The National Ataxia Foundation (NAF) is pleased to announce that 20 promising Ataxia research studies from the United States, Italy, Canada, United Kingdom, France and Portugal were awarded funding at the December 2015 NAF Board of Directors meeting for fiscal year 2016. With the funding of these 20 research studies and the previous research studies funded earlier in 2015, nearly one million dollars were committed in 2015 for ataxia research.

The funding for these important ataxia research projects have been made possible through the generosity of the NAF donors and partners who contributed to the 2015 NAF Annual Ataxia Research Drive, the $200,000 matching research gift from an anonymous donor, our corporate and foundation friends, the Michael and Patricia Clementz Family Endowment Fund for SCA 3 Research, NAF chapters and support groups, individual and group donations, individuals and families who conducted fund raising events, and the NAF Walk n’ Rolls for Ataxia events.

The National Ataxia Foundation gratefully acknowledges all who supported these important ataxia research studies. It is through your generosity that enables the NAF to continue to fund cutting-edge ataxia research studies that brings us closer to ending ataxia. Thank you!

Summaries of these important studies are in this issue of *Generations*, beginning on page 3.
Disclaimer
The National Ataxia Foundation does not endorse products, therapies, services, or manufacturers. Those that are mentioned in Generations are included only for your information. The NAF assumes no liability whatsoever for the use or contents of any product or service mentioned in the newsletter.

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The deadline to submit materials for the summer issue of Generations is May 13, 2016.
National Ataxia Foundation 
Funded Research for FY 2016

Research Seed Money Awards

Katia Aquilano, PhD
University of Rome Tor Vergata, Rome, Italy

Study of the Role of Lipid Dysmetabolism in the Pathogenesis of Friedreich’s Ataxia

Friedreich’s ataxia (FRDA) is an inherited neurodegenerative disease caused by mutations in the mitochondrial protein frataxin (FRX). Complications of FRDA include diabetes mellitus and cardiomyopathy. Understanding the molecular links between FRX mutation and development of metabolic disturbance is of pivotal importance for finding new therapeutic strategies to ameliorate disease’s symptoms.

By using a mouse model of FRDA, we want to assess whether accumulation of intracellular lipids in the form of lipid droplets (LDs) and impairment of lipid degradation could be operative in heart and brain.

We also intend to test whether such events can be ascribed to the decrease of the content of cellular lipases such as adipose triglyceride lipase (ATGL) and lysosomal lipase (Lipa).

Finally, in this research project we aim at identifying the impairment of lipase downstream lipid signaling as a crucial factor in mitochondrial metabolic dysfunction in FRDA.

Our research could therefore give effort in developing new therapeutic approaches and druggable targets to overwhelm cardiomyopathy and neurodegeneration that could be exploited for future clinical research.

Completed on page 4

Research Summary Primer

Research grants made by the National Ataxia Foundation are made in the following categories:

Research Seed Money Awards: 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: One-year grants of $35,000 awarded to encourage young investigators to pursue a career in 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.

Pioneer SCA Translational Awards: One-year grants of $100,000 that will facilitate the development of treatments for the spinocerebellar ataxias.

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

Other Research Awards: The Foundation continues to support the National Ataxia Database, an important tool for clinical research.
Michael Downey, PhD  
University of Ottawa, Ontario, Canada

A New Look at Ataxia7 as a Regulator of Substrate Selection by the KAT2a Acetyltransferase

Spinocerebellar ataxia type 7 (SCA7) is an inherited disease that affects a type of cell in the body called a neuron, which are found in the brain and help us to sense the environment around us. SCA7 patients have difficulty walking and talking. In addition, they experience a deterioration in vision and may even become blind as they grow older.

At the heart of SCA7 is a protein called Ataxin7. All proteins are made of individual building blocks called amino acids and the order and number of these amino acids dictates what they do in the cell. SCA7 patients produce Ataxin7 that has extra amino acids. The reason these extra amino acids cause problems for affected individuals is unknown.

Our proposed project uses cutting-edge protein analysis tools, including a very sensitive instrument called a mass spectrometer, to investigate the idea that these extra amino acids change the way the Ataxin7 physically interacts with other proteins in the cell, preventing them from carrying out their jobs.

Our creative approach to studying SCA7 has the potential to uncover drug targets that can be exploited to prevent the death of neurons in patients and stave off symptoms of the disease.

Dr. Michael Downey

Manolis Fanto, PhD  
King’s College London, Great Britain

Rbfox Prot ein s as Critical Determinants for Cell Toxicity in DRPLA and Other Spinocerebellar Ataxias

Dentatorubropallidoluysian-Atrophy (DRPLA) is a genetically inherited form of ataxia. Whereas all cells in the brain express the diseased gene, some brain areas, are more sensitive to its expression and degenerate earlier. We have identified one protein family, whose expression is different precisely in these brain areas in a mouse model for the disease. We are now planning a series of experiments to verify if this protein, and those closely related to it, are indeed important in sensitizing the neurons to the DRPLA gene. If this is the case, this will be a first step towards devising a therapeutical strategy that aims at protecting these brain areas more substantially than others to delay the disease onset.

CFC Number

The National Ataxia Foundation’s Combined Federal Campaign (CFC) number is 10752.

This program, the world’s largest and most successful annual workplace charity campaign, provides a convenient way to donate to the Foundation.

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

Dr. Manolis Fanto and post-doctoral researcher Dr. Olga Baron
Neurons in the human brain communicate information with one another, enabling coordinated function and protection from injury due to metabolic stress. This communication occurs through receptors, or channels, on the cell surface that recognize small molecules. One such channel is named TRPC3 and it transports positively charged ions to communicate signals within the cell. In mice, mutation of Trpc3 leads to cerebellar ataxia and affects critical pathways important in cerebellar function. TRPC3 is also expressed in the human cerebellum and recently we reported a sporadic ataxia patient with a suspected TRPC3 mutation (p.R762H) predicted to impair the function of this channel. We demonstrated that the human p.R762H mutation behaves like the ataxia-causing mutation in mice and therefore causes disease. This new form of dominant cerebellar ataxia was named Spinocerebellar Ataxia, type 41 (SCA41). The identification of the first patient with SCA41 has raised many questions about this new disease. We propose to investigate SCA41 by 1) developing a human cellular model system to study TRPC3 and characterize its mutations, and 2) broadly evaluate a large population of sporadic and dominant ataxia patients for TRPC3 mutations to better understand the clinical presentation and frequency of this disease.

Specific Aim 1) We will create cell lines, termed induced pluripotent stem cells (iPSCs), from normal and SCA41 patient skin cells that can be differentiated into cerebellar neurons and used to model the function of the human cerebellum in a dish. 1A) The effects of the p.R762H SCA41 mutation will be studied through a series of physiological tests to determine which aspects of channel function are working correctly or not. 1B) Suspected mutations identified in Specific Aim 2 will be tested by developing iPSCs from these patient’s skin cells. We have already found one potential patient to study. 1C) Additional mutations, including the known ataxia mutations in mice, will also be tested by introducing them directly into normal human iPSC cell lines using a method called genome editing. Ultimately, we will be able to study every key region of the protein to predict which changes are likely to cause ataxia in people to improve the diagnosis of future patients. This model system will also provide a means of testing new channel-modifying drug therapies.

Specific Aim 2) To identify new mutations in TRPC3 we plan to evaluate our extensive patient population for changes in the gene. Using a combination of exome sequencing and targeted gene resequencing we will examine undiagnosed dominant families and patients with sporadic ataxia for rare or novel sequence changes in TRPC3. By comparing the potential effects of these rare changes to more common changes found in normal individuals, we can estimate
NAF Funded Research for FY 2016

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whether these are likely to be mutations that may cause ataxia and test them in Specific Aim 1B to see if they damage channel function. This may also help us devise new ways to verify novel mutations in other ataxia genes as well.

Liliana Simões Mendonça, PharmD, PhD
University of Coimbra, Portugal

The Transplantation of Induced Pluripotent Stem Cells (IPSC)-derived Neural Stem Cells (NSC) in Machado Joseph Disease (MJD)

Machado-Joseph disease (MJD) is a progressive and frequently fatal neurodegenerative disease, originally described in people of Portuguese descent, and caused by a mutation on the ATXN3 gene that originates a mutant ataxin-3 protein. Mutant ataxin-3 protein is toxic causing neuronal dysfunction and degeneration in specific brain regions and leading to motor and non-motor symptoms. Although there is no effective treatment for this disease some specific molecular strategies such as gene silencing of mutant ATXN3 resulted in promising outcomes. However, the translation of these therapeutic strategies into clinical application is most probable in symptomatic patients, already with extensive neuronal loss, and therefore we consider that cell replacement will also be needed.

Recently, we demonstrated that cerebellar transplantation of NSC isolated from newborn mice into the cerebellum of adult MJD mice increase neurotrophic factors levels, reduce neuro-inflammation and neuronal loss and trigger a significant and robust improvement of the MJD-associated motor coordination impairments. Moreover, we observed that the transplanted NSC differentiate into neural cells. However, the lack of reliable human NSC sources is a big drawback in the implementation of NSC transplantation in clinical practice. One way to overcome the lack of human NSC sources is to use differentiated cells of the patients that can be reprogrammed to IPSC. Then, IPSC can be induced into NSC and subsequently the mutant ATXN3 mRNA can be silenced.

Therefore, we speculate that it is possible to generate patient-specific NSC depleted of the mutation responsible for the disease. Moreover, we hypothesize that the transplantation of mutant ataxin-3 depleted patient-derived NSC can be used for neuroregeneration of brain lesions of MJD patients promoting functional recovery.

Therefore, the specific aims of this project are: 1) to generate mutant ataxin-3-depleted NSC from fibroblasts of MJD-patients and 2) to evaluate if the transplantation of mutant ataxin-3 depleted patient-derived NSC in MJD-transgenic mice leads to improvement in MJD-associated neuropathology and motor phenotype impairments.

Matching Gifts

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

Please ask your employer if they have a matching gifts program. If they do, your gift and the gifts of your co-workers will double in value. Thank you for your support.
The National Ataxia Registry (PI-Dr. S. Subramony; now supported by the CORDS registry), the National Ataxia Database (PI-Dr. S. Perlman), and the Ataxia Tissue Donation Program (PI-Dr. A Koeppen; now supported at individual sites) have formed the infrastructure for clinical research in the ataxic disorders. They enable ataxia researchers to notify ataxia patients of upcoming research projects, to store and analyze data from those projects, and to examine tissues from ataxia patients to find out how ataxia develops and how the body responds to it.

Four prior National Ataxia Foundation grants (1/1/01-12/13/01; 01/01/04-12/31/14, 1/1/05-12/31/05, 1/1/07-12/31/07) were used to develop 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 John 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. It is also a safe and permanent repository for clinical research data that has already been collected.

The templates for the Rare Disease Network-supported CRC-SCA natural history study (PI-T. Ashizawa) are now part of the National Ataxia Database. Following the end of funding of that project, with the help of the NAF “bridge” grants for the Web-based National Ataxia Database (1/1/14-12/31/15), 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 400 subjects have been enrolled and are pursuing serial examinations and banking of specimens. Five have already resulted from this resource.

The National Ataxia Database will also be open for ataxia researchers to “bank” other clinical data collected, either in the individual’s private data docks (not accessible to other ataxia researchers) or in data docks shared by several researchers.

Paul Rosenberg, MD
Duke University Medical Center, Durham, NC

Contribution of Store-operated Calcium Entry to Calcium Dysregulation in Spinocerebellar Ataxias

The ataxias are a heterogeneous group of disorders that result from degeneration of the cerebellum and its connections to other brain regions. The cerebellum is involved in motor coordination and learning and cerebellar Purkinje neurons play a central role in these processes. Dysregulation of neuronal calcium signaling has emerged as a common feature underlying the dysfunction, degeneration, and death of Purkinje neurons in a number of ataxias, including the hereditary spinocerebellar ataxias. Understanding the mechanisms that mediate calcium fluxes in these ataxias could provide clues for novel therapeutic interventions.

Continued on page 8
dysregulation in this diverse group of diseases is essential for understanding the pathogenesis of these ataxias and for developing effective therapeutic strategies to treat this debilitating group of diseases.

