

# National Ataxia Foundation

# GENERATIONS

THE OFFICIAL PUBLICATION OF THE NATIONAL ATAXIA FOUNDATION

## The Inside Scoop on New Ataxia Research

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## Fighting for Freedom

2018 Annual Ataxia Conference  
Details Announced

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## Just Dance!

Inclusive recreation options that  
will get you moving **Pg 21**

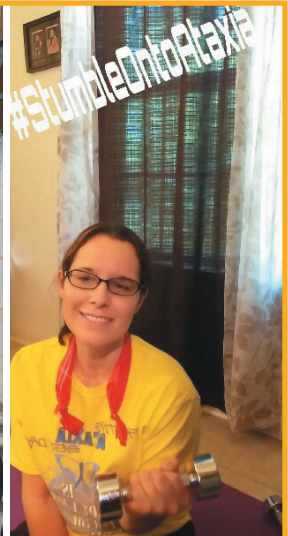
## #StumbleOntoAtaxia

International social media campaign  
takes off **Pg 47**

## Ataxia Events Across the Country

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# Check out the **#StumbleOntoAtaxia** Awareness Campaign on Page 47



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**Deadline for to submit materials for the Winter issue of *Generations* is Friday, October 27.**

Please direct correspondence to:



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## From the Desk of Executive Director Joel Sutherland

Hi everybody! This issue of “*Generations*” provides you, our valued members, with a look at what’s been happening here at the National Ataxia Office. You’ll find stories inside about many of the events taking place around the country in an effort to raise funds, build awareness and energize our overall community. There are many stories that I hope you enjoy, as well as news about current research efforts funded by NAF.

This is an ideal time to look ahead to a very important time for everyone within our Ataxia community. Yes, once again, next month we will kick-off the Annual Research Drive. This campaign begins on October 15th and will end on December 15th. In recent years, we have had the good fortune of having a matching gift donation for the first \$200,000. Unfortunately, that opportunity does not exist in 2017.

Our goal for 2017 remains at \$400,000, but we will need to do it without the matching gift. This year we need to reach this goal one person, one donation at a time and no gift is too small. We need to rally our own individual groups of friends, families and colleagues in an effort to obtain this goal. Here at NAF headquarters we will once again employ an

all-encompassing social media campaign in support of this effort. Last year, because of this Annual Research Drive and other campaigns during the year, we were able to fund nearly \$1.2 million of the best Ataxia research in the world. With your help, we can do it again!

Please, as 2017 comes to a close, our entire Ataxia community hopes that you will make The 2017 National Ataxia Foundation’s Annual Research Drive a top priority for your year-end giving.

**Thank you very much,  
Joel**



## THE DEADLINE FOR SUBMITTING MATERIALS

for the Winter issue of *Generations* is Friday, October 27. Please send articles, your personal story, recaps of Ataxia-related events, photos and reports to [stephanie@ataxia.org](mailto:stephanie@ataxia.org). Thank you.



**CHECKOUT THE NEW NAF WEBSITE! ATAXIA.ORG**

# YOUR DOLLARS AT WORK: A Look at NAF Funded Research

The following are lay summaries from research projects that NAF was able to fund because of generous contributions from our donors. All of these research summaries are of grants funded by NAF for fiscal year 2016. Thank you to each of you who made a donation to last year's Research Drive "Proud Past... Focused Future."

Unless you are a scientist, these research summaries can seem like "Greek" to you, however, it does demonstrate the complexity of science, particularly neuroscience. These summaries were submitted directly from the researchers. While they may be difficult to read, we at NAF think it is important to keep you up-to-date on the science that your membership and donations support.

## SEED MONEY GRANTS

### Study of the Role of Lipid Dysmetabolism in the Pathogenesis of Friedreich's Ataxia



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Friedreich's Ataxia (FRDA) is a neurodegenerative disease also characterized by altered body metabolism and occurrence of intracellular lipids accumulation in several tissues that predispose affected individuals to develop type 2 diabetes. An alteration of lipid management and degradation could be operative, however, the mechanism underlining lipid dysmetabolism are currently underexplored. We have generated a FRDA cellular model consisting in cultured skeletal muscle cells that express low levels of FXN and firstly analyzed some of the main hallmarks of FRDA to validate such model. We found that FXN mRNA expression and protein content was efficiently downregulated. FXN deficient cells displayed increase level of oxidatively damaged proteins as well as decreased mitochondrial activity. In parallel, we found a significant accumulation of intracellular lipids that was

associated with altered level of key components of the pathways responsible for lipid degradation. These data were confirmed in a murine mouse model of FRDA that showed accumulation of lipids in skeletal muscle and decrease level of proteins related to lipid degradation. Our results indicate that impaired lipid degradation in skeletal muscle could contribute to the development of diabetes and suggest that therapeutic strategies aimed at targeting lipolytic enzymes could mitigate metabolic disturbances in FRDA.

### RBfox Proteins as Critical Determinants for Cell Toxicity in DRPLA and other Spinocerebellar Ataxias



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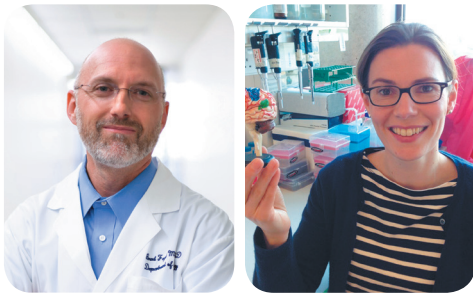
We have identified a change in some genes that control the proper expression of many others in the brain areas responsible for different ataxias. Our most important results show that in DRPLA some cells that were not suspected to be affected by the disease actually suffer early on. These nerve cells are known to be essential for generating ataxia in many conditions. A second

important result is that we have been able to accelerate or slow down disease progression in two ataxias (SCA1 and DRPLA) by interfering with one of the genes we have identified. We think that acting on these genes can be beneficial for all ataxias.

## Development of a Cellular Model for the Functional Characterization of SCA41 Mutations

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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 in 2015 we reported a sporadic ataxia patient with a suspected TRPC3 mutation (p.R762H) predicated 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 proposed 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.

We have succeeded in generating the first ever cerebellar Purkinje cells from a patient with spinocerebellar ataxia type 41 (SCA41) in our laboratory. This is an extremely important breakthrough, as it will allow us to investigate how the disease develops in the brain cells of a patient in the laboratory, without the need for invasive surgical procedures. To make these cells, skin cells taken from a SCA41 patient were used to make stem cells, which are capable of differentiating into any cell type of the body. By treating these stem cells with a specific combination of chemicals, we then stimulated them to develop into Purkinje cells. Work is currently underway to determine how these cells differ from cells made in a similar way using skin samples from unaffected individuals, in order to better understand the progression of the disease.

We further proposed to improve the diagnosis of SCA41 and identify new mutations in TRPC3 by evaluating our extensive ataxia patient population for changes in the gene. Initially we looked at over 300 ataxia patients who underwent whole exome sequencing to identify changes in any of the 20,000 genes in the human genome. We did not find any potential disease causing TRPC3 mutations in these patients, suggesting that SCA41 is a rare cause of genetic ataxia in the population we are studying. However, to more comprehensively address this question, we are currently sequencing TRPC3 in over 800 dominant or sporadic ataxia [patients to identify additional families with SCA41 to aid our understanding of this new form of cerebellar ataxia.

## National Ataxia Data Base

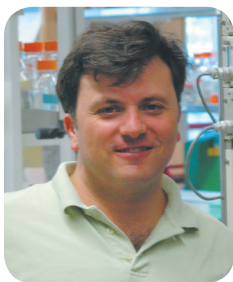


**Susan Perlman, MD -  
University of California, Los  
Angeles, California**

The Natural History Study of and Genetic Modifiers in Spinocerebellar Ataxias (ClinicalTrials.gov Identifier:

NCT01060371), under the direction of Dr. Perlman, continues to recruit subjects and monitor changes in their neurologic examinations. Data are entered into the National Ataxia Database, hosted at UCLA under the direction of Professor Jeanette Papp in the Department of Genetics. The Natural History Study has enrolled over 450 individuals with Spinocerebellar Ataxia types 1, 2, 3, and 6, and has recently expanded to include individuals with types 7, 8, and 10. There are over 18,000 patient forms currently entered in the National Ataxia Database. New forms have been created for refinements to the clinical measures being collected, and the database architecture has been restructured to allow more seamless collaboration between clinical sites.

