring, entertaining, eye-catching, and attention grabbing.”

Leading up to International Ataxia Awareness Day (IAAD) on September 25, 2014, John and Dana produced a daily segment on ataxia. Each day, Dana would describe a new fact about ataxia which was then posted on the NAF YouTube



John and Dana Mauro raising ataxia awareness

channel in the days before IAAD. To see these clips go to <http://tinyurl.com/n9jjb3q>.

John has also been very active in reaching out to the local newspapers and radio stations near and in his hometown in Massachusetts. His latest efforts now include giving presentations to medical students at local colleges and universities where he shares information about ataxia and what it means to live with ataxia.

The NAF sincerely thanks John and Dana Mauro for their efforts and dedication in this wonderful, important step forward. ❖

International Ataxia Awareness Day (IAAD) Get Involved in IAAD Events and Planning

— Friday, September 25, 2015 —

“International Ataxia Awareness Day” (IAAD) is an international effort from ataxia organizations around the world to recognize September 25 as International Ataxia Awareness Day. IAAD has grown over the years, with new ideas being implemented and more people getting involved.

To find out how you can get involved, please download the IAAD Kit on the National Ataxia Foundation’s website, www.ataxia.org, on the IAAD page under the Event Section. On the website you will also find all the IAAD events near you on the Event Calendar under the Event Section as they become available.

Please let the Foundation know about your IAAD event by contacting Lori Shogren at lori@ataxia.org or (763) 553-0020.



Breaking Down Financial Barriers to Diagnostic Testing

Patients who show signs of certain diseases face a unique set of problems. Puzzling symptoms, slow referral to specialists, late or no diagnosis, wrong tests ordered or wrong treatments given, and lack of information about the disease burden patients and caregivers who seek medical answers. Much of this could be avoided simply by having the correct diagnosis.

For many patients, there is a simple path: a diagnostic test may confirm (or rule out) certain conditions. The doctor orders the test, the insurance company pays for the test, and the results may dictate the course of treatment.

But for certain disorders, such as ataxia, testing is not always covered by the insurer. Many of the newer molecular tests are costly – some run many thousands of dollars. Patients seeking answers are put in a difficult position of having to use funds that cover life's necessities to pay for the test, or worse, do without the test – and the insights the test result provides. Overwhelmingly, patients cite lack of insurer reimbursement or prohibitive cost as a major barrier to testing – and many continue to suffer from fear, anxiety, lack of control and helplessness as a result.

Athena Diagnostics has recently announced a

new program to assist in the reimbursement process and to help make diagnostic testing more accessible and more affordable. The Athena Alliance Program was created to expand patient access to a variety of diagnostic methodologies and testing, especially those for rare and esoteric disorders. Athena's focus is on providing patient-centric customer service so that each patient has an individual specialist and a team of dedicated personnel to support them from the time of the order through test results.

The new tiered financial assistance program is based on income levels.

For individuals who have faced financial barriers to accessing the diagnostic tests necessary to make diagnostic and treatment decisions, the Athena Alliance Program may offer what you need.

If your physician has determined that it is medically necessary for you or a family member to receive a laboratory test for a rare or neurological disorder, contact the Athena Alliance Billing Team to engage one of their specialists at 1-800-394-4493.

For more information, refer your physician to www.AthenaDiagnostics.com/alliance. ❖

Recurring Gift Membership Program

The National Ataxia Foundation's Recurring Gift Membership Program makes it easy for you to contribute monthly or quarterly to support the important work of the Foundation.

Simply complete form on the right (page 39) and mail it to the National Ataxia Foundation, 2600 Fernbrook Lane, Suite 119, Minneapolis, MN 55447-4752 offices or fax it to (763) 553-0167.

The National Ataxia Foundation is a 501 (C) (3) non-profit organization, so all donations are tax deductible to the fullest extent allowed by law. Through this program, each January you will receive a statement from NAF showing the amount you have donated during the previous calendar year.

For more information contact the NAF office or visit www.ataxia.org/giving/default.aspx.

NAF Credit/Debit/EFT Authorization Form

☐ Yes, I want to save time & money by joining NAF's Recurring Gift Membership Program.

Personal Information (*Required Fields)

*Name on Account: _____

*Address: _____

*City: _____ *State: _____ * Postal Code: _____

*Country: _____ *Email: _____

*Phone: _____

Gift Information

I Authorize the National Ataxia Foundation to charge my account. (Please select one & fill in amount below)

Select one

Amount

Monthly ☐ 5th of each month (\$10.00 a month Minimum) \$ _____ (Monthly amount authorized)

Quarterly ☐ 5th of March, June, Sept & Dec (\$30.00 a Quarter Minimum) \$ _____ (Quarterly amount authorized)

Notes: _____

☐ **Credit Card Information** ☐ Visa ☐ MasterCard ☐ Discover ☐ AMEX

*Credit Card Number: _____

*CVV Code: (3-4 digit code on back) _____ *Expiration Date: _____

☐ **EFT Banking Information** ☐ Checking ☐ Savings

*Financial Institute: _____

*City: _____ *State: _____ *Phone: _____

*Routing Number: _____

*Account Number: _____

(For EFT please include a voided check or voided deposit slip or we cannot process)

By signing this form, you authorize the National Ataxia Foundation to charge the credit card listed above or instruct your financial institute to debit your account for the amount instructed. The recurring charge will stay in effect until you chose to cancel giving 15 days written notice or by submitting updated information. Your gift will appear on your Account statement automatically. Each **January** you will receive a statement from NAF showing the amount you have donated during the previous calendar year (January-December). **Save a copy of this statement for tax documentation.**

*Signature of Account holder (required) _____ *Date

The National Ataxia Foundation is a 501 (C) (3) non-profit organization, our Federal Tax ID # is 41-0832903. All donations to NAF are tax deductible to the fullest extent allow by law. Phone: 763-553-0020

Mail to: National Ataxia Foundation, 2600 Fernbrook Ln N, Ste 119, Minneapolis, MN 55447-4752 or Fax 763-553-0167

Date Received: _____ Date Initiated: _____

My First Experience at the NAF Annual Membership Meeting

Submitted by Chandu George and Nuthan Prasad (SAMAG – India)

My brother, Nuthan Prasad, and I finally made it to the United States for the first time to attend the NAF Annual Membership Meeting in Denver. We were greeted with freezing weather conditions that we are not accustomed to and, quite frankly, when stepping out of the airport the chill in the air hit me on my face telling me to go home! It was an incredible journey, criss-crossing around the world, misplaced luggage and hotel reservation issues.

After interacting through e-mails, letters, etc. for over 10 years, we finally met the NAF staff. We were excited and felt relieved to have arrived, but the Denver weather and jet lag were all new to me. It took me two days and a fever to adjust and then things started to brighten up for us. Although I have a different accent, along with my slurred speech, it did not stop me from communicating and making new friends! Everyone at the meeting was so kind and supportive.

I was not able to attend all the sessions but the ones I did attend were great. I enjoyed visiting with the exhibitors from CoRDs and the

researchers from Cognition and Action Lab (Princeton and Berkeley universities) but the best thing about the meeting was the Saturday Night Banquet with the lovely dance and music. This is where I experienced many of my “firsts” – like

being asked to dance, dancing on/in my wheelchair, and dancing with new friends that made us feel comfortable and at home.