Recent studies have established the importance of a novel calcium signaling pathway known as store-operated calcium entry (SOCE), which requires the STIM1 calcium sensor, in regulating the calcium dynamics of Purkinje cells and other neurons. While a number of calcium signaling pathways have been implicated in the dysregulation of calcium homeostasis and pathogenesis of ataxia, the possibility that SOCE is involved has not been investigated. The goal of this proposal is thus to determine the role of STIM1-dependent SOCE in the disturbances of calcium handling in ataxias.

Our central hypothesis is that disruption of STIM1-dependent SOCE makes a critical contribution to Purkinje cell dysfunction and degeneration and consequent functional deficits in several types of ataxia. To test this hypothesis we will first investigate whether SOCE contributes to the dysregulation of calcium homeostasis and Purkinje cell dysfunction in established mouse models for several of the ataxias. Second, we will determine the extent to which an increase or decrease in STIM1-dependent calcium signaling might account for Purkinje cell dysfunction and degeneration in ataxia. These studies will begin to elucidate the role of SOCE in calcium-dependent Purkinje cell degeneration in ataxia and may ultimately lead to novel therapeutic options for treating for these degenerative disorders.

Young Investigator Awards

Ricardo Mouro Pinto, PhD
Massachusetts General Hospital Harvard Medical School, Boston, MA

Identification of Genetic Modifiers of Somatic GAA Instability in Friedreich Ataxia by in Vivo CRISPR-Cas9 Genome Editing

Friedreich’s ataxia (FA) is a devastating neurodegenerative disorder for which there is no cure or significant disease-modifying treatment. It is caused by a rare genetic mutation that results in lower levels of an important protein – frataxin – being produced. The most common mutation consists of an expanded stretch of repetitive DNA in the frataxin gene – GAA trinucleotide repeat. The longer the GAA repeat, the less frataxin protein is produced. In addition to being expanded in FA patients, this repeat has a strong tendency for further expanding, not only in transmissions from parent to child, but also throughout the life of the patient, particularly in organs primarily affected in FA. This raises the hypothesis that this process can accelerate the onset and progression of the disease in FA patients.

To date, we have already learned that genes involved in maintaining the integrity of our genomes throughout the life of a cell (DNA repair genes) are involved in the GAA expansion.
mechanism. However, we still have a very limited understanding of how this process occurs. Knowing the key players and understanding this mechanisms in much more detail is very important since it should facilitate the development of therapeutics that target the mutation directly.

In addition, a recent study that looked at ~4050 Huntington’s Disease (HD) patients (also caused by a trinucleotide repeat) revealed that genes involved in various DNA repair pathways are likely modifiers of HD age of onset, further echoing the potential therapeutic impact of targeting these genes.

Our goal, is to use novel genome editing strategies in FA mouse models, namely the CRISPR-Cas9 toolbox, to determine if these genes are involved in the GAA repeat expansion process and whether they modify FA-related symptoms.

Patricia Richard, PhD
Columbia University, New York, NY

Role of the SETX/CHD3 Interaction in the DNA Damage Response and Its Connection to AOA2

Neurological diseases are disorders of the brain, spinal cord and nerves that control the body. Ataxia Oculomotor Apraxia type 2 (AOA2) is a clinical manifestation of the dysfunction of parts of the nervous system (the cerebellum) that coordinate movement and lead to severe motor handicap. AOA2 is a frequent type of autosomal degenerative cerebellar ataxia and is caused by mutations in the Senataxin (SETX) gene. SETX has been shown to be involved in the response to DNA damage.

We recently found that SETX can associate with CHD3, a component of a complex that is able to compact DNA. Compaction/relaxation of chromatin plays an important role in the DNA damage response. After DNA damage, compacted chromatin needs to be relaxed to allow the DNA repair machinery to access to the damage. We found that several AOA2 mutations in SETX can disrupt the interaction. But considerable additional work is required to understand fully the significance of these findings, and how they can be exploited to combat AOA2.

My studies are aimed at dissecting how the SETX/CHD3 interaction affects the process of DNA damage repair and, importantly, leads to AOA2 disease when defective. By using biochemical and molecular biology approaches, I will investigate the function of SETX and CHD3 in response to DNA damage, and how AOA2 mutations disrupt this process. A fuller understanding of the molecular function of the SETX/CHD3 complex in chromatin remodeling and the DNA damage response will lead to a better understanding of ataxia, and ultimately to novel therapeutic approaches to prevent and treat the disease.

Percy Tumbale, PhD
National Institute of Environmental Health Sciences, National Institutes of Health, Research Triangle Park, NC

Expanded Roles for Aprataxin Mutations in Ataxia Oculomotor Apraxia 1 (AOA1)

Ataxia Oculomotor Apraxia 1 (AOA1) is an autosomal recessive ataxia which resembles Friedreich’s Ataxia (FA) and Ataxia-Telangiectasia (A-T) but without the extra-neurological features. The clinical characteristics of AOA1 are difficulty coordinating movements (ataxia),
impaired initiation of saccadic eye movement (oculomotor apraxia), and neuropathy. AOA1 symptoms typically manifest in early childhood, with slow progression until patients become wheelchair-bound within a decade of onset. Currently, there is no treatment to improve or prevent the progression of this disease. AOA1 is caused by mutations in the aprataxin gene (APTX), encoding the protein aprataxin (Aptx). Aptx plays a crucial role in DNA repair, and acts as the proofreader for DNA ligases. Although a wealth of evidence supports a role for Aptx in nuclear DNA repair, it is not known whether that is the only function of Aptx. Aptx localizes to the nucleus and nucleolus, pointing to roles in these organelles. Our data have shown many AOA1-linked Aptx mutations that cause severe symptoms in patients have only a minor impact on Aptx activity. Moreover, Aptx is ubiquitously expressed in human tissues but specifically associated with a neuronal disease, suggesting Aptx mutations may cause AOA1 in patients by other unknown mechanisms. In agreement with this, we have identified an AOA1-linked Aptx mutation that abolishes Aptx nucleolar localization, yet only moderately impairs Aptx activity. Our data point to an extended role for Aptx in the nucleolus. Here we present a research proposal aiming to delineate the links between Aptx nucleolar dysfunction and AOA1. Hypothesis 1: Aptx plays important roles in the nucleolus, and its nucleolar localization is mediated by nucleolar proteins. Hypothesis 2: AOA1-linked Aptx mutations impair Aptx interactions with nucleolar proteins, resulting in loss of Aptx in the nucleolus. Thus, Aptx nucleolar dysfunction is among the causes that contribute to AOA1. Aim 1: Define the molecular mechanism and regulation of Aptx nucleolar localization mediated by its interacting nucleolar proteins, Aim 2: Define the nucleolar functions of Aptx, and how AOA1-linked Aptx mutations impact Aptx nucleolar functions. The studies here explore biological functions of Aptx beyond the presently understood role in nuclear DNA repair. We will establish a molecular platform to explore new links between APTX dysfunction and AOA1. We believe this will lead to development of better strategies to effectively diagnose, monitor, and possibly prevent AOA1 progression.

**Estate Planning and the NAF**

When you make or revise your will or trust, or review your life insurance contracts or retirement funds, please consider naming the National Ataxia Foundation among the charities included as beneficiaries. Your gift to the Foundation can make a huge difference in the lives of those battling ataxia.

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

“I bequeath ____% of my estate (or fund) to the National Ataxia Foundation, a 501(c)(3) non-profit organization located at 2600 Fernbrook Lane, Suite 119, Minneapolis, MN 55447-4752. Federal Tax ID# 41-0832903.”

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

Thank you for your support of the important work of the Foundation.
Molecular Pathogenesis of Spinocerebellar Ataxia Type 12

Spinocerebellar ataxia type 12 (SCA12) is a rare progressive autosomal dominant neurodegenerative disease. SCA12 is caused by a CAG trinucleotide repeat expansion (normal <28 triplets, disease 46–78) in the promoter region of the gene PPP2R2B, a regulatory subunit of the common cellular phosphatase, PP2A. Clinically SCA12 is characterized by midlife-onset of movement abnormalities, with prominent tremor and gait disturbance, and less consistently psychiatric and cognitive disturbances. Pathologic findings include generalized loss of cells in the cerebral cortex and cerebellum, with prominent loss of Purkinje cells. While we do not yet know how the SCA12 mutation leads to neuronal loss, our preliminary findings suggest that the mutation may function to increase the activity of the PPP2R2B promoter. We hypothesize that the mutation causing SCA12 increases expression of the primary PPP2R2B transcript and protein, with a resultant shift in PP2A targeting, resulting in alterations of the phosphoproteome and eventually neurotoxicity. The goal of this proposal is to develop and characterize cell models of SCA12 to test this hypothesis. This knowledge may lead to novel therapeutic treatment targets for SCA12 and possibly other ataxias and related disorders.

Advanced Induced Pluripotent Stem Cell-based Models of Machado-Joseph Disease

Machado–Joseph disease (MJD), or spinocerebellar ataxia type 3, is a neurodegenerative polyQ disease and the most common of the dominantly inherited ataxias worldwide. Despite important progresses in the knowledge of the patho-}


cological mechanisms involved we still miss effective therapies. Advances in this field depend on innovative and predictive models of disease for which there is an urgent need for both mechanistic and preclinical studies. Among such models, the induced pluripotent stem cells (iPSC) are the leading tools, offering the promise of enabling major ground-breaking advances. Disease-specific stem cells and the resulting differentiated cell types offer an unprecedented opportunity to investigate the molecular mechanisms and to perform preclinical drug screening. Nevertheless, the use of these cells and their differentiated derivatives still present challenges due to line-to-line variations, experiment-to-experiment differentiation variations and genetic instability. To overcome these issues, identify and later easily assess typical signatures associated with disease mutations, we will produce isogenic patient-specific lines and differentiate these cells into mature cerebellar neurons from MJD patients-derived iPSCs and
isogenic controls. This will allow the genetic determinant to be challenged in strictly identical cells that do not differ in any way in terms of their genome. We will further use these cells to develop and implement standardized, robust medium/high throughput methodologies for quantitative analysis of specific defects to investigate pathomechanisms and drug screening in MJD.

We expect this project can make a truly important contribution to the field of ataxias and particularly of Machado-Joseph disease by providing the models and methodologies to enable significant advances in the knowledge of the mechanisms of MJD and provide the tools for pre-clinical identification and validation of new effective therapies for MJD.

Su Yang, PhD
Emory University, Atlanta, GA

Developing the MANF-based Therapeutic Approach for Spinocerebellar Ataxia 17

Spinocerebellar Ataxia 17 (SCA17) is a progressive neurodegenerative disease that is genetically inherited. The cause of SCA17 is a specific mutation in the gene encoding a protein named TATA box binding protein (TBP), which makes TBP become misfolded and toxic. SCA17 is characterized by prominent neuronal loss in the cerebellum, and patients display a broad spectrum of symptoms, including ataxia, parkinsonism, dementia and psychiatric abnormalities. There is currently no effective treatment for this devastating disease.

In our previous study, we identified a protein named mesencephalic astrocyte-derived neurotrophic factor (MANF), whose expression level is reduced in the cerebellum of a mouse model of SCA17. Increasing the amount of MANF in that mouse model ameliorated SCA17 disease phenotypes. MANF is also known to be neuroprotective in other disease conditions including Parkinson’s disease and ischemic stroke. These facts suggest that MANF could be a therapeutic target for the treatment of SCA17. Our research is aimed at developing MANF-based therapeutic approach for SCA17. We have screened a collection of 2000 US Food and Drug Administration (FDA)-approved compounds and natural products, and found several compounds that can stimulate MANF expression in cultured cells. We will continue to test if these compounds can manage SCA17 disease phenotypes when given to our SCA17 mouse model.

Sign Up for 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 regarding ataxia.

Take a moment right now to send your e-mail address to joan@ataxia.org so you don’t miss out on receiving important information from the Foundation.

Please make sure to add naf-eblast@ataxia.org to your address book or “safe sender” list to make sure you get the e-mails, or check your spam folder.
The result of our study would have an immediate impact on the development of SCA17 treatment, as the compounds to be tested are already FDA approved. Furthermore, as cerebellum degeneration is common among other SCA types, the MANF-based therapeutic approach could have broad implications for the treatments of other SCA types as well.