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



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Purkinje neurons play a central role in the control of motor coordination and learning by the cerebellum and signaling regulated by calcium ions is critical to these functions of Purkinje neurons. The dysregulation of this calcium signaling has emerged as a common feature underlying the dysfunction and degeneration of Purkinje neurons

that contributes to impaired motor coordination in a number of hereditary spinocerebellar ataxias (SCA1, SCA2, SCA3, SCA6, SCA15/16) and other ataxias. Determining the mechanisms that contribute to this calcium dysregulation is thus important for understanding ataxia pathogenesis and for the further development of therapeutic interventions for treating these disorders that target calcium regulation and its functional consequences. Recent studies have established the importance of a calcium signaling pathway known as store-operated calcium entry (SOCE), which requires the STIM1 calcium sensor, in regulating calcium signaling in cerebellar Purkinje neurons. However, the potential role of the STIM1-regulated SOCE pathway in the dysregulated calcium signaling in SCAs and other ataxias has not yet been investigated. The long-term goal of our project is to test the hypothesis that the STIM1-SOCE pathway contributes to disturbances in Purkinje neuron calcium regulation in ataxias. We are taking two approaches to test this idea. In one line of investigation, we are analyzing mice with genetic alterations in the STIM1-SOCE pathway. These studies are revealing that changes in the activity of STIM1-SOCE regulated calcium signaling lead to age-dependent problems with motor coordination and motor learning and to alterations in the properties of cerebellar Purkinje neurons that resemble those found in other forms of ataxia. In a second series of studies, we are beginning to investigate the role of the STIM1-SOCE pathway in hereditary SCAs that are known to have impaired calcium regulation. The support of this project by the National Ataxia Foundation has enabled us to carry out fundamental studies to begin to test our hypothesis and, importantly, has facilitated valuable interactions with investigators in the ataxia research community that are essential for carrying out this project.

## YOUNG INVESTIGATOR RESEARCH AWARD

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



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I study Ataxia Oculomotor Apraxia type 2 (AOA2), a neurological disorder that affects a part of the brain (the cerebellum) responsible for movement coordination. Most patients are diagnosed in their teenage years and slowly lose their autonomy over time, and ultimately need a wheelchair and lose their speech abilities, among other symptoms. In 2004, mutations in the gene *Senataxin* (*SETX*), later found to affect the DNA damage response, have been shown to be responsible for AOA2. We previously found that *SETX* protein associates with *CHD3*, a protein that is capable of changing DNA compaction states and influences DNA damage repair. In order to understand the role of the *SETX/CHD3* complex and its link to the disease, I used biochemical approaches and molecular biology tools to investigate the role of *SETX* in DNA compaction and gene expression in normal and DNA damage conditions. I am also using CRISPR/Cas9 technology to edit *SETX* and study the impact of known mutations on *SETX* cellular functions. I found that while the absence of *SETX* does not have a significant impact on DNA compaction, the *SETX/CHD3* complex seems to regulate the expression of a subset of specific genes. The CRISPR cell lines are still under construction and will hopefully help dissecting further the functions of *SETX/CHD3*.

Altogether, my data has brought us closer to better understand the function of *SETX* and the *SETX/CHD3* complex in normal cells. We are therefore closer to obtaining a better understanding of which roles are not fulfilled when *SETX* is mutated or absent, and ultimately closer to understanding the basis of AOA2, and neurological disorders in general.

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



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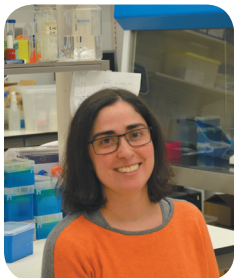
Ataxia Oculomotor Apraxia 1 (AOA1) is an autosomal recessive ataxia which resembles Friedreich's Ataxia (FA) and Ataxia-Telangiectasia (A-T) but without the extra-neurological features. The clinical characteristics of AOA1 are difficulty coordinating movements (ataxia), impaired initiation of saccadic 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 human *Aprataxin* gene (*APTX*), encoding the protein *Aprataxin* (*APTX*). *APTX* plays a crucial role in DNA repair. 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* also localizes to the nucleus and nucleolus, pointing to roles in these subcellular regions. Our data have shown many AOA1-linked *APTX* mutations that cause severe symptoms in patients have variable impacts 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.

With NAF grant funding, we identified an AOA1-linked *APTX* mutation that abolishes normal *APTX* cellular localization, yet only moderately impairs *APTX* DNA processing activity. This data point to an extended role for *APTX* in the subcellular compartment known as the nucleolus.

We hypothesize impaired nucleolar APTX activity may contribute to AOA1. We tested the idea that novel nucleolar protein factors dictate APTX targeting and function. By using APTX as bait to identify stable APTX binding proteins in human cells, we uncovered a new APTX binding protein, APTX Nucleolar Associated Factor (ANAF), which we hypothesize regulates APTX nucleolar activity and targeting. We demonstrated that an AOA1-linked APTX mutation with impaired nucleolar localization also fails to interact with ANAF in human HEK293 cells and in biochemical reactions in vitro. Moreover, we show that ANAF accelerates APTX catalytic activity in biochemical studies. The National Ataxia Foundation Young Investigator Research Award has provided key seed support for the study of ANAF-APT X interactions and their relevance to AOA1 pathology. Ongoing work stemming from this initiative seeks to probe the functional significance of the ANAF-APT X axis in mediating APTX biochemical and cellular function. This research will expand our knowledge of the underlying causes of AOA1 and may also help to develop better strategies to effectively diagnose, monitor, and possibly prevent AOA1 progression.

## POST-DOC FELLOWSHIP AWARD

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



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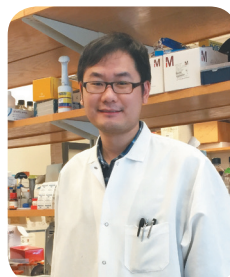
Machado-Joseph disease (MJD), or spinocerebellar ataxia type 3, is neurodegenerative polyQ disease and the most common of the dominantly inherited ataxias worldwide.

Despite important progresses in the knowledge of the pathological 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 are producing isogenic patient-specific lines and differentiating these cells into mature neurons. 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.

### Developing the MANF-based Therapeutic Approach for Spinocerebellar Ataxia 17



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Spinocerebellar Ataxia 17 (SCA17) is a progressive neurodegenerative disease caused by CAG trinucleotide repeat expansion in the gene encoding TATA box binding protein (TBP). SCA17 is characterized by prominent neuronal loss in the cerebellum, with Purkinje cells being the most vulnerable. There is currently no effective treatment for this devastating disease. Our previous study identified a protein named Mesencephalic astrocyte-derived neurotrophic factor (MANF), whose expression was decreased in the cerebellum of SCA17 knock-in mice. Moreover, overexpressing MANF via genetic approaches was able to ameliorate SCA17 pathology in this mouse model.

The aim of this project is to develop potential therapeutic approaches for SCA17 by exploiting the protective capacity of MANF. By screening a library of 2,000 FDA approved chemicals, we identified several chemicals which could increase MANF expression in mammalian cell culture. We focused on one of such chemicals, piperine. We treated SCA17 knock-in mice with piperine by daily oral gavage. The treatment started at 3-month of age, and lasted till the mice reached 5-month old, at which age the mice were known to display deficits in various behavioral tests, including rotarod, balance beam and pulling strength. The mice treated with piperine showed significantly better performances in these tests, compared with control group treated with saline. Pathological examination revealed improved Purkinje cell morphology in mice with piperine treatment. We also identified the cellular mechanism underlying piperine-mediated protection. Therefore, our study established MANF-inducing chemicals, especially piperine, as a promising therapeutic agent for SCA17 treatment. We are currently in the process of submitting the manuscript to scientific journals for publication. I would like to thank National Ataxia Foundation for providing me the funding to accomplish this important research.

## Unravelling Pathomechanism of Muscle

## Dysfunction in an Autosomal Recessive Cerebellar Ataxia 2 (ARCA2) Mice Model



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Adck3 knockout mice (Adck3KO), a mouse model of autosomal recessive cerebellar ataxia 2 (ARCA2), indicates dysregulated lipid and glucose homeostasis as pathological features of the disease. Our investigation demonstrates that these mice are hypercholesteremic and show tissue-specific dysregulation in cholesterol and triglyceride metabolism. Our preliminary results from skeletal muscle indicate that these mice might have less energy store to substantially sustain high energy demanding situation like exercise. Overall, it appears that dynamics of neutral lipid synthesis, storage and degradation is primarily affected in Adck3KO mice in a tissue-specific manner. Our ongoing exploration of the metabolic status of skeletal muscle of Adck3KO mice will delineate the underlying basis of exercise intolerance seen in these mice as well as in ARCA2 patients.

## PIONEER SCA TRANSLATIONAL RESEARCH AWARDS

### ASO Targeting of Bidirectional Transcripts and RAN Translation in SCA8



**Laura Ranum, PhD, University of Florida, Gainesville, Florida**

With Pioneer grant funding from the NAF, we have been working to better understand how the SCA8 expansion mutation causes disease and

to develop a drug to treat this disorder. A key tool has been a mouse model of disease that we previously generated. By examining our SCA8 mice we discovered that the repeat expansion mutation behaves in a couple of unexpected ways. First, in 2006 we showed that the SCA8 CTG•CAG expansion mutation is expressed from both strands of DNA. This means that two mutant expansion RNAs are produced, one with a CUG and the other with a CAG repeat. A second surprise was our 2011 discovery that the SCA8 expansion RNAs produce unexpected and toxic proteins that accumulate in patient brains. These proteins were a big surprise because they do not have an “AUG start signal.” For decades, scientists have thought that an “AUG start signal” was absolutely required to make proteins. This discovery changed that fundamental understanding. We named this process repeat associated non-ATG (RAN) translation and the resulting proteins RAN proteins.

Since our initial discovery of RAN translation in SCA8 RAN proteins have been found in a growing number of expansion diseases including: myotonic dystrophy types 1 and 2, amyotrophic lateral sclerosis/frontotemporal dementia (ALS/FTD), Huntington disease (HD), fragile X tremor ataxia syndrome (FXTAS) and spinocerebellar ataxia type 31 (SCA31). Our recent research on SCA8 has been focused in three main areas.