The icing on cake for me was when I was awarded with the first “International I am the Strength Behind Ataxia Award,” and was able to give a short speech that was appreciated by all.

The hardest part came when we had to start saying goodbye to all of our new friends. We, again, criss-crossed the globe to reach our home in India. Here is an interesting thing to note, we almost circled the whole globe in the space of 10 days.

We will treasure the warmth,

love and support we received at the NAF AMM for the rest of our lives!

If you would like to contact me, here is my e-mail address: india.ataxiagroup@gmail.com.

Thanks and Best Regards.



Left to right: Nuthan Prasad and Chandu George at the 2015 Annual Membership Meeting

**Are you a member of the National Ataxia Foundation?
Become an NAF member or renew your membership online
today at www.ataxia.org. YOUR MEMBERSHIP MATTERS!**

Lesson Learned

Submitted by Pinalben "Pinky" Patel

Jemi was nine when she died and I was two-and-a-half years older. Jemi and I looked like twins, although she was a little shorter. My Mom often dressed us in the same outfits. We looked similar on the outside, but we could not have been more different on the inside. Our personalities were very different, which caused us to not always get along. We fought over everything. My mom told me that she had to get identical presents for us on holidays and each of our birthdays so we wouldn't fight. Everyone in the family also teased us that they'd have to find identical twins for us to marry to keep peace between us!

In 1985 when my family immigrated to the U.S. from India, I was four and Jemi was one. A couple of years later, I fell sick with the flu and began displaying the classic symptoms of Friedreich Ataxia (FDRA). Jemi followed a few years later and began showing symptoms after a sickness. Finally in 1992, a diagnosis that was started in Lima, Ohio ended in Atlanta, Georgia. A confirmation of FDRA was not the only news my family had to deal with at the time. We found out that we had to go back to our village in India.

My sister and I were visibly wobbly. It was especially difficult for relatives in India to see us that way. They persuaded my parents to try herbal and spiritual medicines. My parents, although unsure, agreed to try some of their suggestions. They hoped for the holistic approach to work, despite their education. So we tried Ayurvedic (a system of Hindu traditional medicine native to the Indian subcontinent and a form of alternative medicine) and Homeopathic medicine for a couple years from certified shamans. It

did not appear that it was working as they'd hoped. One day, a door-to-door witch doctor came to our village selling drugs. He claimed they were all natural with no side effects. My parents were hesitant because of the lack of results with the alternative treatments, but decided to try this on my sister and the results were more than disappointing. It seemed the drugs turned out to be too much for her heart and she died of heart failure at age nine, just six months later.

It was very hard on my parents and ever since the tragedy, my parents have put their foot down for me and don't acknowledge any of the "miracle cure" talks from anyone. Unfortunately, there is no cure for FDRA yet. But at least there is medicine that may help ease some of the atrocious symptoms and help prolong activity. Exercise and an active lifestyle is the only sure treatment for FDRA or any ataxia, even now! ❖



Our family

Schwan's Cares Campaign

The Schwan's Cares fundraising campaign needs your help. The goal is to raise \$5,000 for NAF by January 30 2016. Schwan's will give 5% of your product purchases back to our campaign and you'll get great food for your friends and family!

To support the campaign, please visit www.schwans-cares.com/campaigns/18377-research-education-and-support-for-ataxia.

One Day at a Time

Submitted by Tamara Schuman

I search Spinocerebellar Ataxia (SCA) websites for recommendations, current research, disability issues, etc. They often help to distinguish between current theories and scams. There are many people all over the globe like me. Ataxians tend to be a positive but realistic group of information-seekers and givers (not always, thank goodness, but generally). The periodic venting always stimulates an empathetic discussion that never starts with the words, “At least...” I find the discussion helpful, as well as enlightening. It’s better to be primarily hopeful and not hopeless, but continuous positivity just isn’t my style. I’m happy to have the occasional “Pity Party.”

Although there are over 40 different types of ataxia, the issues confronting affected persons are similar. Since ataxia is characterized by a loss of coordination, often people’s balance, gait, and speech is most noticeable to the uninitiated. Through reading web posts, I’ve come to realize most people with ataxia lie somewhere on a spectrum. As usual, I’m somewhere in the middle symptomatically. There are those more or less affected, people at different life stages, financial levels, varying support network sizes, and approaches to coping.

Two themes seem to be universal on ataxia websites, however. Firstly, everyone wants their ataxia to go away, get dramatically better, or be curable. Spoiler alert – it won’t, it’s not likely to, and it’s not. Certainly various devices, supplements, and strategies do make a difference, but that varies from person to person. Secondly, people are often mourning the person they used to

be – the runner, the mountaineer, the worker, the intrepid traveler, the jazz dancer. That’s often a big factor in their process toward acceptance of ataxia. So far, my coping strategies keep me doing all that I can and are effective more often than not. I stay in the game, get up every morning, value my village (pardon the pun), scoot, and blah, blah, blog. Although my effort toward acceptance is usually on an uphill trend, I haven’t found it to be a straight line. Like life, someday you’re the bug, someday you’re the windshield.

The websites also reveal those who are trying to figure out what is due to ataxia and what is due to age. I figure since both are progressive and incurable, it probably doesn’t much matter. I just follow treatments the ataxians recommend – good nutrition, exercise, and sleep. That works for pretty much everything anyway and it’s free.

Ataxians and their loved ones want to be able to predict the neurological progression of the disorder. Wouldn’t we all? Since the cause, age at onset, and manifestation of symptoms vary, so does the progression. The best piece of advice I ever got was to take one day at a time. Everyone is different (duh).

At some point, we all embark on the “Eternal Quest” for an answer. I’m all for seeking appropriate treatment from knowledgeable physicians and expecting respectful care. But when I found myself getting angry for various unfounded reasons, I had to face some hard truths about both me and ataxia. No one was going to give me an answer to something that had no solution. Spinocerebellar Ataxia (SCA) is an orphan disease ►►



Tammy and Earl with their grandchildren Sarah, Zoe, Lexi, and Kyle

in that it's rare and most people, including many healthcare providers, don't know much about it. I live with it and did the homework. It wasn't a particular provider's fault that I knew more about my condition than most health professionals.

I did see a neurologist who specialized in the Group of Movement Disorders (Parkinson's, SCA, Huntington's). She answered all my questions, helped me apply for disability, encouraged

me to read the research literature, and wrote the "I'm Not Drunk" letter. But she made it clear that there was nothing else she could offer beyond symptom management, annual follow up, and to be cautious of cure or treatment claims.

The lesson: There is likely no "Holy Grail" for Spinocerebellar Ataxia. It is what it is.

You can contact Tammy for more information at schumant@hotmail.com. ❖

Pearls of Wisdom

Submitted by Pete Meyerhoff (pmeyerhoff@comcast.net)

As the oldest member (89) of my ataxia support group I am often asked to supply "pearls of wisdom."