Pankaj Kumar Singh, PhD
Institut de Génétique et de Biologie Moléculaire et Cellulaire (IGBMC), Illkirch-Strasbourg, France

Unravelling Pathomechanisms of Muscle Dysfunction in an Autosomal Recessive Cerebellar Ataxia 2 (ARCA2) Mice Model

Mutation in AarF Domain Containing Kinase 3 (ADCK3) gene leads to autosomal recessive cerebellar ataxia 2 (ARCA2). The prevalent features of the disease include ataxia, cerebellar atrophy, ubiquinone deficiency in muscle and exercise intolerance. The pathogenic protein ADCK3, is a putative mitochondrial kinase and based on its homology with yeast CoQ8 proteins, is proposed to have an undefined role in the biosynthesis of small lipid coenzyme Q (CoQ). Our recently created constitutive Adck3 knockout mice (Adck3KO) recapitulate many pathogenic features of the disease, including ataxia, CoQ deficit in the skeletal muscle and mild exercise intolerance. Further careful investigation of pathogenic changes in these mice reveals a mitochondrial defect specifically in the skeletal muscle.

Mitochondria are dynamic organelle involved in oxidative respiration and energy production and lie at the center of cellular growth and metabolism. Mitochondrial diseases due to defects in respiratory chain complexes and consequent impairments in the electron transport chain are quite prevalent. These diseases have mild to severe pathological consequences depending upon the extent of dysregulation in mitochondrial performance and metabolic harmony. Exercise intolerance is one such consequence of compromised mitochondrial activity, caused due to reduced oxygen consumption and increased anaerobic metabolism in the skeletal muscle. Exercise intolerance seen in ARCA2 patients and in Adck3KO mice could thus be a consequence of defective mitochondrial function and metabolic homeostasis in the skeletal muscle. This proposal therefore, intends to uncover the fundamental basis of mitochondrial/metallic perturbation in the skeletal muscle of Adck3KO mice. Our emphasis will be to identify a molecular target, which can be modulated in the skeletal muscle to improve respiratory performance and alleviate physiological irregularities including exercise intolerance in Adck3KO mice. Moreover, cellular pathways and molecules affected upon ADCK3 deficiency in muscle can further be targeted in the cerebellum to investigate if they could also underlie cerebellar dysfunction and ataxia in ARCA2. Together, delineating the underlying basis of skeletal muscle dysfunction in ARCA2, this study will help finding a potential therapeutic target for the disease.

Continued on page 12
Laura Ranum, PhD
University of Florida, Gainesville, FL

ASO Targeting of Bidirectional Transcripts and RAN Translation in SCA8

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.

Wendy H. Raskind, MD, PhD
University of Washington, Seattle, WA

Oligonucleotide-based Therapy in BAC-Mouse Models of SCA14

SCA14 is one of the autosomal dominant spinocerebellar ataxias that are not caused by expansion of a DNA repeat sequence. It is a typical SCA and like others, there is no treatment to prevent, stop or slow its progression. We previously discovered that SCA14 is caused by mutations in the gene for the enzyme protein kinase C gamma (PKCγ). We created transgenic mouse lines that carry the normal human PKCγ gene or one of two SCA14-associated mutated forms, along with the gene’s normal regulatory information. In these lines human PKCγ is made in the central nervous system everywhere it should be and at the correct times in development. The PKCγ protein that contains one of the mutations forms large aggregates in cerebellar Purkinje cells. The other mutation causes Purkinje cells to develop abnormal dendrites. Dendrites are nerve cell processes that receive signals from other nerve cells. Mutant PKCγ protein is toxic.

Thrivent Choice Works

The National Ataxia Foundation is a participating organization of the Thrivent Choice Works program of Thrivent Financial. If you are an eligible member of Thrivent Financial, please consider directing your Thrivent Choice Dollars to the NAF. For more information, please visit www.thrivent.com/making-a-difference/living-generously/thrivent-choice/.
to cells, but the normal human one is not. Mice that have only one working copy of the mouse PKCγ gene do not develop Purkinje cell abnormalities and appear neurologically normal. Established and investigational treatments for other diseases provide reasons to be encouraged about the possibility to develop targeted treatment for SCA14. In cancers where abnormal protein kinases play a role, medications that block the kinase are being used successfully to treat patients. Short nucleotide sequences that suppress or alter the mutant gene are being studied in patients with other inherited neurodegenerative disorders. Therefore, we propose to study the effect of suppressing production of the abnormal human PKCγ protein on the cerebellar abnormalities that develop in the mutant transgenic mice. The experiments we propose are a first step towards identification and study of therapeutic agents in patients with SCA14.

Young Investigator for SCA Awards

**Sarah Goetz, PhD**  
*Duke University, Durham, NC*

*Exploring the Role of Primary Cilia in SCA11 Pathogenesis*

My lab studies primary cilia – tiny projections that resemble antennae and are found on most cells. Like antennae, cilia function to receive certain types of signals from neighboring cells and help to coordinate a response. Cilia are therefore very important during embryonic development, and genetic disruptions of cilia cause a variety of heritable developmental disorders. In my prior work, I identified a protein, TTBK2, that plays a unique role in controlling the assembly of cilia. The gene that encodes this protein was also separately found to be mutated in SCA11. Three different SCA11-associated mutations all produce a nearly identical truncated form of TTBK2. The goals of my research are to examine how this truncated protein is causing degeneration of the cerebellum. We will test whether and how these truncations interfere with the function of the normal TTBK2 protein in cilia formation. We will also test whether reducing the function of TTBK2 or losing cilia within the adult cerebellum can cause degeneration of that tissue and ataxia, using mutant mice as a model. Though this proposed work we hope to gain a better understanding of the molecular mechanisms that cause SCA11-associated pathology as well as to define a novel role for primary cilia-based signaling in maintaining neural function in the adult brain.

**Giorgio Grasselli, PhD**  
*The University of Chicago, Chicago, IL*

**Role of SK Channels in Cerebellar Purkinje Cells in the Pathophysiology of Spinocerebellar Ataxia**

Recent promising results for the treatment of ataxia have been obtained in mouse models as well as in pilot clinical trials with drugs enhancing the activity of a type of potassium channels named SK. These channels are able to lower the excitability of the neuron and decrease the variability of its spike firing and regulate its spike patterns. However, it is still largely unclear what role is played by SK channels in preventing ataxic symptoms and, more in general, the impairments in the neuronal circuit of the cerebellum that cause these symptoms.

We propose to clarify the role of SK channels

*Continued on page 16*
specifically expressed in the major type of neurons in the cerebellum (Purkinje cells, PC), responsible for the sole output of cerebellar cortex. We will investigate in particular the role played by SK channels in these neurons in the generation of motor impairments and in the generation of neuronal electrical output of PC. To do this we will use a new mutant mouse that will be soon available in our laboratory, lacking SK channels specifically in PC (a PC-specific SK2 knockout mouse). We will analyze the gait of these mice, in order to determine whether SK channels in PC play a major role in the generation of ataxic symptoms and whether PC are the major targets of drugs enhancing the activity of SK channels. Moreover we will analyze the major features of PC electrical output that are regulated by SK channels (spiking variability and spiking pauses). Finally we will identify common features in other models of ataxia for the components of gait control and PC physiology. We will use a mouse lacking completely SK channels (constitutive SK2 knock-out) and a mouse lacking the calcium channels responsible for SCA6 (CACNA1A knockout) and partially rescued for the expression of the fragment of this protein, shown to have an independent function as a transcription factor. In this way we will isolate the role played by the channel from the role played by the transcription factor. This proposal will pave the way to a mechanistic understanding of the role of SK channels in spinocerebellar ataxia and to the design of more effective therapeutic strategies for this disorder.

Kenneth Matthew Scaglione, PhD
Medical College of Wisconsin, Milwaukee, WI

Investigation into Polyglutamine in Dictyostelium

Two of the three major genetic categories of the Spinocerebellar ataxias (SCAs) are caused by the presence of repetitive genetic elements. Many of these repetitive genetic elements are made into proteins and result in the formation of toxic clumps of protein. Investigation of how these clumps of protein cause toxicity is typically performed by introducing these proteins into model organisms where they recapitulate the toxic features observed in human disease. We observed that one organism normally makes proteins that share similarity to the ones that clump in human disease. We have also observed that this organism resists protein clumping and see if we can translate that finding to treat human disease.
Spinocerebellar Ataxia Type 6 (SCA6) is a type of dominantly inherited ataxia that impacts overall motility and can also present with impaired eye movements. There are currently no treatments that are effective in the clinic for SCA6. In an effort to identify viable options for SCA6 therapy, we recently generated transgenic fruit flies that express the toxic protein in this disease. Through various experimental approaches, we found proteins that ameliorate SCA6-like toxicity in intact animals. Here, we propose to determine the mechanism of neuroprotection in this model of SCA6, with the hope to target it for therapy in the near future.

Dr. Wei-Ling Tsou

**Brain Donation Program**

If you have Friedrich Ataxia and are interested in helping ataxia research by donation of your brain and tissue after death, please contact Dr. Koeppen for information and details.

Arnulf Koeppen, MD  
Professor-Emeritus of Neurology  
Professor of Pathology  
Albany Medical College,  
Research and Neurology Services  
Stratton VA Medical Center  
113 Holland Ave., Albany, NY 12208  
(518) 626-6377 Fax: (518) 626-6369  
E-Mail: Arnulf.Koeppen@va.gov

If you have any other form of ataxia and are interested in helping ataxia research by donation of your brain and tissue after death, please contact the National Ataxia Foundation for information and details at (763) 553-0020 or susan@ataxia.org.

**Study of Cardiomyopathy in Friedreich’s Ataxia Patients**

A new IRB-approved study at Weill Cornell Medical College on Friedreich’s Ataxia is recruiting patients between 18 to 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 contact: Aileen Orpilla at (646) 962-4537 or aio2001@med.cornell.edu.

**iSearchiGive**

iSearchiGive.com is a search engine powered by Yahoo! Search and iGive.com. It is the Internet’s first online shopping mall where a portion of each purchase is donated to a charity of your choice. Use it to search the web, and your favorite cause receives money for every qualified search. iSearchiGive.com is totally free, with no hidden fees. Please sign up today and indicate that the National Ataxia Foundation is your favorite cause to support for the important work of the Foundation.
International Ataxia Awareness Day (IAAD)

Get Involved in IAAD Events and Planning
— Sunday, September 25, 2016 —

“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 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. Leading up to IAAD as information becomes available you will find all the IAAD events near you on the Event Calendar under the Event Section on the NAF website.

Please let the Foundation know about your IAAD event by contacting Lori Shogren at lori@ataxia.org.

Share Your Awareness Message

You, your family, your friends, and/or your co-workers can share your ataxia awareness message(s). Take a photo or video of yourself or your group with your message(s) and send it to naf@ataxia.org. Below are some message examples. Hard copies of these examples are available on the NAF’s website www.ataxia.org and can be requested by contacting the NAF at naf@ataxia.org or (763) 553-0020.
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 held in recognition of International Ataxia Awareness Day (IAAD). Walk n’ Roll, which began in 2007, is held in cities across the U.S. Walk n’ Roll for Ataxia has raised more than $1,885,000 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.