### **Characterization of RAN proteins in SCA8.**

Our recent efforts in SCA8 have been directed at understanding the impact of RAN proteins on the disease. For these studies, we are looking at where in the brain the various RAN proteins accumulate using both our mouse model and human autopsy tissue. Additionally, we are using our mouse model to better understand at what age RAN proteins are expressed and their effects over time so that we can better understand their effects on aging. Through these studies, we now have substantial evidence that RAN proteins accumulate in multiple brain regions and that these proteins cause degenerative changes in the brain.

### **How and why are RAN proteins made and can we stop them?**

A second major effort in the lab is aimed at understanding how RAN proteins are created and developing ways to block the production of these proteins. Because the rules that cells use to make these proteins are different from those used to make most proteins in cells, we are developing new strategies to block their production. This will allow us to understand the contribution that these proteins make to the disease and we hope will lead to therapeutic strategies that will improve the lives of patients in the future.

Because RAN proteins have now been found in so many diseases RAN translation has attracted a lot of additional researchers. Our lab and many other laboratories and pharmaceutical companies from around the world are engaged in trying to understand exactly how these proteins are made and to develop drugs that can specifically block their production.

### **Why do some people with SCA8 expansions get sick and others do not?**

In a third area of research for SCA8, we are trying to understand why some people with SCA8 expansions develop disease and others do not. We have collected more than 70 different families with the SCA8 mutation for these studies. Most of these families have only a single affected individual but families with multiple affected individuals tend to have variations in the specific sequence within their repeat expansion tract. We are now testing the effects of these sequence variations on how the gene mutation is expressed to better understand how it increases disease risk. Understanding this puzzle may help us identify the triggers of disease and allowing us to help more people with SCA8 expansions stay healthy like their healthy relatives.

### **Therapeutic development.**

Finally, in collaboration with Ionis Pharmaceuticals we are working to develop a drug for SCA8 that will reduce both the RNA and proteins that are made from the SCA8 repeat expansion. The overall idea for this drug is to synthesize small stretches of DNA called antisense oligonucleotides (ASOs) that can bind to and degrade the mutant RNAs. The degradation of the mutant RNA will

also address the mutant RAN protein problem because the degradation of the RNA will prevent the RAN proteins from being made. Because these drugs do not cross the blood brain barrier they are delivered directly to the central nervous system in the mice by injection into the brain. A similar drug developed by Ionis, has recently received FDA approval for the treatment of a disease called spinal muscular atrophy. This gives us confidence that this approach is technically feasible and has strong potential for SCA8. We are now testing this approach in our mice.

## Oligonucleotide-based Therapy in BAC-Mouse Models of SCA14



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**Key Personnel: Dong-Hui  
Chen, MD, PhD  
Martin Darvas, PhD**

We established two mouse models of SCA14 that each carry a missense variant in the human gene for protein kinase C gamma (PKC) known to cause SCA14. PKC is mostly produced in cerebellar Purkinje cells. PKC aggregates into clumps in the Purkinje cells of mice that carry one of the mutations. In mice with the other mutation, the dendrites (the branched extensions of nerve cells that receive signals from other cells) become abnormal in number and appearance. Both SCA14 mouse models have motor problems in comparison to mice with the normal human gene. The aim of our study was to investigate the effects of reduction of mutant PKC expression on these brain abnormalities. We designed short hairpin RNAs (shRNA) that selectively suppress the production of transgenic human PKC RNA (sh-PKC) and a control shRNA (shScramble) that should not interact with PKC and tested them in cell culture. We found that in comparison to cells that were given PKC and shScramble, PKC expression in cells given PKC and shRNA-WT was

reduced by a maximum of 60%. We then packaged the most suppressive shRNAs into a virus (AAV), modified to prevent replication.

The next phase was to test the suppression of human PKC in the brains of mice. Targeted or scrambled shRNA in AAV was delivered to deep cerebellar nuclei of 5-month old mice by stereotaxic brain injection. Four weeks later, in mice treated with sh-PKC we found that in the areas reached by the AAV the PKC RNA level was strongly reduced as compared to the level in mice treated with shScramble, and we did not observe cerebellar neurotoxicity. Although the AAV did not penetrate deeply into the cerebellum, these preliminary results are encouraging. We plan to adjust the injection protocol to allow greater spread. We will then evaluate the specificity of RNA suppression and the effect on brain pathology. These studies during the presymptomatic stage can yield information about prevention, delay of onset, or slowing of progression of brain pathology. Comparison of the outcomes in the two mutant lines will reveal whether the effectiveness of PKC suppression is generalizable across the SCA14-mutation spectrum associated with different brain pathologies. Once we have proof of principle of efficacy, we will age some treated mice to evaluate effect on neurologic manifestations.

## YOUNG INVESTIGATOR FOR SCA RESEARCH AWARDS

### Exploring the Role of Primary Cilia in SCA11 Pathogenesis



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Primary cilia are tiny antenna-

like projections that are found on most cells in vertebrates. 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 the development of many different tissues and organs, with genetic disruptions of cilia causing a variety of heritable developmental disorders. Primary cilia are also present on cells in most adult tissues as well, although their functions in those contexts are still poorly understood.

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 a sub-type of spinocerebellar ataxia, SCA11. Three different SCA11-associated mutations all produce a nearly identical truncated form of TTBK2. The goal of my NAF-funded research was to examine how this truncated protein is causing degeneration of the cerebellum. We showed that the presence of SCA11-associated truncated TTBK2 partially blocks the function of the normal TTBK2 protein in cilia formation, which could explain why SCA11 is dominantly inherited. Using mouse models, we have also shown that removal of the *Ttbk2* gene specifically from adult tissues results in motor deficits in the mice, as well as cellular changes in the cerebellum that are similar to other mouse models of SCA. We plan to publish a manuscript reporting our findings on the SCA11-associated mutations within the upcoming months. We are continuing to build on the findings that were made possible through NAF funds to better understand the requirements for TTBK2 as well as primary cilia in the adult brain, and particularly the cerebellum. In the long-term we hope to define the requirements for cilia-based cell signals in the neurons of the adult brain, as well as the connections between cilia and neurodegenerative conditions.

## Role of SK Channels in Cerebellar Purkinje Cells in the Pathophysiology of

## Spinocerebellar Ataxia



**Giorgio Grasselli, PhD**  
- University of Chicago,  
Chicago, Illinois [ggrasselli@uchicago.edu](mailto:ggrasselli@uchicago.edu)

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.

The generous support provided by the NAF with this Young Investigator - SCA Research Award allowed the further development of Dr. Giorgio Grasselli's research line on the pathophysiological mechanisms underlying SCA and on the role played in it by SK channels. Thanks to the award a new mouse strain with a Purkinje cell-specific mutation for the SK2 subunit (the only SK subunit present in cerebellar Purkinje cells) could be completed, tested and confirmed for the functional effectiveness of the mutation. The analysis of the gait of these new mutant mice showed a significantly different motor strategy caused by the mutation, with longer and less frequent steps, showing that the lack of SK2 specifically in Purkinje cells has a relevant effect on motor behavior. Also, an increased excitability of cerebellar Purkinje cells was identified as an electrophysiological correlate of the motor behavior, consistent with the role played by SK channels in limiting the excitability of neurons.

As a model of SCA6 a new ataxic mouse developed in the lab of Dr. Christopher

Gomez (Dept. of Neurology, The University of Chicago) was chosen. This mouse model bears a combination of mutations in CACNA1A (the gene responsible for SCA6) which has been named “KIKO” (Knock-In of the humanized Q14 variant of CACNA1A and Knock-Out of the mouse variant) and causes a reduction of expression of IACT, the protein comprising the poly-Q expansion associated with the disease. The mutant mice were compared with control littermates and mice with a rescue expression of the protein IACT specifically in Purkinje cells (“rescue” mice). These “KIKO” mice have a heavily ataxic phenotype, that is reduced in the “rescue” mice. The assessment of the electrophysiological properties of Purkinje cells in these mice showed impairments at several levels. Among these, in “KIKO” mice the synaptic connectivity of Purkinje cells with their inputs was found to be altered (both with parallel fibers and with climbing fibers). Additionally, the excitability of Purkinje cells was increased, reminiscent of the increased excitability observed in the Purkinje cell-specific mutant for SK2. This therefore supports the hypothesis that an increased excitability -possibly dependent on SK channels- may play a role in alterations of motor coordination. However, further experiments will be needed to prove this hypothesis.

These results set therefore the ground for further studies, necessary to complete a mechanistic understanding of the role of SK channels in spinocerebellar ataxia and to design more effective therapeutic strategies for this disorder.

I would like to express again my deep gratitude to the National Ataxia Foundation which allowed me to further develop my research line on ataxia.



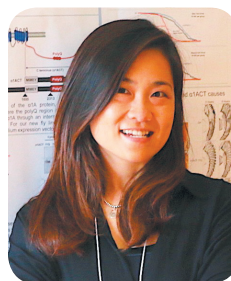
### Investigation into Polyglutamine in Dictyostelium

**Kenneth Scaglione, PhD -  
Medical College of Wisconsin,**

**Milwaukee, Wisconsin [scaglione@mcw.edu](mailto:scaglione@mcw.edu)**

One class of the Spinocerebellar ataxias (SCAs) are caused by the presence of an expanded CAG tract in the coding region of specific genes. This CAG expansion results in the expression of a protein with an expanded polyglutamine tract. Proteins with long polyglutamine tracts are prone to aggregate and be toxic to cells, therefore identification of ways to suppress polyglutamine aggregation is important. We have found that unlike other commonly used laboratory model organisms the social amoeba *Dictyostelium discoideum* is resistant to polyglutamine aggregation and toxicity.