Here are a few:

Go to the bath room often – men at least three times a day, women twice as often. Don't wait for the urge to go, that may be too late. A floor-to-ceiling pole (about \$200 installed) is very useful getting on and off the toilet. You can stand up holding on to the pole with one hand leaving the other hand free to pull down your pants.

The bath room has always been a very private place. Ataxia can change that. Leave the door open so that you can call for help. Turn the fan on.

Forget about vanity. Use your walker, use your wheelchair, put on your bib, use your cane, and speak very slowly. Whatever you do, do it slowly. Motto: "Slower is faster." A trip to the hospital is a big time delay.

Exercise is good, push yourself to do it regularly.

At a restaurant with your wheelchair, sit on the corner of the table, even if you project into the aisle behind you. When I say corner I mean the 90 degree angle formed by two sides of a square table. This allows room for the elbow rests of your wheelchair to slip next to the table. You can get really close to the table this way. Don't forget to put on your bib. Sitting at any table with

glasses containing liquids, slide them over to you before lifting to drink. This minimizes spilling.

When taking pills, don't lift your head "to wash them down," this agrees with the professional ataxic advice to tuck in the chin when swallowing.

Keep a plastic, easy-to-clean barf can close to your bed, just in case.

The floor to ceiling pole for the bathroom also works well to get into and out of bed.

For those of us that are in a wheelchair, making a 90 degree turn to sit on a sofa is difficult. An ordinary walker helps a lot here. Put the walker in front of the wheelchair by the sofa, stand up holding on to the walker, make your 90 degree turn using very small steps, sit down on the sofa.

MRIs of your cerebellum do not cure. But taken years apart and displayed side by side they can provide scientific proof that your ataxia has or has not gotten worse. Maybe you don't want to know.

If you should fall, heaven forbid, don't get up right away. You are upset. Just stay there a while. Plot your strategy. People will want to help you right away get back up. This may be okay if you are not hurt. If you are alone, decide on the best strategy. Scoot over to a table or other handhold? Take your time, calm down. ❖

The National Ataxia Foundation

58th Annual Membership Meeting

Soaring Mile High for a Cure

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Chapter and Support Group News from Around the Country

Alabama Ataxia Support Group

Submitted by Becky Donnelly

The group met January 31 in Birmingham with 17 members. Our speaker was Chris Amick, a Service Dog Trainer with Global K9 Services LLC, in Birmingham. We enjoyed a delicious lunch followed by a time of fellowship.

A business meeting followed as the active membership list was updated, followed by assignments of Cell Group Leaders who will keep up with the people in their group and make the Support Group aware of needs. The inactive members will still be contacted regarding meetings and socials. The yearly agenda was set with three meetings and luncheons and three socials.

Breakout sessions followed with the theme "What's on your mind?" which resulted in much discussion. Juanita Dorroh ended our meeting by asking questions from Bennett Cerf's "Book of Riddles" and everyone left with smiles on their faces!



Members of the Alabama Ataxia Support Group at their January meeting



The Arizona Ataxia Support Group meeting in February featured (left) assistance dogs and speakers from Power Paws, and (right) Dr. Larry Schut.

Arizona Ataxia Support Group

Submitted by Angela Li

The Arizona Ataxia Support Group had a wonderful February meeting complete with a delicious potluck, knowledgeable speakers, and great company.

We had wonderful speakers and adorable assistance dogs from Power Paws. We were educated on different types of assistance dogs and the wide range of tasks they are able to accomplish for us.

We also had the privilege of having Dr. Larry Schut, a neurologist from the family that founded the National Ataxia Foundation, join our group to give advice on visiting the doctor. He addressed how to prepare for a doctor's appointment as well as questions to ask.

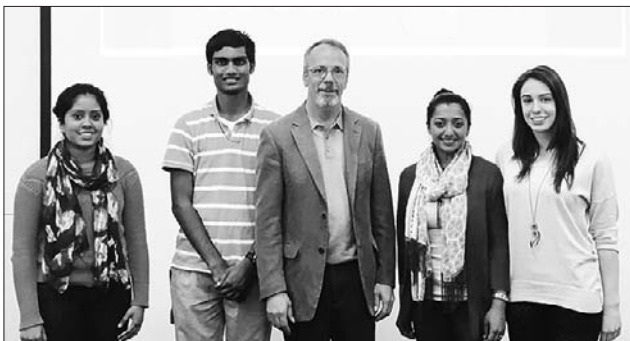
In addition, we were so excited to hear that one of our support group members, Bob Michaels, announced his newly-published book, "Strong Medicine," about improving your independent living program, which can be purchased on Amazon. We look forward to our next meeting in May.

Central Massachusetts Ataxia Support Group

Submitted by John Mauro

As the co-leader of the Central MA support group over the last four years I have focused on different ways to educate the public about ataxia. In the last few months, I have been invited to speak to first-year medical school students, staff members, and a few local rehabilitation centers to help improve the way they work with people who have ataxia. My next focus is to work with the local fire, EMTs, and police departments.

I recently had the pleasure of sharing my presentation “What is Ataxia” at UMass Amherst University. The presentation starts with my life before ataxia and goes through the two long years when I finally got diagnosed with sporadic ataxia. Additionally, I focus on many of the difficulties one would deal with having ataxia. In the last 15 minutes, I shared many ideas how the audience could get involved to spread awareness through their school and community.



Left to right: Nadja Arifovic, Akshata Sonni, John Mauro, Rahul Bussa, and Rupini Alla

Delaware Ataxia Support Group

Submitted by Joe DeCresenzo

The group held a meeting in mid-November in Newark. Our guest speaker was Sarah LaFave, Founder and Executive Director of Lori's Hands.

Lori's Hands is a Community Health Service Learning process whereby college students spend a few hours each week visiting and volun-

teering their services for the chronically sick in the area. Their volunteer work may include grocery shopping, light house work, yard work, or just companionship – reading or talking with their clients. The goal is multi-purposed: it provides a learning tool for the students through discussions about the clients' life experiences, it provides a greater sense of compassion for those in healthcare educations, and it is a welcomed stress reliever and/or help in accomplishing household tasks for the chronically sick or their caregivers. The university sponsoring Lori's Hands created a credit course, where students learn about the impacts of various chronic illnesses on both patients and their families, and get first-hand interaction with patients with these illnesses. The program is currently only at the University of Delaware, but plans are to expand it to campuses around the United States.



Sarah and Liz (one of the first student volunteers and now a grad student at Columbia University) with members of the Delaware Support Group

Northern California Ataxia Support Group

Submitted by Alan Acacia

Things are going very well for the group. We are pleased to have accomplished so many of our objectives in under one year!

Joanne Loveland, our Group Facilitator, spoke at our April 2014 meeting. She had observed that having quarterly meetings and raising funds at the walk-n-roll was not increasing our

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membership significantly. She suggested a new set of objectives to increase communication and connection in the coming year.

The four objectives were:

1. Re-do our roster to reflect local groupings.
2. Find contact people for each area.
3. Create a newsletter.
4. Consider developing our own website.