— 2016 Walk n’ Roll Events and Contact Information —

Walk for Dave
Liverpool, NY – August 6
Marc Alessipianoman 345@hotmail.com

Cleveland Walk n’ Roll
Cleveland, OH – August 21
Susan Kresnye skkresnye@norbencompany.com

Michigan Walk n’ Roll
Ann Arbor, MI – August 27
Elizabeth Sullivan elizsull@umich.edu

Tri-State Walk n’ Roll
Jersey City, NJ – August 27
Kathy Gingerelli kgingerelli@msn.com

Minnesota Walk, Stroll n’ Roll
St. Louis Park, MN – September 10
Terry Sweeney mnataxiawalk@yahoo.com

New England Walk n’ Roll
Location TBD – September 10
John Mauro john@ataxia.org

Denver Run, Walk n’ Roll
Denver, CO – September 11
Charlotte DePew cdepew77@comcast.net

OC/LA Walk n’ Roll
Orange County, CA – September 17
Cindy DeMint cindyocataxia@gmail.com

Atlanta Walk n’ Roll
Duluth, GA – September 24
Greg Rooks atlantaataxia@gmail.com

Concord Walk n’ Roll
Concord, CA – Date TBD
Brian Petersen smileypetersen@yahoo.com

Utah Walk n’ Roll
Salt Lake City, UT – September 24
Jenny Durrant jenny@utahataxia.org

Western PA Walk n’ Roll
South Park, PA – September 24
Donna Eiben donnaeiben@ataxia.org

— For more information, please visit www.ataxia.org/events/walk_n_roll.aspx —
Taking Care of Your Emotional Health in Ataxia

By Lisa Ord, PhD, LCSW and Amy Henderson, MSW, CSW

Ataxia, like any other chronic mental or physical condition, can wreak havoc on your emotional well-being – if you let it. Just as physical symptoms can accompany a chronic illness, so can emotional symptoms. These emotional symptoms often take the form of difficult feelings, such as anger, fear, frustration, and sadness. If these emotions are viewed as yet another symptom of chronic illness, they can and should be treated alongside the other, sometimes more obvious physical symptoms. While emotional ups and downs are a normal part of life, it is what you choose to do with the emotional downs that can influence your overall wellbeing. Catching the downs and doing something about them can mean the difference between a normal “blue” day and spiraling into a clinical depression.

Individuals with chronic illness are at risk of social isolation, especially when mobility is an issue. Many studies have elucidated the connection between social isolation and depression, loneliness, increased stress, and low self-esteem. Some effective strategies to combat social isolation are to join a support group, rebuild or strengthen family ties or friendships, use technology to video chat (FaceTime or Skype) with friends and family, and join a faith group or community social group. An added benefit is that, in many cases, members of faith and community groups can also be very helpful with transportation to gatherings.

When difficult emotions, such as fear, powerlessness, anger and resentment, set in, take a look at your self-talk. Your brain is listening, what are you telling yourself? Try this simple exercise to demonstrate the power of your brain: I want you to think of a lemon. A big, bright yellow lemon. Imagine you are holding it in your hand and turning it over very slowly. You feel the bumpy peel and the slightly oily surface. Now imagine you are slicing into the lemon, as you cut out a nice slice, the juice trickles down the knife. Now bring that slice up to your nose and inhale the pungent citrus aroma. Put that slice in your mouth and bite into it. What is happening to your body right now? Did you wince? Are you puckered up and salivating? But, where is the lemon? That’s right, it’s not actually right in front of you, you created the whole experience with your mind. If you tell yourself you are miserable, your brain listens and, much like your reaction to the lemon, you feel even more sad, lonely, depressed and miserable.

One of the best ways to deal with difficult emotions is to record them, whether you choose to write them down on paper, type them or speak them into a recording device, the act of recording them helps trap those difficult emotions and allows you to get them out of your head, keeping them in perspective. The act of writing out our emotions engages our brains differently than just thinking about them and...
helps us process and cope with our problems more effectively. Besides writing or speaking about your difficult emotions, you might also try keeping a Gratitude Journal. Each night before bed, recount at least five things for which you are grateful or that have made you happy that day. Because you find what you look for, you will start to pay attention to the positive things in your life. Besides, looking for the positive makes us feel better about life, others, and ourselves. Having difficulty finding things to be grateful for? Don’t worry, research shows that just the act of searching for things to be grateful for releases feel good chemicals in our brains!

Anxiety is another common emotion that arises with chronic illness and can sometimes result when you find yourself worrying too much about the future. During these times, ask yourself, “Is there something I can do right now about my future?” If there is, do it! If not, let it go. Imagine yourself filling a helium balloon with your worries and allowing them to float away into the sky and eventually out of sight.

A few additional techniques for chasing away anxiety are distraction, mindfulness, and self-compassion. It is impossible for two thoughts to occupy the same space in our minds at the same time. Much like a radio that can only tune into one station clearly at a time, our minds only tune into one thought clearly at a time. This makes distraction a powerful tool to combat the thoughts that make us anxious. Thinking of the words to a favorite song, listening to an audio book, watching a movie, being of service to someone else, or anything that is enjoyable and engrossing can be good ways of diverting your attention from your anxiety.

Quite simply, mindfulness is the technique of bringing your attention to the present moment and just noticing, non-judgmentally, what “is” (no more, no less). Mindfulness comes out of Buddhism and is a skill that is developed through practice. Studies have shown that mindfulness-based interventions for stress depression, and anxiety are very effective. Calming properties of mindfulness meditation link body and mind, thus creating a quiet and peaceful state in both.

Be kind and patient with yourself. Allow yourself to have the compassion for yourself that you would have for another in your situation. Having self-compassion is not wallowing in self-pity; rather, it is recognizing your own humanity and feeling tenderness, sympathy, and caring for yourself. Have you ever had a difficult time quieting that critical voice inside your head? Remind yourself that often your self-critic has good intentions. Believe it or not, your self-critic actually wants you to grow, learn, reduce pain and deal with uncomfortable feelings. Your self-critic just thinks the fastest road there is motivating you with fear, embarrassment or shame. Try reassuring your self-critic that you have the same goals, and you choose self-compassion.

It is easy to forget skills and tools for changing our emotional state when we are in the throes of anxiety and depression. Make yourself a toolbox with small representations of these techniques, a CD of calming or happy music, your Gratitude Journal, pictures of friends and family members with whom you can talk, the words “Mindfulness” or “Self-Compassion” to remind you, or simply record a written or spoken list of things to do and make it readily available so you can refer to it when needed.

Lastly, a therapist or social worker can be a great ally, and many hospitals or health clinics have social workers on staff. Not only are social workers trained to be excellent problem solvers and resource givers, they are excellent listeners! Being able to talk about your concerns and worries with someone who is objective can be very therapeutic. Giving voice to your difficult emotions without feeling that you are adding to the burdens of your friends and family is very important. Because our friends and family love us, it is a natural inclination for them to want to solve problems and make things better. Sometimes we just need a kind and compassionate “listen.”
Membership Drive Begins in May

Why a NAF Membership? Membership is a partnership between you and NAF. As a member you are a stakeholder in the organization, investing in NAF’s capacity and future to provide important programs and services for ataxia families.

As a member you are strengthening the organization’s ability to provide important ataxia publications, maintaining a current NAF web site, and creating ataxia awareness. Membership support brings world-class scientists together through programs such as the NAF Ataxia Investigators Meeting (AIM) and offering a multi-day ataxia conference through the NAF Annual Ataxia Conference. Membership support also helps in the printing and distribution of ataxia publications, including *Generations*, development of local support groups, the expansion of ataxia social networking sites, and much more.

There are various levels of membership; each entitles you to receive the quarterly news publication, *Generations*, as well as a discount registration rate in attending the National Ataxia Foundation’s Annual Ataxia Conference. There is also an opportunity to become a Recurring Gift Member. Recurring Gift Members truly strengthen NAF’s capacity to serve the ataxia community through the monthly, quarterly, or annually pledges received from these members. Whatever level of membership you select, you can trust that you are part of an organization that is making a significant impact on your behalf.

You will be receiving an NAF Membership Drive Letter in mid-May. Please support the 2016 NAF Annual Membership Drive and please ask others to become NAF members. Thank you!

DC Metro Abilities Expo

The DC Metro Abilities Expo was held in Chantilly, Virginia, December 4-6, 2015. NAF’s booth was in a prime location at the front of the hall and was manned over the three-day period by Glenn and Carolyn Davis and John Lane.

In addition to ataxia families, some nurses and therapists, physical and occupational, stopped by our booth. Several students in those fields also stopped to collect information and to learn about ataxia.

Some attendees and exhibitors, seeing our banner, stopped to ask, “What is ataxia?” It was a wonderful opportunity to enlighten them and spread awareness about ataxia.

It was interesting to walk through the exhibit hall and see the wide variety of exhibitors. In addition to the many options for accessible vehicles, wheelchairs, equipment and supplies, there were exhibits and workshops about accessible travel, self-defense, video games for those with disabilities, and much more.

The Abilities Expo provides an opportunity for our members to access a variety of information all in one place and for NAF to connect with caregivers, patients, and the disability community as a whole.
The NAF Board of Directors along with the NAF Southcentral Region would like to invite you to attend the

National Ataxia Foundation
60th Annual Ataxia Conference
March 10-12, 2017

Join us in San Antonio for the Annual Ataxia Conference!

— 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.

2017 NAF AAC “Support Our Conference” Campaign
http://ataxia.donorpages.com/2017AACLetterWritingCampaign/

For more information on San Antonio, visit www.visitsanantonio.com.

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Share Your AAC Stories & Photos

Personal stories and photos from our readers are a valuable part of Generations. Do you have a story or photo from the 2016 AAC that you would like to share? Please submit them to joan@ataxia.org to be considered for publication. The deadline for submissions is May 13.
Someone once said “Those who can, do. Those who can do more, volunteer.” Each year, since 1974, the standing US president has issued a special proclamation declaring National Volunteer Week in honor of volunteers. This year National Volunteer Week is April 10-16.

The National Ataxia Foundation gratefully recognizes our amazing volunteers for their generosity of time and in giving of their talents to help further our mission. Our volunteers continue to do so much in creating awareness, raising funds, and supporting the ataxia community.

The NAF Support Group Leaders, Chapter Presidents, and Ambassadors bring understanding and support to their local communities. Our lead organizers and wonderful volunteers who participate at the NAF events and Walk n’ Rolls are creating ataxia awareness and raising funds to support vital programs and services.

The exceptional volunteers who participate in clinical trials and market research studies as well as those who have registered for the CoRDS Ataxia Patient Registry are selflessly moving Ataxia research forward.

Our remarkable members of the NAF Medical and Research Advisory Board and to the peer research reviewers. They all volunteer their priceless expertise to help guide us in developing current and accurate information on ataxia and in supporting the best science in the world.

The incredible volunteers who commit their time and expertise at the Annual Ataxia Conference. Without all of these dedicated volunteers, speakers, Birds of a Feather Facilitators, and others there would not be a conference at this high level.

The dedication and commitment of a volunteer Board of Directors who have given so much of their time and talents to help further the important mission of the National Ataxia Foundation.

Thank you to all of our volunteers that speak at local events and to civic groups who create better awareness of ataxia.

A heartfelt thank you to all of you who recognize International Ataxia Awareness Day through events, letting others know about ataxia at work, school, in your neighborhoods, or through press releases, wearing ataxia awareness items, obtaining government proclamations, or telling one friend or stranger about ataxia.

The National Ataxia Foundation celebrates the amazing contributions made by the NAF volunteers...the best volunteers on the planet! We are truly grateful to all of you in making a significant impact on the lives of those affected by ataxia. We warmly welcome others to also join in volunteering for the National Ataxia Foundation.

Thank you!
I was interviewed at a gig at Utica Brews early in December by Melissa Krull from Time Warner. Melissa learned about me from Facebook and is also friends with the manager of the Utica Brews. It came out so fantastic, I couldn’t be happier with it. I talked about my ataxia, and music. It is my hope it brings some awareness about ataxia. http://www.twcnews.com/nys/central-ny/news/2015/12/23/strumming-to-a-different-tune--guitarist-fights-ataxia.html

On February 1st I had the pleasure of being interviewed by Heidi Haines on 106.1 FM radio. I sincerely appreciate the wonderful opportunity to talk about, and spread awareness of ataxia. https://www.youtube.com/watch?v=FdUmO_a-inI

I will also post my musical performance on 106.1.

I love standup comedy, so recently I decided to try it at Utica Brews’ open mic night. My delivery was not as quick as I would like, I slurred words sometimes, and I often paused to breathe, which are symptoms of my ataxia. However, I knew this might be the case, but I wanted to do it anyway to show that anyone with a “disability” can still do new things. https://www.youtube.com/watch?v=UM3IRkD5sx4

Utica Brews hosted a fundraiser for ataxia on February 20 with great food, music and vendors. I also performed at this fundraiser. The event was so much fun. I’m not sure how much money we raised yet, but it was a blast, I haven’t had that much fun in a while. We had four musical acts scheduled, but people just showed up with their instruments, so we had eight different acts. The more the merrier! I was playing, and a sax player and bassist just came up and followed me, and everyone loved what we created. It was just one of those magical happenings, by accident, and we had so much fun with it, we are discussing putting something together. They understand, because of ataxia, I might not follow them, so they are more than happy to let me do my thing, and follow me. There is a video of it, that I will post to YouTube soon.