The goal of this proposal was to investigate what molecular pathways may be responsible for protecting against polyglutamine aggregation in *Dictyostelium discoideum*. We have systematically investigated known protein quality control pathways and found that they are not responsible for suppressing polyglutamine aggregation in *Dictyostelium discoideum*. To identify novel genes responsible for suppressing polyglutamine aggregation we employed a non-biased genetic screen on cells overexpressing a polyglutamine tract that we can visualize polyglutamine aggregation. From this screen we have identified novel genes that suppress polyglutamine aggregation and we are currently investigating how they suppress polyglutamine aggregation in *Dictyostelium discoideum*, in a test tube, and in human cells. We believe these continuing studies will lead to new ideas towards developing strategies to suppress polyglutamine aggregation, and as such may lead to new strategies to treat SCAs caused by polyglutamine expansion.



### Mechanisms of Neuroprotection by DnaJ-1 in Spinocerebellar Ataxia Type 6

**Wei-Ling Tsou, PhD - Wayne**

**State University School of Medicine, Detroit,  
Michigan**

**[mscaglione@mcw.edu](mailto:mscaglione@mcw.edu)**

Spinocerebellar Ataxia Type 6 (SCA6) is a type of dominantly inherited ataxia that impacts overall motility and is also associated with impaired eye movements and double vision. 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. These new fly models express human 1aCT protein with a normal (11Q) or expanded (33Q and 70Q) polyglutamine repeats. Expression of the pathogenic version of 1aCT in *Drosophila* displays the progressive neurodegenerative nature of this disease. The goal of the *Drosophila* models of SCA6 is to enable rapid investigations toward understanding the biology of disease in this disorder and to find therapeutic options for this type of ataxia. We used the fly models to identify cellular mechanisms that regulate the longevity and handling of the toxic protein in the cell, in order to find targets that we can use to suppress toxicity from pathogenic 1aCT. Through various experimental approaches, we found that the heat shock protein DnaJ-1 markedly ameliorates SCA6-like toxicity in intact animals. Interestingly, there were no other heat shock proteins or chaperones that directly suppressed the SCA6-like toxicity in the fruit fly. Various experiments lead us to conclude that DnaJ-1 suppresses 1aCT-dependent degeneration not by directly handling 1aCT, but instead by cooperating with other proteins of the chaperone family. We will continue to determine the mechanism of neuroprotection in this model of SCA6, with the hope to target it for therapy in the near future.

**What NAF Researchers Say About Your Support**

**“THANK YOU!!!** Support from the National Ataxia Foundation, through this two-year Pioneer Award and several other previous grants over the years has been hugely helpful in moving our Ataxia research forward. Over the years funding from NAF has served as seed funding for larger grants from the NIH. I am pleased to say that Pioneer Grant funding from the NAF helped us to secure special funding from the NIH of a Jacob Javits Neuroscience Investigator Award from the NIH. This is a special seven-year grant awarded to investigators for paradigm shifting research. While my lab feels very fortunate to have received this award this brings me back to you. Our discovery would not have been possible without the participation of Ataxia patients and families like you. These patient donations were critical for our translational discovery which I am thrilled to say, has sparked a new field of research. While this research area began with blood donations from Ataxia patients, the additional focus on this problem by researchers all over the world has substantially accelerated our efforts to cure Ataxias and other diseases that have a similar disease mechanisms.” -Dr. Laura Ranum

The work described by Dr. Laura Ranum happened because of the initial seed-money grants she received from NAF, thanks to donations from people like you!

**Stay up-to-date –  
get on our email list**

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

# Living With Ataxia (SCA6)

Submitted by Judith Outcalt Perry, Franklin, NC

No one can chart their future. We can make plans, but that is different than knowing what the future will be. The year I fell and broke my hip, was the year I learned to live in a new reality. I was a person with a disabling condition and I could yield to defeat or find ways to live with it.

The thought of my children and grandchildren inheriting my defective gene is terrifying. I think of what happened to my father and ponder what will happen to me. I want to leave my children a legacy of hope, to live well until the day I die, and I do not want to give up or give in to Ataxia. I am afraid for my children to see me in my crippled state and need to over-come this fear. My children need to see me as a fighter and know I can live a satisfying and enjoyable life despite Ataxia.

I cannot expect a cure in my lifetime, which will return my body to its normal state. The damage has been done, but I do hope to stay connected with my world. I need to be able to communicate with others. I have the need to know my Ataxia does not define the person I am.

Falling and breaking my hip in the fall of 2015 was a turning point in my life. I could no longer ignore the devastating impact that Ataxia had on my day-to-day life. I spent nine long weeks in a rehab/nursing facility learning to walk again and live with a degenerative condition. Without the intense physical therapy, I might well have spent the rest of my life in nursing home care.

I cannot say enough about physical and occupational therapy in recovering from a broken hip or other bodily trauma. For me, it has also been a powerful influence in learning to accept the slow decline of physical ability associated with Ataxia. Although therapists learn the techniques of their trade, they also seem to develop a sense of individual patient needs. My therapist took the

time to see the “whole” person, not just a person who broke her hip. They wanted to know what motivated me and what made me the person I am. Their goal was to help me learn to live in a strange new body both in terms of a hip reinforced with a metal device and a faulty cerebellum taking its toll on voluntary movement.

Unfortunately, therapy paid for by Medicare or private insurance is strictly regulated and requires assessment and monitoring. Basically, it will not cover therapy once the patient is no longer showing improvement. With Ataxia, I will slowly lose ground no matter what I do, but I firmly believe therapy slows down the progression and gives me the skills to prevent another fall.

Because my insurance will no longer pay for therapy, I go to a fitness center three times a week and work with a personal trainer who not only has a background in physical therapy but did research on Ataxia to design a program just for me. We work on muscle strength, balance, and coordination. His sense of humor and happy spirit motivates me.

I call him my gentle giant as my 4'11" frame next to his 6'7" makes for some comedy.

I am lucky to be able to afford a personal trainer. People with movement disorders benefit from on-going physical therapy. IF ONLY INSURANCE COMPANIES COULD SEE THE LIGHT! Therapy costs much less than nursing home care.

Learning to live with Ataxia is an on-going process. I exercise my body at the gym and exercise my brain with writing. I am working on a memoir about the year I broke my hip. I have started a blog where I can chronicle my day-to-day thoughts about living with Ataxia. You can find me at <https://ataxiatalk.blogspot.com>.



Judith Outcalt Perry

# The Day I Learned I Could No Longer Jump

Submitted by Jay Armstrong

Six months after being diagnosed with cerebellar degeneration, six months after a neurologist examined an MRI of my brain, I'm staring at my physical therapist, Denise, and she's daring me to jump.

I smile and look around the St. Lawrence Rehabilitation Center. There are three other patients in the activity center with me. Two women walking slow on a treadmill and Bill, a former Navy Captain, who is the proud owner of a new titanium hip. Bill is pedaling a stationary bike and according to St. Lawrence lore, Bill has never smiled. Ever. I'm the youngest one in the activity center by at least 20 years. Surveying the room, like the true gym class hero I still think I am, I swell with pride believing I'm the most able body in the room.

"Denise, need I remind you that I'm an athlete. A collegiate soccer player. I've been jumping my whole life." Denise playfully rolls her eyes. This is only my third appointment at St. Lawrence but Denise and I already share chemistry. It's December. Football season. I'm an Eagles fan. She's a Giants fan. In between sets of squats and leg raises I tell her Eli Manning is overrated and she tells me that the stereotypes regarding the jerkiness of Eagles fans is apparently true. She is funny and real and in just our few hours together I stake her as the most compassionate person I ever met.

During a set of lunges Denise tells me that Bill just lost his wife of 40 years to breast cancer. Her brown eyes swell, and then she tells me she lost her grandmother to the same disease. Denise and I both look at Bill, we watch him slowly pedal. She tells me it's her goal to make him smile today.



L-R: Haley, Cindy (Wife) Jay, Chase & Dylan

To be honest, I've avoided writing this story for some time now. I guess by writing it, by pinning down its facts, I'm forced to further accept certain truths. I assume I did what most of us do when we don't have the energy, courage, or conviction to deal with truth. We tuck it away, like a debt, in the darkness of a desk drawer and do our best to forget about it. But memories, with just the right stimulus,

can be resurrected without warning. They sit up, blink, open the drawer and leak into the light and remind you that memories, like debts, can be avoided for only so long before they must be attended to.

The stimulus today was a basketball bouncing off the concrete. My son, Chase, is in the backyard, dribbling the length of the patio and shooting on a little net he received for his fourth birthday. He's six now and he's getting good at dribbling, jump shots, and layups. He's quickly learning about the earthly battle between the human body and gravity. Chase makes a jump shot and celebrates. As it often happens with sons, he feels me—his father, eyes looming because he looks up, with his

own blue eyes and finds me framed in the window. “Come out and play Dad!”