Since April we have updated our roster. We have published "The Ataxia Community Newsletter" each quarter. A system of local area contact people has been set up for six different parts of Northern California. In each part there are area contact Persons, who establish e-mail or phone contact with members in their area, and welcome new local people interested in becoming members. The role of a contact person is to reduce the isolation that many people with ataxia experience. The work has only recently started. Possibilities for the future include setting up carpools to our quarterly meetings, and having local members get to know each other outside of meetings.

Finally, in mid-March our treasure Brian Wong created a beta version of our very own website!

Turnout for the January meeting was the highest in several years – 34 people.

The program presentation by our own members – "How to Access the Internet" – was a big draw. It focused on websites most useful to us, such as NAF's site, and local sites, such as Ataxia Friends California, a new site founded by support group members.

The business meeting focused on introducing our new Local Area Contact program. Shirley Hanks, Area Contact Coordinator, emphasized

her commitment to assist and be available to contact persons. Most members felt OK about the newsletter's longer length, appreciated Joanne's "News You Can Use," and requested future articles on helpful devices and utensils, as well as on medical research discoveries.

If you are a NAF member in Northern California, we invite you to join our community. We need your help in reaching out to the estimated 7,000 people with ataxia in our part of the state. Contact Shirley Hanks at Shirley@Hanks.com. You will be warmly welcomed!



Members of the Northern California Ataxia Support Group

New Hampshire Ataxia Support Group

Submitted by Jill Porter

The group met last Saturday despite snow flurries. We introduced everyone, shared types of ataxia, informed the group that New Hampshire State Bill (SB142/2015) was introduced by State Senator Boutin and we are following its progress.

The caregivers and friends then left the group and met separately returning to the group prior to the end of our meeting time. This was our first meeting of this type.

Feedback from the meeting included sharing of different symptoms, PT, weighted silverware, airport travel experiences & ADA transport systems. From the caregivers side we shared experiences about making homes more accessible, emergency alert systems, stair lifts and ramps, home care services, community transportation ►►

systems, family involvement, support and dynamics and how we take care of ourselves.

Greater Atlanta Ataxia Support Group

Submitted by Dave Zilles

The group held their meeting on February 21 at Emory Center for Rehabilitation Medicine in Atlanta. Once again we had a great turnout and were honored to have two great speakers. One was Ms. Derona King from Citizens Advocacy of Atlanta and DeKalb. Citizens Advocacy is a diverse community-based organization which creates and supports relationships between an ordinary citizen who is living a “good life” and a person with disability who is vulnerable to isolation and exploitation. Our second was Mr. Mark Biernath with the firm Nadler Biernath LLC who presented on the ABLE Act. His law firm specializes in Special Needs and Elder Law. Both of these presentation were very interesting and well received. There was a lot of discussion regarding the new ABLE Act.

Our next event will be the Annual Lake Lanier Picnic in June.



Members of the Atlanta Ataxia Support Group

Tri-State Ataxia Support Group

Submitted by Kathy Gingerelli

We held our last meeting on November 13. After the introductions were made we moved on and had a few questions/answers to provide the newest arrivals of the evening.

Our first speaker of the evening was Michael LaValley, a Special Needs Planner for New England Financial, a MetLife Company. Michael gave a very detailed and informative talk about the importance of making your future more secure with financial planning. We learned that there are special legal considerations to consider when planning wills, trusts or guardianships. We also learned that “denial” is the number one reason for not doing anything; it’s the “nothing will happen to me” mentality. On top of providing our group with helpful information, Michael is also a newer member of our group.

Our next speaker of the night was one of our members, Ian Bouras. Ian is a musician who has had to devise a new way of creating music since his ataxia diagnosis. Ian now performs live audio looping and proves to him, and others, that an ataxia diagnosis is not a limitation but an opportunity to be first at anything we do. Check out a sample of Ian’s music at www.sdmrecords.com or videos on YouTube.

Our final topic of discussion of the night was to share the sad news that our very own Dr. Ann Hunt is leaving New York and will be moving to Boston. Dr. Kuo will be at our meetings to keep the group informed on any Ataxia updates.

Submitted by Kathy Gingerelli

The first meeting of 2015 was our annual potluck/welcome night. While we did have a smaller than usual turnout and a few new faces to welcome.

We started the meeting with introductions and a little conversation; the group spoke about subjects of interest to be covered for 2015. We talked about the NAF Annual Membership Meeting and asked anyone going to bring back information for the next meeting. We heard from doctors and students about research studies being done

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for ataxia.

Conversation flowed throughout the evening as questions and answers were given.

This meeting ended after 8:30 p.m. and left-overs were handed out. We all said good-bye and are looking forward to meeting again in March.



Members of the Tri-State Ataxia Support Group

Greater Denver Ataxia Support Group

Submitted by Charlotte DePew

The group met January 18 at Swedish Medical Center. About 35 enjoyed a potluck lunch with four new members. Everyone gave brief introduction and shared something, an ataxia “AH-HA” they found works well for them, or asked if someone had recommendations for a particular ataxia problem.



Members of the Great Denver Ataxia Support Group

This meeting’s topic was the new and highly talked about Balance Vest. It was presented and demonstrated by Stephanie Dunn, Physical Therapist at the Longmont Life Care Center. Stephanie spent fitting several ataxians and all experienced some degree of improvement in mobility/speech. Some had almost instantaneous improvement and some were subtle over time.

Utah Ataxia Support Group

Submitted by Nancy Willard

The group had a great turn out for our quarterly meeting November 11 at the Moran Eye Center in Salt Lake City. We celebrated the huge success of our first Walk n’ Roll, with a recap of the day by Nancy Willard. Ryan and Jenny Durrant presented us with a wonderful slide show presentation capturing special moments.

Lisa Ord, PhD, LCSW, discussed dealing with anxiety and depression for both those living with ataxia, their families, and caregivers. She discussed the importance of dealing with ataxia in small steps and shared “10 Best Stress Reducers” in some detail with the group. In a nut shell, they are as follows:

- Breathe slower
- Take a short walk
- Have some fun
- Try a massage
- Talk it out-stay cool
- Have a good cry
- Learn to relax
- Turn to your friends

Also mentioned was the importance of laughter. “We need to find something to laugh about, as laughter is good medicine. A good belly laugh is great!” Dr. Ord also discussed, “Unhelpful thinking Styles,” found at www.psychologytools.org. Dr. Ord said all too often we allow ourselves to become victims of our own negative thoughts. “Recognize when these things [thinking styles] are not helpful and change to positive self talk.” She also ►►

mentioned, “Tell self, yes, this is frustrating, yet I can go on.” She encouraged us to write 100 things we like about ourselves and to focus on the things we can do.

Dr. Ord introduced Sophia Ahmed-Masters of Social Work; Yumna Subhani, Chemistry Undergrad student; Leigh Ann Higa, Genetic Counseling Intern; Ally Armstrong; and Kevin Luiz-Physical Therapy students. Sophia discussed seven stages of grief. Acceptance, the seventh step, allows us let go of negative behaviors and move on in a positive direction. Leigh Ann got us all involved in a mindfulness activity of meditation, a time without any judgment. She stated the importance of dedicating at least five minutes each day to our self through mindfulness activities. Also mentioned was the Beck Depression Inven-

tory and information for an outreach crisis center in the Salt Lake Area, providing free 24-hour crisis support for anyone in need at (801) 587-3000.