I did standup comedy again Friday, February 19, and the ataxia event Saturday, so I feel like ataxia has opened a new door of creativity for me, that I would never have found without ataxia’s help, so I hope this encourages others to always create, move, grow, learn, no matter what. We certainly spread awareness about ataxia, as I have talked to a lot of people about it, and even people who weren’t able to make the event, wanted to contribute, so they gave me money beforehand.

All in all, we hopefully raised a few dollars, but we definitely spread awareness about ataxia, and are thinking of doing another. I like to do these things and want to do more so that I can help show others with ataxia, or any “disability” that it doesn’t mean life is over, you can still grow and try new things.
Genes in Inherited Neurologic Disorders Study #HUM00041414

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

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

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

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

If you would like further information or are interested in participating, please contact:
Dr. Margit Burmeister, PhD or Dr. Erin Sandford
Molecular & Behavioral Neuroscience Institute
University of Michigan
5063 BSRB, 109 Zina Pitcher Place, Ann Arbor MI 48109-2200
Telephone: (734) 647-2186; (734) 615-3359
E-mail: margit@umich.edu or esandfor@umich.edu

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National Ataxia Foundation

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The Box

Submitted by Dr. Kitty Lorraine Greene

Several years ago, when my children were very young, our home burned. Fortunately, none of our family was harmed, but the fire was complete in its destruction of the dwelling and its furnishings. In the days following the disaster, I spent much of my time wandering through the debris, sorting through the ashes and picking up whatever remnants of my life I could find. Among the ashes, I found a bracelet given to me by my high school sweetheart and the very discolored remains of a tiny locket given to my daughter Becky by her godparents. I found pieces of our photograph albums, blackened and waterlogged. All of these things I carefully kept in a cardboard box. I became so depressed over these attempts to find things that my husband decided it was best to hire someone to grade over the rubble, and in doing so to bury whatever remained.

Over time I came to accept the loss of our home, and to work on starting over again, but for years beyond the day of the fire, I carried the box with me. And every now and then, I got it out and examined each charred and distorted item it held. Of each I asked myself silently, “Do I still need this? Can I let this go?” In the beginning, my response was always, “No, I can’t let it go,” but over the years, I found that it was possible to say “Yes, I can,” to a few things at a time and to discard these, until finally only one or two items remained.

More recently in my life I have had occasion to reflect on the meaning of the box, and to understand an analogy it may hold for my life. I have come to think of the box as a container, much like the “container” which holds the values and concerns of greatest importance to me. Like the contents of the box, the things carefully placed in my value system early in life, for example – materialism, career success, educational status, and happiness – have been subjected to examination over time. As the years have passed and my sense of what is important in life has deepened and matured, most of the things have been found wanting. Not surprisingly, they have been easily let go of. Happiness, the peace which comes with understanding who you are and what you are meant to be, is the only value which remains when faced with the question, “Can I let this go?” It is that one solid item of value that describes for me what infinitely matters.

In loving memory
Dr. Kitty Lorraine Greene (SCA2)
Mother • Grandmother • Educator

Visit our website: www.ataxia.org
Like us on Facebook: www.facebook.com/ataxiafoundation/timeline/
Follow us on Twitter: https://twitter.com/NAF_Ataxia
My sister Aileen was diagnosed with SCA7 in her thirties. She was already having a little difficulty with her balance about a year before the diagnosis and suffered a nasty fall while at work. No one in the family had a clue to what was going on and several of her doctors couldn’t figure it out at first either. Several possibilities, Peripheral Neuropathy or some other type of neurological condition, were mentioned. She was finally referred to a specialist at the UCLA Neurology Clinic. Even after the formal diagnosis, it was difficult to explain to relatives and friends exactly what Spinocerebellar Ataxia was, let alone pronounce it. The future, for many people holds promise and great expectations, but for us, it had become the great unknown.

Aileen inherited ataxia from our mother, whose onset occurred much later in life (symptoms started in her sixties). SCA7 is a type of ataxia where onset occurs earlier for each succeeding generation and symptoms become much worse. This type of ataxia affects mobility, speech, swallowing, and vision. Aileen’s daughter, Francesca, was in her teens when she started falling regularly and her vision became progressively worse. I can’t imagine what went through Aileen’s mind when she found out that her precious daughter was also going through this.

My twin daughters and I (Catherine and Clarissa) also inherited SCA7. I have an autistic teenage son, Clarence, and I’m hoping that he has not inherited it. It was especially hard on my daughters, as they had just graduated from high school when their symptoms started to appear. Their senior year was a struggle but they were not about to let SCA7 get in the way. They both earned and received their degrees in 2009. Finding work is another story. Looking for a job in 2009 was tough enough for a person without a disability (given the recession), but for my girls, it probably seemed like climbing Mt. Everest. They had to rely on someone to drive them from place to place and where we lived, public transportation was a major hassle. Catherine actually worked for the YMCA for about a year, but commuting drained her physically (and probably mentally too). Imagine getting yourself and a walker on one dial-a-ride van to another, with multiple transfers, taking a total of two hours each morning just to get to your part-time job. She had to quit after about a year as her physical condition did not allow her to continue. My husband and I are particularly heart-broken because we know that Catherine and Clarissa had bright futures ahead of them only to be shattered by ataxia. Their continued strength and resolve is a result of their loving relationship with their aunt Aileen. As for my mom, I am unable to take care of her due to my worsening symptoms and she lives in a nursing home now.

I’ve always been very thankful to have Aileen as my sister. Her struggles taught me to appreciate and love life. Ataxia affected us in our prime and we could have given up in many ways. It takes
so much determination, perseverance, practice and a lot of patience just to get out of bed, dressed, or prepare a meal. My sister was feisty and did not let her condition get in the way of demonstrating her love to family and friends. She and I talked frequently and I learned quite a bit from these conversations. Since she had a much earlier onset than the rest of us, I learned to cope through her experience.

The memory of my sister will stay with me forever. She grew up as any fun-loving kid, active and played like a tomboy. I loved her bubbly personality. I remember her being so excited to tell us one day over dinner that she was elected class president of her kindergarten class. After graduating from college, she worked as a pre-school teacher at an all-girls Catholic school. We are originally from the Philippines and I moved to the United States in 1986 and my sister followed in 1990. We asked our parents to join us in 1999. They moved here to help us with our children.

In a way, Ataxia changed her personality from a fun-loving and talkative person to being very quiet as her symptoms got worse. Over time, her ability to speak was diminished but in spite of that, I know that she was trying to communicate to me her sincere love and appreciation. Her caregivers have nothing but praise, admiration, and love for her and miss her very much. For Aileen, she always told her caregivers, “Family time is the best time of all!”

In memory of Aileen, I work to raise awareness and hope others will follow. It is also my hope that research will finally find a cure to end this condition. I know it will benefit not just my family but everyone’s with this debilitating ataxia!
Greater Houston Area Ataxia Support Group
Submitted by David Brunnert

The November meeting was held at the Women’s Hospital of Texas with 15 attendees. There was a brief orientation to the facility and then introductions with our connection to ataxia.

We were honored to have Dr. Huda Zoghbi, Baylor College of Medicine, at the meeting where she gave a tremendously enlightening presentation.

Some of the concepts she shared:
• Current treatment research can be classified into three broad categories:
  – Pharmaceutical
  – Gene therapy
  – ASO ... Antisense oligonucleotides
• The potential benefits of Deep Brain Stimulation (DBS)
  – Pursuing beneficial behaviors:
    – Safe, gentle exercise. Especially exercise that enhances balance.
    – Pharmaceutical doses of vitamin E. Why? Vitamin E is beneficial to the cells mitochondria.
  – Avoiding harmful behaviors:
    – Trauma ... injury, excessive psychological or emotional stress
    – Alcohol
    – Medicines that have an effect on the cerebellum (consult your physician).
    – Sleep apnea
  – She also answered a number of questions about other potential therapies including RNAi, Cabaletta, Riluzole, PNKP overexpression, etc.

David Brunnert will be passing the leadership of the group to another individual. He expressed it was tremendously rewarding to lead the group and will continue to be involved. The new group leader will be Ashley Grayson.

If you would like more information or like to be added to the mailing list for this group, please contact Bonnie Sills at (713) 944-5183 or texasnanow@ol.com or Ashley Grayson at (832) 530-0866 or ashley.grayson90@gmail.com. We are stronger together!

New Hampshire Ataxia Support Group
Submitted by Jill Porter

December

At our December meeting we had a group of seven which included our service dog members, Denim and Dory. The meeting took place at our new location, Villa Crest Nursing and Retirement Home in Manchester. The group found the facility welcoming and comfortable.

We caught up with each other sharing what’s been happening, medications folks are taking, how they feel they are responding to them, adaptive equipment and home modifications, and life in general. We also talked about the role of support groups in fundraising for the Annual Walk n’ Roll events and requested the topic be on the Leadership Meeting Agenda at the AAC.

January

Fortunately, the New Hampshire Ataxia Support Group was able to meet January 23, in the morning, without any snow in the area.
with us at the beginning of next week and we will set another date, possibly March 19th. Wait for confirmation on that. Information for both NH and MA will be presented by Service Link.

Members shared their stories as all had not been together before. We updated the caregivers on the Concord Regional Visiting Nurse Association (CRVNA) “Powerful Tools for Caregivers” program. The next class will start on Wednesdays, May 11 - June 15, at Wesley United Methodist Church, 79 Clinton St., Concord. If you are interested, you are requested to register by calling CRVNA at (603) 224-4093 ext. 5815 as class size is limited.

As for the AAC, Donna Gorzela, Doug Place and Jill Porter are registered to attend. We will bring information back to share with the group.

This year the Ataxia Awareness Walk ‘n Roll will be held in RI on September 10th. We await more details and are considering options for something more local to NH. Members would, of course, have the option to participate in either or both events, as they need not be scheduled on the same day. Other topics discussed included: thickening liquids, adaptive tableware and the benefit each of us has found in being a part of this support group.

We focus on helping each other by sharing, enjoying the fellowship, building friendships and being flexible within the group and as a general practice in our daily lives. If you have inquired about our group and have not yet attended, we encourage you to “Save The Date” of future meetings and join us. Friends and family are always welcome. And for those of you who have not kept up with attending we invite you to join with us again, meet new members and share and learn along with the group. It’s the SHARING that is so important in the SUPPORT we give to one another as we continue along our paths with ataxia.
appreciated what he had to offer. You can visit his website at http://walkingwithataxia.com/index.html if you are interested or want to reach out to him (he travels around the world sharing his experience with ataxia).

Northern CA Ataxia Support Group
Submitted by Joann Loveland

Our first meeting of 2016 was on January 16th. Forty-three attended the lunch, business meeting and program. During our business meeting, we had introductions from first time visitors; the local area contact people were introduced and shared how they are connecting with our members in their areas. We discussed fundraising for 2016 and where we would like to see continued progress and focus.

Joanne Loveland will be moving to AZ this year, so leadership will be restructuring. Our program speaker was speech pathologist Mary Zic. She discussed how she can evaluate, educate and provide therapy in voice, speech, swallowing, language and cognitive-linguistic disorders. She also discussed insurance and Medicare coverage. After a very informative talk Mary finished the session by having everyone take turns acting out a secret word or phrase. It has been a long time since most of us have played charades. Great idea, Mary!

Denver Area Ataxia Support Group
Submitted by Charlotte DePew

Our last quarterly group meeting on January 16 was held on a sunny, spring-like day with several new members attending. As usual, we started with a potluck lunch. It is a time when both new and not-so-new members have an opportunity interact and share.

Charlotte then gave updates and information on the Orlando Ataxia Conference and planning our 2016 Run, Walk ‘n Roll. During the round-table introductions, several issues/concerns generated robust discussion (e.g., physician or
Los Angeles Ataxia Support Group
Submitted by Lora Morn

The Los Angeles Ataxia Support Group attended the Los Angeles Abilities Expo February 5-7. We had a booth thanks to the NAF. Daniel Navar and Jo Ann Gomez manned the booth on Friday; Lora Morn, Harvey and Julie Kahn and Jeremiah Hume and family on Saturday; and Lora Morn on Sunday.