I smile and wave. Not now. Not today. Some days my body aches too much. Some days my brain does weird things. Some days it convinces me that I’m trapped on the Tilt-a-Whirl, buckled to the back of a big black bird, a sneaker tumbling in the dryer, or I’m just frat party drunk. Because some days, the fixed world spins, glides, tumbles and wobbles off its axis at speeds beyond what my eyes, my undamaged brain can comprehend. And I guess, some days, I just don’t play because... because I simply can’t risk the embarrassment.

Before my diagnosis, I believed that I would do physically heroic dad things, like carrying all three children off to bed like footballs, each tucked under my arm, after they fall asleep on the couch. I believed I would be the MVP of father-son baseball games, my children and I would run 5k’s together and, on a perfect summer morning when the sky was veined with golden light, we would ride bikes along the New Jersey coastline. But we age and learn that real life always falls incredibly short of the one we imagined, the one we planned. Yet despite our protests, it’s the unplanned life that teaches us more than our fantasies ever will.

“Jay are you ready?”

“Eagles are always ready to fly.”

“Ok, I’ll be right here, beside you, just in case.” Bill is riding a stationary bike. He is straight-faced and staring at me. “Hey Denise, can you go make Bill smile? He’s freaking me out.”

“Just concentrate on what you’re doing.”

“Denise, I got this. Need I remind you again, I’m an athlete.”

In the last few months my coordination, vision, balance and motor skills have all gotten worse. Not at breakneck speed, but slowly. Little things, things I’d taken for granted- handwriting, climbing stairs, and carrying a few bags of groceries have become difficult. For a brief time, doctors thought I had ALS, then Huntington’s Disease and then MS.

Denise levels her eyes at me. “I want you to jump.

As high as you can.” I bend my knees, swing my arms back and forth and try to jump. I try and try and try and try but I just can’t do it. I just can’t force my feet to leave the floor. My brain screams “Jump!” But the message is not delivered as if some internal chord that transmits important messages had been severed.

I shake my head. “No Denise. I can’t jump.”

“It’s ok Jay. You don’t have to do it, relax. Take a seat. Let me check on Bill.” Denise returns, tells me she offered Bill her best joke and he didn’t crack. Didn’t even flinch.

“Denise, I’ve had enough for today.”

When you think of your future self you envision your best self. Happy and unblemished. You’re the hero of your own movie. I limp into the locker room, find a folding chair, stare into my lap and began to digest the fact that I had lost the ability to jump. It occurred to me, right there in that empty locker room, on that folding chair that I would not be the man, the father I envisioned myself to be. A father running, jumping through life with his children. A father playing basketball in the backyard with his son. A father who is fast and coordinated and who teaches his boy the aerodynamics of a layup as the evening sun vanishes from the suburban sky. I open the locker room door to find Bill in the hallway, sitting in his wheel chair, as if waiting for me.

I offer a little half-smile and before I can turn Bill speaks, “Hey,” he still had those steely grey Navy captain eyes, eyes that didn’t look at you, eyes that looked through you. Bill clears his throat, shifts his weight on his God-given hip and says, “Don’t give up kid.”

“Thanks.” And then, in a very subtle, a very unprovoked way, he smiles.

*Jay Armstrong is a husband, father, teacher, writer, and Ataxian who uses the power of writing and storytelling to harbor hope. You can contact him at [writeonfighton@gmail.com](mailto:writeonfighton@gmail.com)*

## A Wheelchair is not the Endgame

By Pinalben "Pinky" Patel

My name is Pinky Patel and I am a freelance writer with FA. I have heard many being afraid of the wheelchair. In this story I'm trying to show that it is not the end of the world to be using one. As long as you have a fit upper body, there is no reason for this fear.

I'm sorry, but I don't consider wheelchair users disabled. I am a very happy person - there are only a few things I despise in life. And one of them is the comment, "She's in a wheelchair just like you but she did this and that." Looking at me, people thought I didn't need a power wheelchair and could maneuver a manual wheelchair with my arms. I was diagnosed with Friedreich's Ataxia (FA), a degenerating neuromuscular disease since I was almost 11 years old, and had been using an electric wheelchair from age 16.

After I began using the power wheelchair, I was able to transfer in and out of it virtually by myself for some years. I was able to bathe, brush my teeth, dress, and take care of my personal hygiene throughout high school.

The beginning of my progression from just wheelchair user to FA-er was in the sophomore year of high school when I was diagnosed with insulin-dependent diabetes. Another FA symptom the doctors found while I had been at the hospital was the thickening of my heart walls, and so I began taking a pill once a day for that, too.

Two years later, I fainted at school, and had another ER visit. The trip turned out to be also due to FA. When I got to the hospital, the doctors found I had Bradycardia (slow heartbeat) and needed a pacemaker implanted to regulate my heartbeat...

I started college in the fall after high school graduation, but I also started needing help in all my personal-care from that time. People



Pinalben "Pinky" Patel

wondered why I drove my wheelchair so drunken-like, why I didn't transfer myself to and from my wheelchair, or why I couldn't dress and bathe myself like other wheelchair-users.

Of course, those comparing queries aggravated me, but I kept the anger in my mind. Instead of raging at the askers, I calmly educated them about FA. I found that I prefer their questions to them forming conclusions of laziness or petulance.

I applauded them for their willingness to learn about me. They were not asking to be rude; they were just uninformed about my condition. There are so many different disabilities out there, and every one can't know about every disability. I can only imagine how boring the world would be if everyone knew about everything.

During the last years of high school, I developed a hearing problem. I was able to hear fine when I only had to listen to one person speaking, such as in classrooms and one-to-one conversations. My friends teased me about this problem. They said that I only listened to what I wanted to hear, and I remember getting annoyed at their taunting. I never liked being mocked for my disability, but I did not know that this problem was related to FA. Since I did not know, I couldn't expect my friends without FA to understand. Thus, I endured their jokes with a smile even throughout the four years of college.

While looking for a job after college, I began to go to support groups about FA and related diseases online. I finally found out the reason of my hearing problem in those groups -- it is called Auditory Neuropathy (AN). It happens to many people with FA, and it basically means I cannot hear well on the phone and any situation where there are two noises or more occurring at once.

I also never knew my weakened eyesight was the cause of FA until I met others in my situation online. I saw many wheelchair users and non-wheelchair users wear glasses like I did. But even

after LASIK I had shaky vision, depth perception, and needed to wear prescriptions when I wanted to see things clearly from a couple feet.

Nowadays, I can't drive my power chair, and my scoliosis and curling fingers are more prominent. My vision is 20/2500 and getting worse. But that doesn't embarrass me in public or keep me from mingling with fellow able-bodied writers.

Some wheelchair users can stand or take a couple steps. Being in a wheelchair is not the same for all wheelchair users. It is not even the same for every person with FA and related diseases. I am lucky to have friends from school (who stopped teasing me after I explained about the AN) and my support groups.

I don't care what strangers or distant relatives think of me. Although I want to scornfully say you can't judge a book by its cover, I would always patiently explain my situation to anyone who asks. They only ask because they care, and realizing that will make you happier than being ignored. Always show your whole self everywhere.

## Tips to Help Manage Your Bowels

The focus of the 2017 International Ataxia Awareness Day was learning more about the symptoms associated with Ataxia. The most common symptom of Ataxia is uncoordinated movement in the hands and legs, however, there are many other symptoms that Ataxians face with this disease. One of those symptoms, that may not be particularly pleasant to discuss but one in which many with Ataxia may struggle, is bowel incontinence.

**Dr. Susan Perlman, NAF's Medical Director, has provided the following suggestions for this symptom:**

- If bowel incontinence is due to loose stools, then bulking agents such as Metamucil and others can help.
- If it is due to a weak sphincter, Kegel exercises (see directions below) can help or a silastic ring can be implanted to restore sphincter tone.
- If it is due to chronic constipation, with stool leaking around the constipation in an uncontrolled fashion, then treating the constipation should help.
- Some patients with severe bowel incontinence may elect to have a colostomy placed.

### **Kegel exercises:**

1. Find your pelvic floor muscles.
2. Squeeze your pelvic floor muscles as hard as you can and hold them (squeeze three to five seconds and relax for five seconds).
3. Do sets of repetitions of squeezing (start with five repetitions: squeeze, hold, relax).
4. Increase lengths, intensity, and repetitions every couple of days.
5. Perform Kegel exercises three to four times during the day.

Dr. George (Chip) Wilmot, Director of the Ataxia Clinic at Emory University, added that being seen by other doctors such as your Primary Care Physician, Gastroenterologist or a specialist in Geriatrics for incontinence may be helpful. Some clinics may have a continence clinic to which you can be referred.

Work closely with your doctor to seek out therapies and medications for the symptoms of ataxia that can be treated.

# Adaptive Dance

*Finding New Ways to Do the Things You Love*

Most everyone likes to move to music. Have you ever wanted to express yourself, but couldn't figure out how? Adaptive dance might be that creative outlet you've been looking for.

Adaptive dance is a term often associated with dance/creative movement for those with differing abilities and physical challenges. There are classes throughout the United States where you can learn how to express your inner self and get your groove on! There are even adaptive dance/creative movement training programs available for dance/movement therapists so that they can help introduce the joy of dance and movement to persons in rehabilitation, health promotion programs, and nursing homes. Along with taking a class on adaptive dance, you may find that the social interaction may make you feel less isolated, more confident and there may be a physical and psychological benefit as well.