This was a very interactive, open forum meeting full of great information that we can all benefit from. ❖



Members of the Utah Ataxia Support Group

Measuring Ataxia in Children

Children with disorders of/damage to the cerebellum wanted for a study of motor control at Massachusetts General Hospital

Researchers are seeking children and adolescents below 18 years of age with disorders of/damage to the cerebellum (the “small brain”) to participate in a study to develop a brief clinical test battery to rate the severity of cerebellar motor ataxia in children.

Participation would involve one visit to the Massachusetts General Hospital (MGH) lasting up to 40 minutes. Participants will be asked to perform a battery of tests of motor control. There is no medication and no imaging involved.

Participants will receive an ice cream gift certificate as an acknowledgement for participation. We will provide free parking.

Your participation in our study is of great importance and will lead to the development of

a clinical rating scale for cerebellar motor ataxia in children with cerebellar disease.

Children may be eligible to participate in this study if they meet the following criteria:

- Below 18.0 years of age
- Have a disorder of/damage to the cerebellum (i.e. from damage to the cerebellum due to tumors, hemorrhage, stroke, ischemia, infection, pure and complex hereditary ataxia, autoimmune disease, and other disorders that affect the cerebellum)

• Are able to come to one study visit lasting approximately 20-40 minutes

If you are interested in enrolling in this trial, please contact Dr. Franziska Hoche, MD, at fhoche@partners.org or (617) 726-3669.

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 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 – Atila and Bear

www.ataxia.org/forum/toast.asp

NAF CHAT ROOM

Moderator – Della (ddpokernut@yahoo.com)

www.ataxia.org/connect/chat-rooms.aspx

NAF FACEBOOK GROUP

www.facebook.com/group.php?gid=93226257641

NAF FACEBOOK FANS

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

NAF YOUTUBE CHANNEL

www.youtube.com/user/NatlAtaxiaFound?feature=mhum

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E-mail: kelly3902me@yahoo.com

Group Blog: <https://ataxiama.wordpress.com>www.ataxia.org/chapters/Maine/default.aspx**— MARYLAND —****CHESAPEAKE CHAPTER PRESIDENT****Carolyn Davis** – Vienna, VA

(703) 759-2008

E-mail: ccnafpres@gmail.com

www.ataxia.org/chapters/Chesapeake/default.aspx**MID-ATLANTIC SOCIAL SUPPORT GROUP LEADER****Bailey Vernon, Health Educator**

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NAF Directory

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– MASSACHUSETTS –**BOSTON AREA SUPPORT GROUP LEADERS**

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www.ataxia.org/chapters/Boston/default.aspx

CENTRAL MA SUPPORT GROUP LEADER

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– MICHIGAN –**DETROIT AREA SUPPORT GROUP LEADER**

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www.ataxia.org/chapters/Detroit/default.aspx

WESTERN MICHIGAN SUPPORT GROUP LEADER

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– MINNESOTA –**CENTRAL MN SUPPORT GROUP LEADER**

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E-mail: mbinnebose@hotmail.com
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TWIN CITIES SOCIAL GROUP

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Maryann Sweeney – Minneapolis, MN
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www.ataxia.org/chapters/TwinCities/default.aspx

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Lori Goetzman

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(507) 282-7127
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www.ataxia.org/chapters/LoriGoetzman/default.aspx

– MISSISSIPPI –**MISSISSIPPI CHAPTER PRESIDENT**

Camille Daglio
Hattiesburg, MS
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www.ataxia.org/chapters/Mississippi/default.aspx

– MISSOURI –**KANSAS CITY SUPPORT GROUP LEADERS**

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Lois Goodman
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(816) 257-2428
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AMBASSADOR

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www.ataxia.org/chapters/RogerCooley/default.aspx
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(417) 379-3799
Email: sjrheinecker@gmail.com
www.ataxia.org/chapters/Rheinecker/default.aspx

– NEW HAMPSHIRE –**NEW HAMPSHIRE SUPPORT GROUP LEADER**

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– NEW JERSEY –**NEW JERSEY SUPPORT GROUP LEADER**

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Tri-State Support Group Leader

Denise Mitchell
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www.ataxia.org/chapters/Tri-State/default.aspx

Kathy Gingerelli
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– NEW YORK –**CENTRAL NEW YORK SUPPORT GROUP LEADER**

Mary Jane Damiano – N. Syracuse, NY
Judy Tarrants – Fabius, NY
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TRI-STATE SUPPORT GROUP LEADER

Denise Mitchell – Bronxville, NY
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www.ataxia.org/chapters/Tri-State/default.aspx

Kathy Gingerelli – Parsippany, NJ

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– NORTH CAROLINA –

TARHEEL SUPPORT GROUP LEADERS

Jerry and Tammy Hauser – Advance, NC

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Ron and Donna Smith – Garner, NC

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www.ataxia.org/chapters/Tarheel/default.aspx

– OHIO –

GREATER CINCINNATI AREA SUPPORT GROUP LEADERS

Jennifer Mueller – Lexington, KY

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Julia Soriano – Cincinnati, OH

(513) 899-1195

E-mail: julia@epivision.com

www.ataxia.org/chapters/Cincinnati/default.aspx

CLEVELAND AREA SUPPORT GROUP LEADER

Carmen Pieragastini – Willowick, OH

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E-mail: willowpier@roadrunner.com

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

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

– PENNSYLVANIA –

CENTRAL PA SUPPORT GROUP LEADER

Christina Rakshys – Allentown, PA

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Michael Cammer – Downingtown, PA

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Facebook Group:

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

www.ataxia.org/chapters/CentralPA/default.aspx

POSITIVE PEOPLE IN PA SUPPORT GROUP LEADER

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WESTERN PA SUPPORT GROUP LEADER

Donna Eiben – South Park, PA

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S.G. Website: nafwesternpasupportchapter.weebly.com

www.ataxia.org/chapters/SouthPark/default.aspx

– RHODE ISLAND –

RHODE ISLAND SUPPORT GROUP LEADER

Anabela Azevedo – Bristol, RI

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www.ataxia.org/chapters/Rhodelsland/default.aspx

– SOUTH CAROLINA –

AMBASSADOR

Brad Forth – Greenville, SC

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– TENNESSEE –

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Vicki Tyler – Nashville, TN

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– TEXAS –

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

www.ataxia.org/chapters/Houston/default.aspx

NORTH TEXAS SUPPORT GROUP LEADER

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– UTAH –

UTAH SUPPORT GROUP LEADERS

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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

S.G. Website: www.utahataxia.org

www.ataxia.org/chapters/Utah/default.aspx

NAF Directory

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— VIRGINIA —

CHESAPEAKE CHAPTER PRESIDENT

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— WASHINGTON —

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Sherry McLaughlin – Port Townsend, WA

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— WISCONSIN —

WISCONSIN SUPPORT GROUP LEADER

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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

— INDIA —

INDIA SUPPORT GROUP LEADER (SAMAG)

“Seek a Miracle Ataxia Group”

Chandu Prasad George

Hyderabad, Secunderabad, India

Mobile: 0091-9989899919, 0091-9885199918

E-mail: sam_ataxiaindia@yahoo.comS.G. E-mail: india.ataxiagroup@gmail.com**Facebook Group:** <https://www.facebook.com/ataxiain>S.G. Website: www.ataxia.inwww.ataxia.org/chapters/Chandu/default.aspx

— PAKISTAN —

AMBASSADOR

Sajjad Jaider – Sindh, Pakistan

0092-(300) 8221850

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Studies of Brain and Behavior in Individuals with Premutations of the Fragile X gene (FMR1)

We currently are seeking individuals who carry a premutation allele of the Fragile X gene, FMR1. Some individuals with this premutation allele may show signs of Fragile X-associated Tremor/Ataxia Syndrome (FXTAS) which is characterized by motor and cognitive issues. This study aims to better understand these issues and their bases in the brain in individuals with FXTAS.