Some people on our support group e-mail list came to the Expo so we were able to put faces to the names! It was great to meet them.

Our speaker, Erica Brooks, an Occupational Therapist at Anschutz University Hospital, gave us very helpful information on handicap aides. Some are simple and available inexpensively in local chain-stores. Some items can be found on the Internet at reduced prices. All items help only on an individual basis. Erica told us where items can be purchased, what items require professional adaptation/recommendation and physician order for reimbursement. Attendees played/manipulated many aides. Very interesting and thought-provoking questions surfaced.

Atlanta Ataxia Support Group
Submitted by Dave, Greg, Lealan and Diane

We had a great meeting on Saturday, February 6th. Our guest speakers were Heather Nadler and Mark Bierrnath, who are Estate and Special Needs Attorneys. They presented information about the Able Act.

The Atlanta Ataxia Support Group
Chapter and Support Group News
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We obtained information about assistive technology and hope to have Ability Tools come speak at a meeting. They have a device lending library, which allows people to try a device before they purchase it. The Metro Access had information on transportation services. We also learned about what the Braille Institute has to offer for people with physical disabilities. There were many more interesting booths with lots of information for people with physical disabilities.

India (SAMAG) Ataxia Support Group
Submitted by Chandu George

Our entire family attended the National Conference on Rare Diseases, “Raising Awareness” by Dr. Ramaiah (IORD), on February 7. It was a fun-filled family outing to Vijayawada City for us. Dr. Ramaiah gave us a chance to speak there. My sister spoke on being diagnosed with Friedreich Ataxia and the difficult journey living with a rare disease. She also spoke about how our family has been burdened with both brothers also being diagnosed with ataxia, yet our family has accepted our condition and is dedicated to raise awareness on ataxia in our society, provide practical solutions to counsel newly diagnosed Ataxians and continue to serve as Ataxia Patient Advocates. Dr. John Forman, New Zealand Rare Disease Advocate, came to listen to my sister’s speech at the conference. He presented us with a lovely plaque.

Arizona Ataxia Support Group
Submitted by Mary Fuchs

The Arizona Ataxia Support Group had their last meeting on February 12 at the Ability360 Center in Phoenix. We had a great turnout of 22, with two new members. We started with an awesome potluck, then a short meeting with focus on IAAD plans.

Our first speaker was Dr. Larry Schut. He gave an update on latest ataxia news. Our second speaker was Patty Hatton, a Therapeutic Recreation Specialist. Patty talked about adaptive equipment.

Chandu George (right) with his sister Vijaya (left) at the National conference on Rare Diseases in India

The Arizona Ataxia Support Group

Photo by David Garcia
### NAF Merchandise

#### BOOKS
- **Healing Wounded Doctor-Patient Relationships**  
  *by Linda Hanner* with contributions by John J. Witek, MD  
  $10
- **Living with Ataxia: An Information and Resource Guide**  
  *by Martha Nance, MD* (2nd ed. 2003)  
  $14
- **Managing Speech and Swallowing Problems: A Guidebook for People with Ataxia**  
  *by G.N. Rangamani, PhD* with contributions from Douglas E. Fox, MS (2nd ed. updated 2006)  
  $7.50
- **Ten Years to Live**  
  *by Henry J. Schut*  
  $8.75
- **There’s Nothing Wrong with Asking for a Little Help … and Other Myths**  
  *by Dave Lewis*  
  $10
- **Evaluation and Management of Ataxic Disorders: An Overview for Physicians**  
  *by Susan L. Perlman*  
  $5

#### SHIRTS/MISCELLANEOUS
- **IAAD T-Shirt** Sizes S to XXL  
  $10
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  $25
- **NAF Denim Shirt** w/ white NAF logo  
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- **“Ataxia is Not a Foreign Cab” Sweatshirt**  
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- **“Ataxia is Not a Foreign Cab” Magnet**  
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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 – Atilla 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?id=93226257641

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

NAF YOUTUBE CHANNEL
www.youtube.com/user/NatlAtaxiaFound?feature=mhum

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

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

— MISSOURI —

KANSAS CITY SUPPORT GROUP LEADERS
Jim Clark – Gladstone, MO
(816) 468-7260

Lois Goodman – Independence, MO
(816) 257-2428
www.ataxia.org/chapters/KansasCity/default.aspx

ST. LOUIS AREA SUPPORT GROUP LEADER
Sarah “Janeen” Rhinecker – St. Louis, MO
(417) 379-3799
Email: stlataxia@gmail.com
www.ataxia.org/chapters/StLouis/default.aspx

AMBASSADOR
Roger Cooley – Columbia, MO
(573) 474-7232 before noon
E-mail: rogercooley@mediacombb.net
www.ataxia.org/chapters/RogerCooley/default.aspx

— NEW HAMPSHIRE —

NEW HAMPSHIRE SUPPORT GROUP LEADER
Jill Porter – Manchester, NH
(603) 626-0129
E-mail: jilleporter@comcast.net
www.ataxia.org/chapters/Bedford/default.aspx

— NEW JERSEY —

NEW JERSEY SUPPORT GROUP LEADER
Priya Mansukhani – Bridgewater, NJ
(908) 685-8805
E-mail: priyamans@gmail.com
TRI-STATE SUPPORT GROUP LEADERS
Kathy Gingerelli – Parsippany, NJ
(973) 334-2242
E-mail: kgingerelli@msn.com
Denise Mitchell – Bronxville, NY
E-mail: markmegan2@gmail.com
www.ataxia.org/chapters/Tri-State/default.aspx

— NEW YORK —
CENTRAL NEW YORK SUPPORT GROUP LEADER
Mary Jane Damiano – N. Syracuse, NY
Judy Tarrants – Fabius, NY
(315) 683-9486
E-mail: markmegan2@gmail.com
www.ataxia.org/chapters/CentralNewYork/default.aspx

TRI-STATE SUPPORT GROUP LEADERS
Kathy Gingerelli – Parsippany, NJ
(973) 334-2242
E-mail: kgingerelli@msn.com
Denise Mitchell – Bronxville, NY
E-mail: markmegan2@gmail.com
www.ataxia.org/chapters/Tri-State/default.aspx

— NORTH CAROLINA —
TARHEEL SUPPORT GROUP LEADERS
Ron and Donna Smith – Garner, NC
(919) 779-0414
E-mail: rsmith@sacherokee.com
E-mail: dsmith@sa-pr.com
Tammy Hauser – Advance, NC
(336) 998-2942
E-mail: deaconwfu@msn.com
www.ataxia.org/chapters/Tarheel/default.aspx

AMBASSADOR
Jodie Kawa – Brevard, NC
(828) 384-814
E-mail: jodiekawa@citcom.net

— OHIO —
GREATER CINCINNATI AREA SUPPORT GROUP LEADERS
Jennifer Mueller – Lexington, KY
(513) 284-2865
E-mail: jenmu@yahoo.com
Julia Soriano – Cincinnati, OH
(513) 899-3195
E-mail: julia@epivision.com
Group Blog: http://ataxiafoundationcleveland.blogspot.com/
www.ataxia.org/chapters/Cincinnati/default.aspx

CLEVELAND AREA SUPPORT GROUP LEADER
Carmen Pieragastini – Willowick, OH
(216) 272-5588
E-mail: willowpier@roadrunner.com
www.ataxia.org/chapters/Cleveland/default.aspx

— 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/38899359793205/

— PENNSYLVANIA —
CENTRAL PA SUPPORT GROUP LEADER
Michael Cammer – Downingtown, PA
(610) 873-1852
E-mail: michael.cammer62@hotmail.com
Facebook Group:
https://www.facebook.com/groups/1475283086068548/
www.ataxia.org/chapters/CentralPA/default.aspx

WESTERN PA SUPPORT GROUP LEADER
Donna Eiben – South Park, PA
(412) 655-4091
E-mail: dawn.eiben@verizon.net
Ed Schwartz – Venetia, PA
(724) 941-2210
E-mail: eds@ataxia.org
SG Website:
http://nafwesternpasupportchapter.weetley.com/
Facebook Group: https://www.facebook.com/wpaataxia
www.ataxia.org/chapters/SouthPark/default.aspx

— RHODE ISLAND —
RHODE ISLAND SUPPORT GROUP LEADER
Anabela Azevedo – Bristol, RI
(401) 297-8627
E-mail: azevedo70anabela@gmail.com
www.ataxia.org/chapters/RhodeIsland/default.aspx

— TENNESSEE —
MIDDLE TN AREA SUPPORT GROUP LEADER
Alex Cohn – Nashville, TN
(256) 504-0240
E-mail: alex.j.cohn@us.pwc.com
www.ataxia.org/chapters/TN/default.aspx

— TEXAS —
GREATER HOUSTON AREA SUPPORT GROUP LEADER
Ashley Grayson – Houston, TX
(832) 530-0866
E-mail: ashleygrayson90@gmail.com
Facebook Group:
https://www.facebook.com/groups/ataxia.houston/
www.ataxia.org/chapters/Houston/default.aspx

NORTH TEXAS AREA SUPPORT GROUP LEADER
David Henry Jr. – Trophy Club, TX
(817) 739-2886 (contact by e-mail preferred)
E-mail: cheve11e@sbcglobal.net
Facebook Group:
https://www.facebook.com/Ataxiasupport
www.ataxia.org/chapters/NorthTexas/default.aspx

AMBASSADORS
Dana LeBlanc – Orange, TX
(409) 883-5570
E-mail: tilessal@yahoo.com
www.ataxia.org/chapters/GoldenTriangle/default.aspx

Debra Whitcomb – El Paso, TX
(915) 329-0721
E-mail: debrawhitcomb@hotmail.com
NAF Directory
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www.ataxia.org/chapters/Whitcomb/default.aspx

— UTAH —

UTAH SUPPORT GROUP LEADERS
Grant Beutler – Salt Lake City, UT
E-mail: grant.beutler@gmail.com
Jenny Durrant – North Ogden, UT
E-mail: jenny@utahataxia.org
Lisa Ord, PhD, LCSW – Salt Lake City, UT
(801) 587-3020
E-mail: lisa.ord@hsc.utah.edu
Facebook Page: www.facebook.com/utahataxia
S.G. Website: www.utahataxia.org
www.ataxia.org/chapters/Utah/default.aspx

— VIRGINIA —

CHESAPEAKE CHAPTER PRESIDENT
Carolyn Davis – Vienna, VA
(703) 759-2008
E-mail: ccnafpres@gmail.com
www.ataxia.org/chapters/Chesapeake/default.aspx

— WASHINGTON —

OLYMPIC AREA SUPPORT GROUP LEADER
Sherry McLaughlin
(360) 344-2445
E-mail: ccherilynmc@yahoo.com
www.ataxia.org/chapters/Olympic/default.aspx

SEATTLE AREA SUPPORT GROUP LEADER
Milly Lewendon – Kirkland, WA
(425) 823-6239
E-mail: ataxiaseattle@comcast.net
www.ataxia.org/chapters/Seattle/default.aspx

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

— WISCONSIN —

WISCONSIN SUPPORT GROUP LEADER
Jenny Mathison – Madison, WI
(608) 285-5285
E-mail: mjmathison@att.net
www.ataxia.org/chapters/Wisconsin/default.aspx

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
“Seek a Miracle Ataxia Group” (SAMAG)
Chandu Prasad George
Hyderabad, Secunderabad, India
Mobile: 0091-9989999919, 0091-9885199918
E-mail: sam_ataxiaindia@yahoo.com
S.G. E-mail: india.ataxiagroup@gmail.com
Facebook Group: https://www.facebook.com/ataxiain
S.G. Website: www.ataxia.in
www.ataxia.org/chapters/Chandu/default.aspx

— PAKISTAN —

AMBASSADOR
Sajjad Haider – Karachi, Pakistan
0092-(300) 828-1784
E-mail: sajjadhaiderb@hotmail.com

PATIENTS with 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
Calendar of Events

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

SUPPORT GROUP MEETINGS

— Tuesday, April 5, 2016 —
Western PA Ataxia Support Group Meeting
Time: 7 p.m.
Location: Bethel Park Community Center, Park Ave, Bethel Park, PA 15102
Details: For additional information contact Ed Schwartz at (724) 941-2210 or eds@ataxia.org.