To do adaptive dance/creative movement, you can use props like stretch bands, balls, a partner or chose not to use anything at all. The use of props can enhance the overall movement and creative experience. Many adaptive dance/creative movement programs are tailored so that all

abilities can participate. There is even an adaptive version of Zumba which, is a popular fitness program consisting of dance and aerobic exercise routines played to popular, mainly Latin-American music.

You can find more information and videos about Adaptive Dance by visiting the Abilities Expo's website here: [http://www.abilities.com/community/inclusive\\_recreation.html](http://www.abilities.com/community/inclusive_recreation.html)



**JOHNS HOPKINS**  
M E D I C I N E

Approved January 31, 2017

## **ATAXIA RESEARCH STUDY**

Patients diagnosed with cerebellar Ataxia, age 18-75, are needed for a study of short-term memory.

Participation involves 1 visit lasting 1-4 hours. Tests include computerized games and eye tracking.

Receive \$20/hour for your time.

**Call (410) 502-4664 to learn more and see if you qualify. Confidential.**

# Ataxia Clinical Trial Progresses to 48-Week Extension Phase

## BIOHAVEN OPTIMISTIC FOR NEXT PHASE OF TRIAL DESPITE DISAPPOINTING TOPLINE DATA

As NAF previously reported, BioHaven Pharmaceutical Holding Company Ltd. recently completed its 8-week trial of dosing for its drug compound trigriluzole. This is the largest clinical trial for Spinocerebellar Ataxia (SCA) to-date. During the 8-week randomization phase, either the compound or a placebo was given to 141 adults across the U.S. with SCA. Recipients were unaware which they were receiving during this portion of the trial. This phase of the trial compared trigriluzole to the placebo, measuring their impact on Ataxia symptoms.

On October 2, 2017, BioHaven released topline data indicating that trigriluzole did not differentiate from the placebo in treating Ataxia symptoms, according to SARA scores, during the initial 8-week phase of the trial. A higher than expected rate of placebo response may have hampered the ability of the study to detect a signal and Biohaven is performing additional analyses to better understand the

effects of trigriluzole on Ataxia.

The trial did show promising results for safety and tolerability of the compound. BioHaven remains hopeful that trigriluzole will have positive outcomes as a long-term nerve-protecting agent, thereby slowing the progression of Ataxia. BioHaven reaffirmed their commitment to the Ataxia community, as well as their compound, with their plans to see the study through to completion of the 48-week extension phase.

## WHAT HAPPENS IN THE EXTENSION PHASE?

In the 48-week extension phase, all participants will take trigriluzole. The Ataxia progression of participants will be monitored regularly and compared to what would be expected based upon the Ataxia Natural History Study. These results will be analyzed to determine if the medication slows the rate of progression of the disease.



## REASONS TO BE HOPEFUL FOR THIS PHASE

- Trigriluzole, thus far, appears to be safe to take and well tolerated.
- This trial had unexpectedly high reports of improvement in Ataxia symptoms for persons taking the placebo, making it difficult to accurately determine whether the medication is effective or not.
- The topline data results do NOT affect the potential for success in the next phase of the trial.
- A similar clinical trial, for a similar compound, was found to slow the progression for ALS (also called Lou Gehrig's Disease) but did NOT have any effects on symptoms.
- The pharmaceutical industry, as a whole, is better equipped to prepare for Ataxia clinical trials in the future because of this trial.
- This trial proved to the pharmaceutical industry that the Ataxia clinical sites are prepared and competent for clinical trials, potentially encouraging them to investigate applications for Ataxia for their compounds.

## DO YOU HAVE HEREDITARY ATAXIA?

The Masters in Genetic Counseling Program at the University of Maryland School of Medicine is conducting a new research study to better understand how people communicate with their family members about their condition.

We need your help and want to hear **your** story!

**\*Participate from the comfort of your home\***

The study includes just a short survey and a phone interview.

If you are interested in learning more about this study, please follow the link below:

[https://umaryland.az1.qualtrics.com/jfe/form/SV\\_4NoQNDUdT7oqCih](https://umaryland.az1.qualtrics.com/jfe/form/SV_4NoQNDUdT7oqCih)

You can also get information about the study by contacting:

Shannan Dixon, MS, CGC  
[SDelany@som.umaryland.edu](mailto:SDelany@som.umaryland.edu)  
410-706-4713

**We hope to hear from you!**

# National Ataxia Foundation 61st NAF Annual Ataxia Conference

April 5-6, 2018



## Marriott Philadelphia Downtown Philadelphia, PA

Hotel Reservations and Conference Registration open on  
**Wednesday, November 29, 2017**

Hotel reservations for all room types at the Marriott will be made available starting November 29. Reservations at group rate will be available until March 11, 2018. The NAF group rate starts at \$189 +tax for Standard Rooms. **ADA room reservations must be reserved through the NAF office.**

### **Reservations for ADA rooms begin on November 29 at noon CST**

by contacting (763) 553-0020 or [lori@ataxia.org](mailto:lori@ataxia.org). Calls or e-mails prior to noon CST on November 29 to reserve an ADA room cannot be honored. Standard room reservations at the Marriott can be made at <https://aws.passkey.com/go/NATIONALATAXIAaac>

For guests who prefer to phone in their reservation call Hotel Reservations at 1-877-901-6632 and ask for the National Ataxia Foundation's group rate which is under the group name, "National Ataxia Foundation."

### **Conference Registration-Begins November 29**

Registration for the 2018 NAF AAC will open on November 29. You are encouraged to register before February 13, 2018 to receive the early registration discount rate. In addition, members of the NAF pay a lower registration fee to attend the Annual Ataxia Conference. If you are not currently a member of the Foundation go online at [www.ataxia.org](http://www.ataxia.org) or call the NAF office at (763) 553-0020 to become a member or renew your membership. For the latest information on conference registration, program schedule, and area information keep checking the NAF's website [www.ataxia.org](http://www.ataxia.org). Note: The conference will end with the banquet on Saturday night.

**Join us in Philadelphia! [www.discoverph.com](http://www.discoverph.com)**

For the latest information on conference registration, program schedule, and area information keep checking NAF's website – [www.ataxia.org](http://www.ataxia.org)

# Fundraiser and Awareness Event Recaps

## 60 for 60 to Cure Ataxia - Team Ruehl Submitted by Susan Ruehl

Our ride, which took place over the course of three days, Friday - Sunday, July 21 - 23, was great with beautiful weather and sights along the Erie Canal.

We rode 20 miles a day for those three days. We were very happy to have the opportunity to raise awareness about Ataxia and support the NAF at the same time. In total, we rode 60.3 miles when it was completed! The event raised \$16,980 to benefit the National Ataxia Foundation. <https://ataxia.donorpages.com/201760For60/TeamRuehl/>



Standing L-R: Mary Beth Snyder, Susan and Bruce Ruehl  
On bikes: L-R: Charlie and Mary Ruehl

## TN- 60 for 60 Walk and Run to Cure Ataxia Submitted by Karla McMurtry

The Tennessee Walk and Run to Cure Ataxia was held on August 5, at Moss-Wright Park in Goodlettsville, TN. The walk started with the McMurtry Family, but as we grew and began to discuss the event, we had the Todd Family join us, also from mid-Tennessee. While our original goal was to have at least 30 participants, we had an incredible turnout with over 70 walkers, runners, or rollers including ten individuals with SCA2 who participated. We also sent a press release out before the event. The event raised \$5,766 to benefit the National Ataxia Foundation.



TN WnR - TN Walk and Run to Cure Ataxia

## grub BURGER BAR Profit Shares Event - Georgia Submitted by Greater Atlanta Ataxia Support

All three Georgia locations of Grub Burger Bar hosted their Profit Shares event to benefit the NAF and the Atlanta Walk n' Roll to Cure Ataxia on August 21, from 11 a.m. - close. By just mentioning the National Ataxia Foundation to the cashier 15% of the check was donated. The event raised money to benefit the National Ataxia Foundation and the Atlanta Walk n' Roll to Cure Ataxia.

## Houston Abilities Expo Submitted by Dave Cantrell

The Houston Area Support Group (HASG) represented the NAF at the Houston Abilities Expo on Friday - the North Texas Area Support Group, David Henry, Jr. and his mom Karen on Saturday, and Dolly Richardson (HASG) on Sunday. Bonnie Sills, Dave and Amy Cantrell signed up several new members who were not even aware that the Houston Area Support Group existed. It was such a great opportunity to get the word out about Ataxia. We gave away many copies of *Generations* to those who visited our booth.



L-R: Amy and Dave Cantrell, and Bonnie Sills

## Rare Disease Fair - Seattle Submitted by Sandy Lam

Rath Mann and I represented the NAF at the Rare Disease Fair at Westlake Park, Seattle on Saturday, June 3. The event, "CARE FOR RARE" ran from 11 a.m. to 4 p.m.

There were speakers, educational resources and opportunities to connect with others who may be dealing with similar experiences. The event also included face-painting, a photo booth for kids, and live music by Tyler Edwards and DJ Bryan Kretz.



Rath Mann and Sandy Lam, wearing the NAF 60th Anniversary t-shirt.