Eligible participants will be asked to complete the following:

- questions about family medical history and behavior
- tests of thinking abilities
- testing of sensory processing and movement control
- brain activity recording and imaging
- genetics testing

Testing will be conducted at the Center for Autism and Developmental Disabilities at UT Southwestern. Participants will be compensated for their time.

For more information, please contact us by phone at **214-648-5155** or by e-mail at **fragilex@utsouthwestern.edu**

Calendar of Events

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

SUPPORT GROUP MEETINGS

— Saturday, May 2, 2015 —

Boston Ataxia Support Group Meeting

Time: Noon – 2 p.m.

Location: Lahey Clinic, 41 Mall Rd., Burlington, MA

Details: For more information contact Lanie Cantor at laniecantor@gmail.com or Donna Gorzela at (978) 490-9552.

Greater Atlanta Ataxia Support Group Meeting

Time: 1 p.m.

Location: Emory Center for Rehabilitation Medicine, 1441 Clifton Rd. NE, Atlanta, GA

Details: For more information call (404) 822-7451 or atlantaataxia@gmail.com.

Ottawa Ataxia Support Group

Time: 1 – 4 p.m.

Location: Taoist Tai Chi Centre, 2930 Carling Ave., Ottawa, ON Canada

Details: Will include a demo Health & Recovery class led by Taoist Tai Chi instructors. For more information contact Prentis Clairmont at (613) 864-8545 or prentis.clairmont@gmail.com.

Tarheel Ataxia Support Group Picnic

Time: 11:30 a.m. – 3 p.m.

Location: White Deer Park Nature Center, 2400 Aversboro Rd., Garner, NC

Details: The park is entirely handicapped accessible. Attendees encouraged to bring side dish/desert. For more information or to RSVP contact Donna Smith at (919) 779-0414 or dsmith@sa-pr.com.

— Saturday, May 9, 2015 —

Central Minnesota Ataxia Support Group Meeting

Time: 9:45 – 11:45 a.m.

Location: Harvest Bank Branch, 24952 County Rd. 7, St. Augusta, MN

Details: For additional information contact Marsha Binnebose at (320) 248-9851 or mbinnebose@hotmail.com.

North Texas Ataxia Support Group Meeting

Time: 10 a.m. – Noon

Location: Ben Washington Baptist Church, 615 Davis St., Irving, TX

Details: For more information contact David Henry at cheve11e@sbcglobal.net.

Positive People in PA

Ataxia Support Group Meeting

Time: 10 – 11:30 a.m.

Location: Mercy Suburban Hospital, 2nd Floor Walk-up Room

Details: Lunch follows at Applebee's across the street. RSVP is required by Thursday prior to the meeting. To RSVP or for more information please contact Liz Nussear at (610) 272-1502 or at Lizout@aol.com.

— Wednesday, May 13, 2015 —

Willamette Valley Ataxia Support Group Meeting

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

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

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

— Thursday, May 14, 2015 —

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 or Kathy GINGERELLI at kgingerelli@msn.com.

— Saturday, May 16, 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.

— Sunday, May 17, 2015 —

Chi-town Ataxia Friendship Group Meeting

Time: 1 p.m. on the third Sunday of odd-numbered months

Location: Good Samaritan Hospital, 3815 Highland Ave., Downers Grove, IL

Details: For additional information please contact

Continued on page 58

Calendar of Events
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Jonas Cepkauskas at (708) 381-5555 or jonas@chitownataxia.org.

– **Saturday, May 23, 2015** –

Wisconsin Ataxia Support Group Meeting

Time: 1 – 4 p.m.

Location: Hawthorne Library, 2707 W. Washington Ave., Madison, WI

Details: For additional information contact Jenny Mathison at (608) 285-5285 or mjmathison@att.net.

– **Saturday, May 30, 2015** –

New Hampshire Ataxia Support Group Meeting

Time: 10 – 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.

– **Saturday, June 6, 2015** –

Mid-Atlantic Ataxia Support Group Meeting

Time: Noon – 2 p.m.

Location: Grace Fellowship Church, 9505 Deereco Rd., Timonium, MD

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

– **Wednesday, June 10, 2015** –

Willamette Valley Ataxia Support Group Meeting

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

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

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

– **Saturday, June 13, 2015** –

Central Minnesota Ataxia Support Group Meeting

Time: 9:45 – 11:45 a.m.

Location: Harvest Bank Branch, 24952 County ►►

Study ID: HUM00041414 IRB: IRBMED Date Approved: 7/10/2014 Expiration Date: 7/9/2015
HUM00041414 Approved On: 07/20/2010 Project Approval Expires On: 05/19/2011
IRB: «IRB»

Genes in Inherited Neurologic Disorders

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 (incoordination). 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 known causes of ataxia and found to be negative on such a test.

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.

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:
Dr. Margit Burmeister, PhD

Molecular & Behavioral Neuroscience Institute
University of Michigan,
5063 BSRB, 109 Zina Pitcher Place;
Ann Arbor MI 48109-2200
Telephone: (734) 6472186; email: margit@umich.edu

Road 7, St. Augusta, MN

Details: For additional information contact Marsha Binnebose at (320) 248-9851 or mbinnebose@hotmail.com.

Greater Atlanta Ataxia Support Group Picnic

Time: 1 p.m.

Location: Lanier Park, off Buford Dam Rd., Buford, GA

Details: For more information call (404) 822-7451 or atlantaataxia@gmail.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 please 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

Details: For more information contact David Henry at cheve11e@sbcglobal.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, 9900 Talbert Ave., Foundation Valley, CA 92708

Details: For more information contact Daniel Navar at (323) 788-7751 or danieln27@gmail.com or Cindy DeMint at (714) 970-1191 or cindy-ocataxia@gmail.com.

– Saturday, June 20, 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.

– Saturday, June 27, 2015 –

New Hampshire Ataxia Support Group Meeting

Time: 10 – 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.

– Wednesday, July 8, 2015 –

Willamette Valley Ataxia Support Group Meeting

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

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

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

– Thursday, July 9, 2015 –

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 or Kathy Gingerelli at kgingerelli@msn.com.