— Saturday, April 9, 2016 —
Central Minnesota Ataxia Support Group Meeting
Time: 9:45 – 11:45 a.m.
Location: Harvest Bank Branch, 24952 County Road 7, St. Augusta, MN 56301
Details: For additional information contact Marsha Binnebose at (320) 248-9851 or mbinnebose@hotmail.com.

Kansas City Ataxia Support Group Meeting
Time: 2 – 4 p.m.
Location: Northeast Library, 6000 Wilson Rd., Kansas City, MO
Details: For more information contact Lois Goodman at (816) 257-2428 or Jim Clark at (816) 468-7260.

Maine Ataxia Support Group Meeting
Time: Noon – 3 p.m.
Location: Casco Bay YMCA, Freeport, ME
Details: For more information contact Alan and Paula Nadeau at psn92871@roadrunner.com.

Mid-Atlantic Ataxia Social Group Meeting
Time: 1 – 3 p.m.
Location: St. Thomas Episcopal Church, 1108 Providence Rd., Towson, MD 21286
Details: To register for this meeting please visit http://tinyurl.com/ataxia-april2016. This meeting is free to attend and lunch is included. For more information contact Nicola Menucci at (410) 616-2816 or nmennuc1@jhmi.edu.

North Texas Ataxia Support Group Meeting
Time: 10 a.m. – noon
Location: Ben Washington Baptist Church, 615 Davis St., Irving, TX 75061
Details: The meeting room is in a separate bldg. from the church. For more information contact David Henry at cheve11e@sbcglobal.net.

— Tuesday, April 12, 2016 —
Utah Ataxia Support Group Meeting
Time: 7 p.m.
Location: John A. Moran Eye Center, 65 Mario Capecchi Dr., Salt Lake City, UT 84132
Details: For more information contact Dr. Lisa Ord, PhD, LCW at (801) 585-6635 or lisa.ord@hsc.utah.edu.

— Wednesday, April 13, 2016 —
Willamette Valley Ataxia Support Group Meeting – Albany
Time: 11:30 a.m. – 1 p.m. on the second Wednesday of every month
Location: 400 NW Hickory, Albany, OR 97321
Details: For more information contact Jason Wolfer at (503) 502-2633 or wolfer.jason@gmail.com.

— Thursday, April 14, 2016 —
St. Louis Area Ataxia Support Group Meeting
Time: 5:30 – 7:30 p.m. Meetings will be held at on the second Thursday of every month.
Location: Washington University Medical Center, 4444 Forest Park Ave., Rm. 509, St. Louis, MO 63108
Details: For more information contact Janeen Rheinecker at (417) 379-3799 or stlataxia@gmail.com.

— Saturday, April 16, 2016 —
Denver Area Ataxia Support Group Meeting
Time: 1 – 4 p.m.
Location: Swedish Medical Center, Second Floor Conference Center (meeting room TBD), 501 E. Hampden Ave., Englewood, CO 80113
Details: For more information contact Charlotte DePew at (720) 379-6887 or cldepwe77@comcast.net.

Northern California Ataxia Support Group Meeting
Time: 11:30 a.m. – 2 p.m.
Location: Our Savior’s Lutheran Church, 1035 Carol Ln., Lafayette, CA
Details: For more information or to RSVP contact Jen Buehler at (510) 468-6474 or jennbuehler@aol.com.

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Calendar of Events
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**Orange County Ataxia Support Group Meeting**
Time: 2 – 4 p.m.
Location: Orange Coast Memorial Medical Center Hospital, Breast Cancer Center Conference, Room A, 9900 Talbert Ave., Fountain Valley, CA 92708
Details: For more information contact Cindy DeMint at cindyocataxia@gmail.com.

**Rhode Island Ataxia Support Group Meeting**
Time: 11 a.m. – 2 p.m.
Location: Bristol Pocket and Recreation, 101 Asylum Rd., Bristol, RI 02809
Details: To RSVP or for more information contact Anabela Azevedo at (401) 297-8627 or azevedo70anabela@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.

— **Saturday, April 23, 2016** —

**New Hampshire Ataxia Support Group Meeting**
Time: 10 a.m. – noon
Location: Villa Crest Nursing and Retirement Home, 1276 Hanover St., Manchester, NH
Details: For more information or to RSVP contact Jill Porter at (603) 626-0129 or jilleporter@comcast.net.

**Ottawa Ataxia Support Group Meeting**
Time: 1 p.m.
Location: Ottawa Public Library Carlingwood Branch, 281 Woodroffe
Details: For more information contact Prentis Clairmont at (613) 864-8545 or prentis.clairmont@gmail.com. https://www.facebook.com/events/186149635074889/

**Wisconsin Ataxia Support Group Meeting**
Time: 12:30 – 3 p.m.
Location: Hawthorne Library, 2707 E. Washington Ave., Madison, WI 53704
Details: If anyone can offer Emily a ride from Milwaukee, please e-mail her at j4emily@yahoo.com. If anyone can offer Todd Hopkins a ride from Sun Prairie, please call him at (608) 834-9093. Please e-mail mjmathison@att.net if you will be attending.

— **Tuesday, May 3, 2016** —

**Western PA Ataxia Support Group Meeting**
Time: 7 p.m.
Location: Bethel Park Community Center, Park Ave, Bethel Park, PA 15102
Details: For additional information contact Ed Schwartz at (724) 941-2210 or eds@ataxia.org.

— **Saturday, May 7, 2016** —

**Chesapeake Chapter Annual Medical Meeting**
Time: 9 a.m. – 3 p.m.
Location: Theatre Arts Arena at Montgomery College, Rockville Campus, Rockville, MD 20850
Details: For more information contact Carolyn Davis at (703) 759-2008 or ccnafpres@gmail.com.

**Treasure Coast (East Florida) Ataxia Support Group Meeting**
Time: 1 – 3:30 p.m.
Location: Port St. Lucie Community Center, 2195 SE Airoso Blvd., Port St. Lucie, FL 34984
Details: For additional information contact Lisa Cole at (772) 370-3041 or lcole2234@gmail.com.

— **Wednesday, May 11, 2016** —

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

**Thursday, May 12, 2016**

**St. Louis Area Ataxia Support Group Meeting**
Time: 5:30 – 7:30 p.m. Meetings will be held at on the second Thursday of every month.
Location: Washington University Medical Center, 4444 Forest Park Ave., Rm. 509, St. Louis, MO 63108
Details: For more information contact Janeen Rheinecker at (417) 379-3799 or stlataxia@gmail.com.

**Tri-State Ataxia Support Group Meeting**
Time: 6:30-8:30 p.m.
Location: Beth Israel Medical Center, Phillips Ambulatory Care Center (PACC), 2nd Floor Conference Room, 10 Union Square East, New York, NY 10035
Details: For more information contact Kathy Gingerelli at kgingerelli@msn.com or Denise Mitchell at markmeghan2@gmail.com.

— **Saturday, May 14, 2016** —

**Arizona Ataxia Support Group Meeting**
Time: 1 p.m.
Location: FSL Caregiver House in Phoenix
Details: For additional information contact Mary Fuchs at (480) 212-6425 or mary11115@msn.com or Angela Li at (847) 505-4325 or angelali1010@gmail.com.

Central Minnesota Ataxia Support Group Meeting
Time: 9:45 – 11:45 a.m.
Location: Harvest Bank Branch, 24952 County Road 7, St. Augusta, MN 56301
Details: For additional information contact Marsha Binnebose at (320) 248-9851 or mbinnebose@hotmail.com.

North Texas Ataxia Support Group Meeting
Time: 10 a.m. – noon
Location: Ben Washington Baptist Church, 615 Davis St., Irving, TX 75061
Details: The meeting room is in a separate bldg. from the church. For more information contact David Henry at cheve11e@sbcglobal.net.

— Sunday, May 15, 2016 —

Chitown Ataxia Friendship Meeting
Time: 1 p.m.
Location: Advocate Good Samaritan Hospital, 3815 Highland Ave., Downers Grove, IL 60515
Details: For more information contact Jonas Cepkauskas at (708) 381-5555 or jonas@chitownataxia.org.

— Saturday, May 21, 2016 —

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 4, 2016 —

Rhode Island Ataxia Support Group Meeting
Time: 11 a.m. – 2 p.m.
Location: Bristol Pocket and Recreation, 101 Asylum Rd., Bristol, RI 02809
Details: To RSVP or for more information contact Anabela Azevedo at (401) 297-8627 or azevedo70anabela@gmail.com.

— Tuesday, June 7, 2016 —

Western PA Ataxia Support Group Meeting
Time: 7 p.m.
Location: Bethel Park Community Center, Park Ave, Bethel Park, PA 15102
Details: For additional information contact Ed Schwartz at (724) 941-2210 or eds@ataxia.org.

— Wednesday, June 8, 2016 —

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

— Thursday, June 9, 2016 —

St. Louis Area Ataxia Support Group Meeting
Time: 5:30 – 7:30 p.m. Meetings will be held at on the second Thursday of every month.
Location: Washington University Medical Center, 4444 Forest Park Ave., Rm. 509, St. Louis, MO 63108
Details: For more information contact Janeen Rheinecker at (417) 379-3799 or stlataxia@gmail.com.

— Saturday, June 11, 2016 —

Central Minnesota Ataxia Support Group Meeting
Time: 9:45 – 11:45 a.m.
Location: Harvest Bank Branch, 24952 County Road 7, St. Augusta, MN 56301
Details: For additional information contact Marsha Binnebose at (320) 248-9851 or mbinnebose@hotmail.com.

Kansas City Ataxia Support Group Meeting
Time: 2 – 4 p.m.
Location: Northeast Library, 6000 Wilson Rd., Kansas City, MO
Details: For more information contact Lois Goodman at (816) 257-2428 or Jim Clark at (816) 468-7260.

Mid-Atlantic Ataxia Social Group Sailing Event
Time: 10 a.m. – noon
Location: Downtown Sailing Center “A” Dock, 1425 Highway, Ste 110. Baltimore, MD 21230
Details: For more information contact Nicola Mennucci at (410) 616-2816 or nmennuc1@jhmi.edu.

North Texas Ataxia Support Group Meeting
Time: 10 a.m. – noon
Location: Ben Washington Baptist Church, 615 Davis St., Irving, TX 75061
Details: The meeting room is in a separate bldg.
from the church. For more information contact David Henry at cheve11e@sbcglobal.net.

— Tuesday, June 14, 2016 —

Utah Ataxia Support Group Meeting
Time: 7 p.m.
Location: John A. Moran Eye Center, 65 Mario Capecchi Dr., Salt Lake City, UT 84132
Details: For more information contact Dr. Lisa Ord, PhD, LCW at (801) 585-6635 or lisa.ord@hsc.utah.edu.

— Saturday, June 18, 2016 —

Orange County Ataxia Support Group Meeting
Time: 2 – 4 p.m.
Location: Orange Coast Memorial Medical Center Hospital, Breast Cancer Center Conference, Room A, 9900 Talbert Ave., Fountain Valley, CA 92708
Details: For more information contact Cindy DeMint at 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.

— Saturday, June 25, 2016 —

New Hampshire Ataxia Support Group Meeting
Time: 10 a.m. - noon
Location: Villa Crest Nursing and Retirement Home, 1276 Hanover St., Manchester, NH
Details: For more information or to RSVP contact Jill Porter at (603) 626-0129 or jilleporter@comcast.net.

— Tuesday, July 5, 2016 —

Western PA Ataxia Support Group Meeting
Time: 7 p.m.
Location: Bethel Park Community Center, Park Ave, Bethel Park, PA 15102
Details: For additional information contact Ed Schwartz at (724) 941-2210 or eds@ataxia.org.

— Saturday, July 9, 2016 —

Central Minnesota Ataxia Support Group Meeting
Time: 9:45 – 11:45 a.m.
Location: Harvest Bank Branch, 24952 County Road 7, St. Augusta, MN 56301
Details: For additional information contact Marsha Binnebose at (320) 248-9851 or mbinnebose@hotmail.com.