# Join Us in “Fight

NAF National Ataxia Foundation  
**FIGHTING for FREEDOM**  
ANNUAL ATAXIA CONFERENCE  
2018

APRIL 5-6, 2018 • PHILADELPHIA, PA

Philadelphia - hailed as the birthplace of freedom - is the perfect locale to host the 61st Annual Ataxia Conference (AAC). NAF and the Northeast Region are pulling out all the stops with this year's theme, **“Fighting for Freedom.”** Never have we been closer to major breakthroughs in the quest for a cure; with the first SCA drug in phase 2 of clinical trials, and others in the pipeline. For that reason, it's the perfect time to ramp up the fight for freedom from this rare disease and its symptoms. Mark your calendars - we hope to see you April 5-6, 2018 at Marriott Philadelphia Downtown in Philadelphia, PA.

### About the Conference

AAC is the largest gathering of those

affected by all forms of hereditary and sporadic Ataxia in the world. At AAC, attendees will have two days to meet and learn from world-leading Ataxia researchers and clinicians, visit vendor exhibits, and network with others. Sessions at the conference will include topics that help a person with Ataxia manage their symptoms, presentations from some of the top Ataxia researchers and clinicians, small groups that are disease-specific, and updates about the latest in Ataxia research. This year's conference will also include a poster session from the Ataxia Investigators Meeting (AIM) that precedes AAC. The AIM Poster Session, with opportunity to meet Ataxia investigators, will be on Wednesday, April 4, 2018 from 5pm-6:30pm. The complete conference schedule will be available by the winter edition of *Generations*. We hope you'll join us at the 2018 Annual Ataxia Conference!

### Conference Registration

AAC registration will be available online on November 29th at [www.ataxia.org](http://www.ataxia.org). Registration forms will be available in the Winter edition of *Generations* as well. Make sure to get the Member discount! If you aren't a member yet, or need to renew your membership, you can do so online or by calling (763) 553-0020. We encourage everyone to register by February 13, 2018 to receive the Early Registration discount rate.

### Remember!

If you or a dependent have any form of Ataxia, the cost of your registration fee and travel to this conference is tax deductible!  
<http://bit.ly/2wzNVuo>

## Featured Speakers



Jeremy Schmahmann, MD

### Jeremy Schmahmann, MD

Jeremy D. Schmahmann, MD is the Founding Director (1994) of the Ataxia Unit at the Massachusetts General Hospital, Director of the Laboratory for Neuroanatomy and Cerebellar Neurobiology, and Professor of Neurology at Harvard Medical School. Dr. Schmahmann graduated with distinction from the University of Cape Town, South Africa, completed residency in the Neurological Unit of Boston City Hospital, and postdoctoral fellowship in the Department of Anatomy and Neurobiology at Boston University School of Medicine.



David Lynch, MD, PhD

# ...ting for Freedom”

61st Annual Ataxia Conference • April 5-6, 2018

## Help with Travel Costs

Due to the generosity of several donors, NAF can offer Travel Grants to help with a portion of the travel costs associated with attending the AAC. Adults or children with Ataxia are eligible to apply for a travel grant. Applications will be accepted until January 19, 2018. Applicants will be notified of the status of their application after the application deadline and all applications have been reviewed. Applications available online at [www.ataxia.org](http://www.ataxia.org) or by contacting Lori Shogren at [lori@ataxia.org](mailto:lori@ataxia.org) or **763-553-0020**.

## Hotel Reservations

Group rate hotel reservations for Marriott Philadelphia Downtown will be accepted from November 29, 2017 - March 11, 2018. The NAF Group rate starts at \$189 +tax for standard rooms. Reservations can be made online at <https://aws.passkey.com/go/NATIONALATAXIAaac> or via phone at 1-877-901-6632. Be sure to request the “National Ataxia Foundation” group rate! All ADA rooms must be reserved through NAF. Request an ADA room beginning at 12pm CST on November 29th by calling 763-553-0020 or emailing [lori@ataxia.org](mailto:lori@ataxia.org) for your reservation. ADA room types are limited. NAF is unable to provide ADA equipment; however the Marriott does have a limited number of shower chairs available. Please request ADA equipment at the time of your reservation.

## David Lynch, MD, PhD

David Lynch, MD, PhD, is a pediatric neurologist at The Children’s Hospital of Philadelphia and director of the Friedreich’s Ataxia Program. Dr. Lynch received his undergraduate training at Yale College, followed by medical school and Graduate School in Neuroscience at Johns Hopkins University School of Medicine.

## Exhibit at 2018 Annual Ataxia Conference!

The AAC provides a unique opportunity to engage with the Ataxia community. It is a chance to interact directly with a population that can benefit from more information about many types of products and services. Exhibitors experience local, national, and international exposure while supporting an important program for people with a genetic neurological disease. Contact Stephanie Lucas for more information: [stephanie@ataxia.org](mailto:stephanie@ataxia.org) or **763-231-2744**.

### Registration Fees

#### Early Registration Before February 13

NAF Member \$125  
Non Member \$180

#### February 13-March 30

NAF Member \$150  
Non Member \$205

#### After March 30 - On Site

NAF Member \$200  
Non Member \$255

No refunds of registration fees for cancellations received after March 21. Registration at the door is not recommended.

## Fundraisers and Awareness Events (continued)

The goal of the event was to spread awareness of rare disease and connect families. There were 34 rare diseases represented, and over 30 organizations in attendance. It was the first event held in Seattle and we think it was a great success.

### Peters Township Community Day, Venetia, PA Submitted by Ed Schwartz

On Saturday, June 24, Peters Township held their 2017 Community Day. Peters Township, located 20 miles south of Pittsburgh, has held a "Community Day" for 39 years. Representatives from most of the community's civic organizations gather in Peterswood Park to share information about their organization, greet old friends and meet new residents. This year there were more than 160 food, craft, games and vendor booths and some 4,000 to 6,000 people in attendance. In addition, there were children's activities, games and entertainment for the whole family.

For the third year, the NAF was represented by Jake Halaszynski, Linda and Ed Schwartz who greeted and provided information about the NAF, the Western Pennsylvania Ataxia Support Group (WPA), and Ataxia. About two thirds of the people that stopped at the tent, were personal friends of Ed and Linda's and familiar with Ataxia. The ratio of new contacts made to the number of persons in attendance speak to one of the NAF's most significant challenges. (interestingly, even my spell check does not include the word Ataxia)

### Pittsburgh Community TV- Ataxia Awareness Interview

Ed Schwartz, Co-Chair of the WPA Ataxia Support Group and Madalyn Gottschalk, Chair of the WPA Ataxia Support Group Walk, went "Live" on Facebook on Friday, August 4 thanks to Pittsburgh Community Television and host of "Into Pittsburgh", Christopher Whitlatch.

Ed and Madalyn shared information about Ataxia, the NAF, and their upcoming Walk n' Roll in the 30-minute interview. You can find the interview video here by scrolling down the page to August 4, live:

<https://www.facebook.com/pittsburghcommunitytv/>

### Cars of Summer

The Cars of Summer, a car show and family fun event, was held at Green Hill Park, Worcester, MA on July 1-3. There was a live auction, a scheduled-cruise down Shrewsbury St, comedy show, flea

market, food trucks, kid zone, monster truck rides and vendor area. A portion of the admission fee was donated to benefit the National Ataxia Foundation.



John Mauro at the Cars of Summer

The Auburn Ataxia Support Group represented the NAF with an awareness table and a food truck at the event. They offered fried dough with powdered sugar (similar to funnel cake), grilled sausage sandwiches, grilled chicken and french-fries. A portion of the sales was donated to benefit the National Ataxia Foundation.

### The Hank Stoltz Experience

On August 4, Hank spoke with John and Dana Mauro about John's battle with Ataxia and how they are fighting to raise awareness and funding to fight the disease. You can listen to the interview here: <https://soundcloud.com/wcm-ben/totc-ataxia-8-4>



L-R: Senator Michael Moore, Lauri Kurdziel, PhD, Behavioral Neuroscience, Hank Stoltz, Dana and John Mauro

### UnitedHealth Group and Optum

Each year, the employees of UnitedHealth Group, United Healthcare and Optum give their time and money to charitable causes they care about. The United Health Foundation supports employees by:

- Matching employee contributions
  - Honoring employees who volunteer 30 hours with a \$500 grant to their nonprofit of choice
- Their people have contributed more than \$100 to the National Ataxia Foundation this year, and they match their contributions, doubling the impact.

## #AtaxiaRocks

Lisa Cole, from the Treasure Coast Ataxia Support group, started spreading Ataxia awareness throughout her community by painting rocks with colorful images, including #AtaxiaRocks and the NAF website [www.ataxia.org](http://www.ataxia.org) on the decorated stones. Because the "Ataxia Rocks" are so colorful they can bring attention when they are left in random places. They have been placed in the back of taxicabs, the beach and many other places since starting the awareness campaign. Lisa, support group leader, says, "Awareness is the key, plus it's fun." She has her grandkids, great nephew and great niece help make them. She writes everything on the back before sealing, and always has one or two of them with her so she can place them in "just the right spot" when she finds it. If you would like to contact Lisa and help "rock" your community too, please email her at [lisacoleataxia@gmail.com](mailto:lisacoleataxia@gmail.com). You can get more information about the AtaxiaRocks by visiting their Facebook page <https://www.facebook.com/groups/864677347039596/>



## HUMANIFEST

### Humanifest

Submitted by Cheri Bearman

Members of the Happy Hoosiers Ataxia Support Group represented the NAF at Humanifest, the yoga music festival, in Irvington, Indiana on Saturday, August 12, with an awareness table. The festival had more than 20 vendors representing various forms of health and wellness lifestyles,

exercise, health education and awareness, with live music and dance performances. Cheri Bearman, with the help of her son-in-law Brent Woodruff and his three-year-old son Abram Woodruff, got everything to the event and set-up on Friday night, even in a heavy downpour! Cheri manned the awareness table in the morning and Amy Draves and Teresa Coccaro took over in the afternoon. They visited each of the vendors and introduced themselves, explained a bit about Ataxia and handed out the NAF bookmarks, pens and info sheets. We even met a new person with Ataxia at the event and she has joined our group! Humanifest donated \$500 to benefit the National Ataxia Foundation.