– Saturday, July 11, 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

Details: For additional information contact Marsha Binnebose at (320) 248-9851 or mbinnebose@hotmail.com.

North Texas Ataxia Support Group Meeting

Time: 10 a.m. – Noon

Location: Ben Washington Baptist Church, 615 Davis St., Irving, TX

Details: For more information contact David Henry at 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 Lane, Lafayette, CA

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

Positive People in PA Ataxia Support Group Meeting

Time: 10 – 11:30 a.m.

Location: Mercy Suburban Hospital, 2nd Floor Walk-up Room

Details: Lunch follows at Applebee's across the street. RSVP is required by Thursday prior to the meeting. To RSVP or for more information please contact Liz Nussear at (610) 272-1502 or at Lizout@aol.com.

*Calendar of Events**Continued from page 59***Tampa Bay Ataxia Support Group Meeting****Time:** 12:30 – 3 p.m.**Location:** Morsani Center, 13330 USF Laurel Dr. #1013, Tampa, FL**Details:** For more information contact Nygel Lenz at (727) 451-9165 or nygellenz@gmail.com.**– Saturday, July 18, 2015 –****Denver Area Ataxia Support Group Meeting****Time:** 1 – 4 p.m.**Location:** Swedish Medical Center, Spruce C Meeting Room, Second Floor, 501 E. Hampden Ave., Englewood, CO 80113**Details:** For more information contact Charlotte DePew at (720) 379-6887 or cldepew77@comcast.net.**Greater Atlanta Ataxia Support Group Meeting****Time:** 1 p.m.**Location:** Emory Center for Rehabilitation Medicine, 1441 Clifton Road NE, Atlanta, GA**Details:** For more information call (404) 822-7451 or atlantaataxia@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.**– Sunday, July 19, 2015 –****Chi-town Ataxia Friendship Group Meeting****Time:** 1 p.m. on the third Sunday of odd-numbered months.**Location:** Good Samaritan Hospital, 3815 Highland Ave., Downers Grove, IL**Details:** For additional information please contact Jonas Cepkauskas at (708) 381-5555 or jonas@chitownataxia.org.**– Saturday, July 25, 2015 –****New Hampshire Ataxia Support Group Meeting****Time:** 10 – 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.**– Saturday, August 1, 2015 –****Boston Ataxia Support Group Meeting****Time:** Noon – 2 p.m.**Location:** Lahey Clinic, 41 Mall Rd., Burlington, MA**Details:** For more information contact Lanie Cantor at laniecantor@gmail.com or Donna Gorzela at (978) 490-9552**– Saturday, August 8, 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**Details:** For additional information contact Marsha Binnebose at (320) 248-9851 or 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 please 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**Details:** For more information contact David Henry at cheve11e@sbcglobal.net.**– Wednesday, August 12, 2015 –****Willamette Valley Ataxia Support Group Meeting****Time:** 11:30 a.m. – 1 p.m. on the second Wednesday of every month**Location:** Albany General Hospital, 1046 Sixth Ave. SW, Albany, OR 97321**Details:** For more information contact Jason Wolfer at (503) 502-2633 or wolfer.jason@gmail.com.**– Saturday, August 15, 2015 –****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, 9900 Talbert Ave., Foundation Valley, CA 92708**Details:** For more information contact Daniel Navar at (323) 788-7751 or danieln27@gmail.com or Cindy DeMint at (714) 970-1191 or 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.

INFORMATIONAL, AWARENESS, IAAD EVENTS AND FUNDRAISERS

Warriors4Awareness 2015 Race Season

Locations: Winder Barrow, Anderson, Greenville Pickens, Hickory Motor and Crisp County Watermelon Capital Speedways

Details: Team of racers dedicated to bringing awareness to others so that a cure may be found. Also a name of the team of drivers that have committed to help bring awareness and support to the NAF. <https://naf.myetap.org/fundraiser/warriors4awareness/>

– **May 1 - September 30, 2015** –

National Bike Challenge

Details: Ride for fun, to work, anytime you can. This summer goal is uniting 75,000 people from across the country to ride 35,000,000 miles. Visit <https://nationalbikechallenge.org/team/6929> and click “Join” on the page to participate as part of Team NAF.

– **Friday, May 1-3, 2015** –

NY Metro Abilities Expo

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

Location: New Jersey Convention & Expo Center, Edison, NJ

Details: Admission is free. For additional information visit www.abilities.com/newyork.

– **Sunday May 3, 2015** –

Strike Out Ataxia

Time: 4:30 – 7:30 p.m.

Location: Pin Chasers Midtown, 4847 N. Armenia Ave., Tampa, FL

Details: Admission is free to NAF members and a guest. To register for free admission go to www.strikeoutataxia.com, select Participate as an Individual, then select the NAF Member registration and use promo code “NAFmembersONLY.” General admission is \$25. Proceeds benefit the National Ataxia Foundation. For more information call (863) 608-2626 or at www.strikeoutataxia.com.

– **Wednesday, May 6, 2015** –

Missy's Pacific Crest Trail (PCT) Hike for Ataxia

Time: 7:30 a.m.

Location: Pacific Crest Trail

Details: Missy is going to hike the Pacific Crest Trail starting May 2015 to raise awareness for ataxia and in Memory of Allen Prather. Please select the “Make Donation” button to support her efforts. <https://naf.myetap.org/fundraiser/hike4ataxia/>.

– **Friday, May 8-14, 2015** –

Ataxia Support Group Alaskan Cruise

Join the Middle TN Ataxia Support Group on a seven-day cruise to Alaska on the Celebrity Cruise line ship “Solstice.”

Location: The cruise departs and returns to port in Seattle, WA

Details: Price depends on accommodations and how many people go. There are some accessible excursions available too. To make reservations or for more information please contact the trip's travel agent, Jennie Cinadr, at (440) 646-9090 or j.cinadr@cruiseone.com.

– **Saturday May 9, 2015** –

Gunning's Run for Ataxia

Time: 7:30 a.m.

Location: FargoDome, 1800 N. University Dr., Fargo, ND

Details: The Gunning Family and friends will be participating in the Fargo Marathon to raise money and awareness of Spinocerebellar Ataxia (SCA) in honor of Kurt Gunning. Kurt was diagnosed with SCA in 2004. Kurt's daughter, Samantha Gunning, will be completing the full marathon while other family and friends will be participating in the 5K and half marathon events. Please select the “Make Donation” button to support their efforts. <https://naf.myetap.org/fundraiser/GunningsRun/>

– **Friday, May 15-16, 2015** –

Mobility Expo

Time: Friday and Saturday 9 a.m. – 6 p.m.

Location: North Atlanta Trade Center, Norcross, GA

Details: Admission is free. For more information visit www.themobilityexpo.com/home.html.

– **Friday, June 12-14, 2015** –

Chicago Abilities Expo

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

Location: Renaissance Schaumburg Convention Center, Schaumburg, IL

Details: Admission is free. For more information visit www.abilities.com/chicago. ❖

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 November 2014 through March 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.