North Texas Ataxia Support Group Meeting
Time: 10 a.m. – noon
Location: Ben Washington Baptist Church, 615 Davis St., Irving, TX 75061
Details: The meeting room is in a separate bldg. from the church. For more information contact David Henry at cheve11e@sbcglobal.net.

Northern California Support Group Meeting
Time: 11:30 a.m. – 2 p.m.
Location: Our Savior’s Lutheran Church, 1035 Carol Ln., Lafayette, CA.
Details: For more information or to RSVP contact Jen Buehler at (510) 468-6474 jennbuehler@aol.com.

— Wednesday, July 13, 2016 —

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

— Thursday, July 14, 2016 —

St. Louis Area Ataxia Support Group Meeting
Time: 5:30 – 7:30 p.m. Meetings will be held at on the second Thursday of every month.
Location: Washington University Medical Center, 4444 Forest Park Ave., Rm. 509, St. Louis, MO 63108
Details: For more information contact Janeen Rheinecker at (417) 379-3799 or stlataxia@gmail.com.

Tri-State Ataxia Support Group Meeting
Time: 6:30-8:30 p.m.
Location: Beth Israel Medical Center, Phillips Ambulatory Care Center (PACC), Second Floor Conference Room, 10 Union Square East, New York, NY
Details: For more information contact Kathy Gingerelli at kgingerelli@msn.com or Denise Mitchell at markmeghan2@gmail.com.

— Saturday, July 16, 2016 —

Denver Area Ataxia Support Group Meeting
Time: 1 – 4 p.m.
Location: Swedish Medical Center, Second Floor Conference Center (meeting room TBD), 501 E. Hampden Ave., Englewood, CO 80113.
Details: For more information contact Charlotte DePew at (720) 379-6887 or cldepwe77@comcast.net.

— Saturday, July 16, 2016 —

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.

— Tuesday, August 2, 2016 —

Western PA Ataxia Support Group Meeting
Time: 7 p.m.
Location: Bethel Park Community Center, Park Ave, Bethel Park, PA 15102
Details: For additional information contact Ed Schwartz at (724) 941-2210 or eds@ataxia.org.

— Tuesday, August 9, 2016 —

Utah Ataxia Support Group Meeting
Time: 7 p.m.
Location: John A. Moran Eye Center, 65 Mario Capecchi Dr., Salt Lake City, UT 84132
Details: For more information contact Dr. Lisa Ord, PhD, LCW at (801) 585-6635 or lisa.ord@hsc.utah.edu.

— Wednesday, August 10, 2016 —

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

— Thursday, August 11, 2016 —

St. Louis Area Ataxia Support Group Meeting
Time: 5:30 – 7:30 p.m. Meetings will be held at on the second Thursday of every month.
Location: Washington University Medical Center, 4444 Forest Park Ave., Rm. 509, St. Louis, MO 63108
Details: For more information contact Janeen Rheinecker at (417) 379-3799 or stlataxia@gmail.com.

— Saturday, August 13, 2016 —

Central Minnesota Ataxia Support Group Meeting
Time: 9:45 – 11:45 a.m.
Location: Harvest Bank Branch, 24952 County Road 7, St. Augusta, MN 56301
Details: For additional information contact Marsha Binnebose at (320) 248-9851 or mbinnebose@hotmail.com.

Kansas City Ataxia Support Group Meeting
Time: 2 – 4 p.m.
Location: Northeast Library, 6000 Wilson Rd., Kansas City, MO
Details: For more information contact Lois Goodman at (816) 257-2428 or Jim Clark at (816) 468-7260.

North Texas Ataxia Support Group Meeting
Time: 10 a.m. – noon
Location: Ben Washington Baptist Church, 615 Davis St., Irving, TX 75061
Details: The meeting room is in a separate bldg. from the church. For more information contact David Henry at cheve11e@sbcglobal.net.

INFORMATIONAL, AWARENESS, AND IAAAD EVENTS AND FUNDRAISERS

— Friday, April 1-3, 2016 —

59th Annual Ataxia Conference (AAC)
Time: Friday 9 a.m., Saturday 9 a.m., Sunday 9 a.m. – 12:45 p.m.
Location: Caribe Royale Resort, Orlando, FL
Details: Registration fee required to attend. For more information, please visit our webpage www.ataxia.org.

— Thursday, April 14, 2016 —

Annual Chuck and Duck Dodgeball Tournament
Location: Charlton Heights Elementary School, Burt Hills, NY
Details: All proceeds benefit the National Ataxia Foundation (NAF). For more information, contact Andrew Haluska at ahaluska@bhbl.org.

— Friday, April 15, 2016 —

Brain Health Fair
Location: Vancouver Convention Centre, Vancouver, BC, Canada
Details: The Brain Fair is a free, daylong event connecting hundreds of neurology patients, families and caregivers affected by a brain disease, as well as students interested in brain science and the general public interested in brain health. For more information, please visit http://patients.aan.com/go/activities/brainhealthfair.

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— Friday, April 15-16, 2016 —

Mobility Expo
Time: 9 a.m. – 6 p.m.
Location: The North Atlanta Trade Center, 1700 Jeurgens Ct., Norcross, GA 30093
Details: The 2016 Mobility Expo in North Atlanta is about finding one more thing to enhance your independence, self-esteem and quality of life. They welcome individuals with disabilities of all ages and seniors to this exciting event. There will be hundreds of resources for individuals, parents, caregivers and service providers. This free event features over 70 vendors and sponsors showing the latest technologies, products and services to enhance your quality of life and independence. Participate in educational seminars and demonstrations both days. Meet inspirational speakers as well. Come by the NAF booth #314 and say hi! For more information or to volunteer at the NAF booth contact the Atlanta Ataxia Support Group at atlantaataxia@yahoo.com. For more information, please visit http://www.themobilityexpo.com.

— Saturday, August 6, 2016 —

Walk for Dave
IAAD Event and Fundraiser
Location: Onondaga Lake Park, 7199 Onandaga Lake Park Tr., Liverpool, NY 13088
Details: All proceeds benefit the National Ataxia Foundation (NAF). To volunteer and for more information, contact Marc Alessi (315) 506-3260 or mja244@cornell.edu.

— Sunday, August 21, 2016 —

Cleveland 2K Walk n’ Roll
IAAD Event and Fundraiser
Time: 10 a.m. – 2 p.m.
Location: Cleveland Metroparks – Edgewater Park, West Shoreway, Cleveland, OH 44102
Details: All proceeds benefit the National Ataxia Foundation (NAF). For more information contact Susan Kresnye at skkresnye@norbencompany.com.

— Saturday, August 27, 2016 —

Michigan Walk n’ Roll & Symposium
IAAD Event and Fundraiser
Location: University of Michigan Biomedical Sciences Building (BSRB), 109 Zina Pitcher Pl., 5031 BSRB, Ann Arbor, MI 48109
Details: All proceeds benefit the National Ataxia Foundation (NAF). For more information, contact Elizabeth Sullivan (734) 232-6247 or elizsull@umich.edu.

Tri-State Walk n’ Roll
IAAD Event and Fundraiser
Location: Liberty State Park, Jersey City, NJ
Details: All proceeds benefit the National Ataxia Foundation (NAF). For more information, contact Kathy Gingerelli at kgingerelli@msn.com.

Please help us keep your information and schedules up-to-date by e-mailing updates to lori@ataxia.org.
Memorials and In Your Honor

The National Ataxia Foundation is grateful to those who have made contributions in memory or in honor of their friends and families whose names are listed below. This list reflects contributions made in November 2015 through January 2016. 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.

Maria Aglugub-Jacobs
Marc Alessi
Patty Alfonso
Derek Anderson
Paul Bacigalupo
Sharon Baggett
Elle Barnhart
Mary Barros
Alice Battung
Brian Bearb
Betty Beck
Clair Beck
Pierrette Bedard
Cheryl Belsly
Myrt Bengard
M/M Bertussi
Justin Bolinger
Terri Bostic
Doug Boyles
Robert Brethhauer
Cordoba Brother
Miranda Brown
Carole Brown
David Brown
Angela Brown
Peggy Brunner
Clete Brunner
Chris Buechel
Theodore Burdyl
Ann Burke
Michael Cammer
Liam Cannon
Annette Cappella
Robert Carr
Brian Carrick
Linda Carrick
Terrance Carroll
Dennis Castro
Elaine Chang
Yook Chin
Pam Ching
William Chwee
Robert Clausen
Sally Clements
Patricia Clementz

Thomas Cobble
Janice Cohen
Louis Coletti
Mary Coppi-Norman
Debra Covington
Janet R. Coyne
Patricia Crandall
Kennon Davis
DiCicco-Swinkola
Thomas Dolan
Teresa Drakos
Arlo Drury
John Dunn
Buzz Earnhart
Phil Earnhart
Garry Eichholz
Daniel Eustache
Jim Fagg
Jim Fagg
Kitty Falcon
Vincent Ferranti
Kevin Fleming
Patricia Flynn-O’Brien
Cindy Fondulis
Willard Forman
Dora Francis
Robert Fruth
Ruth Furniss
Fran Futrell
Alan Gee
Jeffrey Gibson

Ari Golden
Tanya Goldman
Theresa Goovaerts
Katherine Gorman
John Graziano
Kitty Greene
Marty Greenwood
Stephanie Hales
Robert Hall
Charles Hammond
Raylan Hardigree
Erik Heesaker
George Hicks
Higgins Family
Craig Hindley
Todd Hoag
Meghan Huffman
Krista Humes
Maria Jacob
John Jacquin
Madhavji Joshi
Mac Kelso
Lisa Kelso
Joshua Kirschaum
Judith Kooehn-Lopez
Matthew Klotz
Jamie Kosieraki
Karen Kraynak
Jesse Kuenzi
Normand LaBarre
Patricia Lafferty
Frederick Lafleur
Jim Lally
Lisa Lally
Sandy Lamarack
Nathan Lanz
Jenny Law
Michael Lawlor
Michael Leader
Jennifer Leader
Johna Leidholt
Isabel Luis
Michael Lundquist
Jack MacDonald
Matthew
Malestestnic

Dr. Allan Markowitz
Pat Martin
Chip Masamitsu
Dave Mason
Brent Masserant
Jane Massmann
Marciasele Mathews
David Matley
Mariesi Matykowski
Darrell Maxey
Maurice McDonald
Earl McLaughlin
Gina Metras
Kimberly Michael
Karen Mol
Suzanne Mondy
John Jack Mulka
Stina Nilsson
John Norton
Steve Noyce
Rita Nystrom
Elizabeth O’Hearn
Mary Paetow
Ida Panepinto
Solomon Parades
Sandra Parker
Paula Partilla
Frank Pellegrino
Tammy Perry
Victor Petersen
Eric Peterson
Bennett Phillip
Art Pinkston
Barb Pogulics
Rita Powell-Lobascio
Jack Ragsdale
Laura Ranum
Nate Redman
Gerard Reidy
Shirley Reifenberger
Jennifer Reintjes
Jimmy Richards
Janet Riley
Lori Riley
Sally Riley
Teresa Robinson
Cindy Roderick
Bobby Roos
Mary Rotolo
Leo Ryan
M/M Don
Santa Croce
Santa Croce Family
Danielle Schermal
Marcella Schifrin
Edward Schlesinger
Mary Schlickbernd
Frances Schmidt
Dr. & Mrs.
Lawrence Schut
Edward Schwarz
Derek Semler
Marlene Sequiera
Sienna Shank
Paul Silva
Dana Simpson
Henry Skala Jr.
Doyle H. Smith
Terry Snider
Leon Spears
Abbie Spellman
Ida Mal Spiller
Jenny Spiller
Bob Stackle
Terry Storey
Pearl Straub
Sarah Strickland
Mark Swanson
John Sweeney
Joe Sweeney
Libby Sweeney
Michael Sweeney
Mark Tokarz
Phil Son Turnbull
Jeanette Viveiros
John Walding
David Westrick
Evelyn Wildrick
Karen Wills
Chu Wong
Ing Wong
John Wright Jr.
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 __________________________
Phone________________________________
E-Mail ________________________________

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 – $65
- 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 ________________________________

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 __________________________

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.