Debi Adair	Frederic Benson	Kai Chau	Dawn Dizon	Brenda Graner
Ralph Aiello	Theodore Benson	Keith Chesser	Dorothy	Lawrence Graner
Michelle Alioto	Maddox Bertke	Yvonne Chesser	Douglas-Blank	Jacqueline Gray
Terry Allen	Giovanni	Clarissa Ching	Arlo Drury	Charles Gregory
Crystal Allsopp	Bertussi Jr.	William Chwee	Bonne Dunkelberg	Mike Grimes
Brian Alward	Ronald Beumer	Karen Cocquyt	Andrew Egeressy	Dana Gruenfelder
Ron Anderson	Anna Billings	The CoffeyFamily	David Erkens	Kurt Gunning
Stephanie Blake	Dotty Blank	Roger Cooley	John Erkens	Will Hackett
Geri Anile	Fred Blasberg	Sally Cooley	Daniel Eustache	Jane Haley
Janet Atkins	Justin Bolinger	Mary Coopmans	Margaret Evens	James Hankins
Barbra Ayres	The Bonner Family	Joan Costello	Joseph Falcon	Jim Horne Hankins
Bruce Ayres	Carol Brackett	Maria Cotten	Katherine Falcon	George Happell
Charlotte Ayres	Agnes Brideau	Debra Covington	Trinity Falk	Jean Happell
Sharon Baggett	Angela Brown	Joseph Cox	Matthew Farrow	Susan Harmer
Tracey Balis	David Brown	Russell Crystal	The Fields Family	Karan Hasler
Marion Balser	Miranda Brown	David Culbreth	Sharron Fowler	Carol Haukos
Lori Bandazy	Jackie Brown	Jimmy Dale	Sondra Frank	Heather Hawkins
Gina Barber	Jim Brown	Ronesa Daniels	Donald Freddy	Pennie Haydon
Brandon Barker	Jacqueline	Iswyn Davies	Mike Friend	John Hays
Elle Barnhart	Browning	Carson Davis	Ruth Furniss	Mary Hays
Mary Barros	Jim Browning	Kenyon Davis	Rita Garcia	Dr RJ Healey
Jim Bean	David Brunnett	Page Davis	Judy Gingerelli	Lenore Healey
Cindy Bean	Liam Cannon	Jack Dean	Kathleen Gingerelli	Bill Herrmann
Michel Beaudet	James Carr	Joe DeCrescenzo	Christine Goar	Todd Hoag
Betty Beck	Joe Carroll	Family	Tanya Goldman	Carrol Hofer
Clair Beck	Peter Castaneda	Bruce Devan	Penny Golminas	Todd Hopkins
Connie Becker	Sami Castro	John DiMonte	Terry Golminas	Jordan Hubbard ►►

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.



Sydney Hubbard	Billie Luckoski	Jean Myers	Michael Reminder	Ronna Storm
Krista Humes	Isabel Luis	Tommy Myers	Jim Richards	Pearl Straub
Paul Humes	Scott Lund	John Norton	Sherri Richwine	Harry Stricker
Bonnie Huston	Michael Lundquist	Alayne Novalany	Elizabeth Riley	Bob Sturdevant
Patricia Hysong	Sid Luther	Lanea Oakland	Janet Riley	Teresa Sundquist
Gregory Irwin	Claire Lutz	John O'Brian	Florence Rinaldi	The Sweeney Family
Dorothy Jaber	Robert Lutz Sr.	Patricia O'Brien	Pattie Robles	Alice Tapper
Marilyn Jackson	John MacDonald	Tom O'Connor	Mary Romero	Sandy Taylor
Rinda Janney	Mickey Mackinaw	Brent Ofenstein	Mary Rotolo	Peggy Taylor
Mindee Jensen	The Mahaffy Family	Greg Orf	Rocco Rotolo	Bruce Thomas
Margaret Johnson	John Marten	Ben Oviatt	Cindy Santa Croce	Mark Tokarz
Sandy Johnson	James Martin	Sandra Parker	Dominic	Helen Treloar
Daniel Julien	Richard Martin	Nellie Pascoe	Santa Croce	Helen Treloar
Beatrice Kahn	Bradley Masserant	Kimble Pearce	Donald Santa Croce	Buck Turnbull
Jeff Kahn	Brent Masserant	John Pellegrino	Joe Santa Croce	Phil Turnbull
Frank Keeling	Victor Masserant	Izzy Penston	Robert Santa Croce	Heather Urick
Dru Keene	Family	Own Penston	Matthew Schlarman	Antoinette Varron
Lisa Kelso	John Mauro	Cody Peterson	Ronald Schneider	Anna Vibberts
Mac Kelso	Frank McConville	Eric Peterson	Larry Schut	Eleanor Vibberts
Erin Kiernan	Gloria McConville	Erin Peterson	Loretta Schut	Shirley Vodicka
Joshua Kirschbaum	Maurice McDonald	Lea-Anne Peterson	The Schwartz Family	Marlea Waddell
Donna Klotz	Bettylou McIntosh	The Peterson Family	Carol Segura	Wayne Walters
Jamie Kosieraki	Gregory Mead	Scott Pettengill	Derek Semler	Olive Westhoff-
Helen Krugman	Younger Meade	Nina Piatetsky	Cheryl Serge	Derrington
Robert Krugman	James Misselli	Eric Pogulis	Sally Shelley	Betty
Normand LaBarre	Dorothy Moetsch	Jill Porter	Veronica Silva	Westmoreland
Jim Lally	Suzanne Mondy	Ken Porter	Dana Simpson	David Westrick
Jennifer Leader	Curtis Montgomery	Rita Lobascio	Aaron Sims	The Whipple Family
James Lehr	Earl Moore	Don Pracht	Henry Skala Jr.	Page Whitmore
Johna Leidholt	Jack Moore	Janet Pracht	James Skok	Robert Wibracht
Tony Lewendon	Kai Moreland	Jeffrey Pracht	Doyle Smith	Faye Williston
Harriet Lewis	Dolores Morello	David Price	Kathryn Smith	Virgie Wince
Sylvie Leyerle	Chad Morgan	Julie Quinlivan	Kathryn Smithers	Yingling Family
Billy Lloret	Kathryn Morgan	Shirley Quirk	Terry Snider	Erik Zalenski
Maggie Loeffler	Jacob Mrockowski	Charity Ranger	Abbie Spellman	Anna Zaske
Joyce Lokken	Taylor Munsterman	Paula Raynor	Jenny Spiller	Hitomi Zeller
Walter Lowry	Gordon Musilli	Jennifer Reintjes	David Stein	Rona Zelniker
Ron Lucken	Bubba Myers	Richard Relmond	George Storm	Jonathan Zilles

Remembering NAF in Your Will

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

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

Over the years these individuals, who have

chosen NAF as a beneficiary, have given anywhere from a few thousand dollars to nearly one million dollars. Their forethought and benevolence has enabled the Foundation to support promising ataxia research and to provide meaningful programs and services to ataxia families across the country.

Perhaps this is the time to consider adding the National Ataxia Foundation in your will. For more information, please call NAF at (763) 553-0020 or e-mail mike@ataxia.org.



National Ataxia Foundation

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

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Looking for Ataxia Merchandise?
Please visit our store
at www.ataxia.org!

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.

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.

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 _____