L-R: Cheri Bearman, Teresa Coccaro and Amy Draves

### Living Life with Ataxia

Submitted by Lisa Cole

On June 20, Helen and Carly Magnuson and I were on WPTV Channel 5, a local news station that covers most of south Florida, explaining what Ataxia is and how it affects those who are diagnosed with it. We made people aware of our 60 for 60 to Cure Ataxia on Saturday, June 24 during the interview too!

A client of mine, mentioned me to a client of hers, who mentioned me to her producer at Channel 5. By being persistent and wanting to get the word out, the interview happened. It was a great experience! You can enjoy the interview here: <http://www.wptv.com/news/health/living-with-ataxia>



Lisa Cole, Carly & Helen Magnuson

We want to hear about your fundraising success stories – send them to [stephanie@ataxia.org](mailto:stephanie@ataxia.org)



# 2017 Ataxia Research Drive

**2017 Ataxia Research Drive Kicks Off October 15th**  
**October 15 - December 15, 2017 • Goal - \$400,000**

We all know that the answer to beating Ataxia lies in the research - help NAF fund the best science! Researchers are at a pivotal time for Ataxia - with one medication in clinical trial and more in the pipeline. NAF has received 84 research grant applications for next year. It's our turn to step up and give researchers the support that they need, so that they can look for the answers that we need. Join NAF's 2017 Research Drive!

- **Make an individual donation, or organize a team and set your own goals**
- **All donations are tax-deductible**
- **More than \$1 million in Ataxia research was funded last year**

Visit [www.ataxia.org](http://www.ataxia.org) or call 763-553-0020 for more information.  
Donate online at [www.ataxia.org/ResearchDrive](http://www.ataxia.org/ResearchDrive)

# Support Group News



## Greater Atlanta Ataxia Support Group

*Submitted by Greater Atlanta Support Group*

On Saturday, July 15, the Greater Atlanta Ataxia Support Group

held their support group meeting and had a great turnout to hear about Genetic Ataxia testing from MNG Labs as well as an update on research from Dr. Chip Wilmot. MNG Labs are in Atlanta and offer a complete list of Ataxia testing for SCA and FDRA. Also discussed was the Georgia STABLE - Savings Plan for People with Disabilities, launched on June 14, 2017. This savings program opened a year after Georgia's Governor signed the Georgia's Achieving a Better Life Experience (ABLE) Act. The law allows individuals with disabilities and their families to contribute to a tax-exempt savings account that can be used for maintaining health, independence and quality of life. For more information on the Georgia STABLE program, visit <http://georgiastable.com>.



Greater Atlanta Ataxia Support Group

accommodate those in S.E. Florida.

Howard Freedland, Sue and Dan's son, updated the group on how the Tapas for Ataxia evening went. He was happy to share that the evening raised \$2000 for the NAF. He also talked about some of the other fundraising projects that he is working on with the NAF.

Our speaker, Dan, printed out several pages of various exercises his physical therapist has him do. He tried to show a few of them, and let the sheets do the explaining. He also had information on the "Swallow Study" he did and the effortless swallow exercise. He suggested places where someone could go for treatment, if interested.



Treasure Coast Ataxia Support Group

Everyone was eager to share the various exercises they do and the equipment they use. It proved to be a very good session of sharing and exchanging of information.

We are so glad to report that our group meetings are becoming a much warmer gathering as we all get to know each other better. We are finding that it is becoming easier to open-up and discuss our issues so that we can learn from each other. There is a desire to socialize with one another now and many of us look forward to attending the meetings.

Lisa's boyfriend of 17 years, Ronnie, asked his sign guy if he would do a banner for us, and they did it for us, free! Next time we won't block them!



## Treasure Coast Ataxia Support Group (TCASG)

*Submitted by Lisa Cole & Sue Freedland*

The Treasure Coast Ataxia Support Group met on Saturday, July 8 in Palm Beach Gardens, FL. There were 11 people who attended the lunch meeting in the Clubhouse in Canterbury, an area within the PGA National Community. This was our first meeting in Palm Beach Gardens and we hope the change will also

## TCASG Meeting-August 5

*Submitted by Lisa Cole & Sue Freedland*

The Florida Treasure Coast Ataxia Support Group met in Port St. Lucie, FL, on August 5 from 1-3:30p.m. There were nine people attending the meeting at the PSL Community Center. We enjoyed a light lunch and social time. Lisa had folders for everyone filled with NAF information. In the future, the minutes from the previous meeting will be included.



Treasure Coast Ataxia Support Group  
at Buffalo Chophouse

## Greater Denver Area Ataxia Support Group

*Submitted by Charlotte DePew*

The Greater Denver Area Support Group held a great potluck lunch meeting on Saturday, July 15 at Accessible Systems in Englewood, Colorado. There was about 25 individuals at the meeting that received an update on plans for the Seventh Annual Denver Run, Walk 'n Roll scheduled for September 10 at Denver's City Park Pavilion. Bob Williams, father of Mike Williams (1972-2016), our event's honoree, shared Mike's artworks that will be available for silent auction at our event. Mike left a very positive mark upon our world.

Our speaker, Cathy Everitt, provided interesting

and useful information on palliative care. The goal of palliative care is supportive care to improve quality of life for both patient and care provider.



## Arizona Ataxia Support Group

*Submitted by Rita Garcia and  
Mary Fuchs*

The Arizona Ataxia Support group met on Saturday, August 5 at Ability 360, in Phoenix.

Our speaker was Chrystie Cherry, Wellness Dietician at Banner Health. Chrystie is the daughter of one of our members, Karen Shelton. She talked about the basics of good nutrition and the premise of a healthful diet in prevention of chronic disease in maintaining good health. Her talk and slide presentation were very informative, followed with questions from our members.

The meeting ended talking about our IAAD fundraising and awareness event, "Italian Night for a CURE", on October 7, a fun night which will include a dinner, raffle and an Italian costume party.



Chrystie Cherry-Wellness Dietician

## Matching Gifts

Please ask your employer if there is a Matching Gift Program. If so, you and your co-workers donations may be doubled to support the work of NAF. Thank you.



# NAF Staff Directory, Directory of Chapters, Support Groups, Social Networks and Ambassadors

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

If you or a loved one 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 of the NAF staff at [lori@ataxia.org](mailto:lori@ataxia.org) or (763) 553-0020.

The use of these names and contact information for any purpose other than requesting information regarding the NAF or joining a chapter support group without NAF's written permission is strictly prohibited.

## NAF Staff Directory:

Joel Sutherland, Executive Director	(763) 231-2748 <a href="mailto:joel@ataxia.org">joel@ataxia.org</a>
Julie Braun-Mahler, Director of Operations and Development Specialist	(763) 231-2745 <a href="mailto:julie@ataxia.org">julie@ataxia.org</a>
Sue Hagen, Patient and Research Services Director	(763) 231-2742 <a href="mailto:susan@ataxia.org">susan@ataxia.org</a>

Lori Shogren,  
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and Service Director (763) 231-2743  
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Stephanie Lucas,  
Communications  
Manager (763) 231-2744  
[stephanie@ataxia.org](mailto:stephanie@ataxia.org)

Jan Stewart, Office  
Assistant (763) 231-2746  
[jan@ataxia.org](mailto:jan@ataxia.org)

## Social Networks



NAF Facebook Page  
<http://bit.ly/2sj5fC3>

NAF Facebook Group  
[www.facebook.com/groups/NAFmail](http://www.facebook.com/groups/NAFmail)



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



NAF Twitter  
[https://twitter.com/NAF\\_Ataxia](https://twitter.com/NAF_Ataxia)



NAF LinkedIn  
[www.linkedin.com/company/nationalataxiafoundation](http://www.linkedin.com/company/nationalataxiafoundation)

## BRAIN TISSUE DONATION PROGRAM

Ataxia researchers have made many discoveries because of donations of brain tissue from those affected with Ataxia. One researcher said the following about brain donation, "This tissue is very precious." The National Ataxia Foundation's Brain Donation Program was established to allow those who desire to donate their brain upon death so that researchers can find more answers.

If you are interested in learning more about brain donation, you may contact Sue Hagen, NAF Patient and Research Services Director, at [susan@ataxia.org](mailto:susan@ataxia.org) or (763) 231-2742.

## Chapters, Support Groups and Ambassadors

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

### Alabama

#### Alabama Support Group Leader

Becky Donnelly-Hover, AL

(205) 987-2883

E-mail: [donnelly6132b@aol.com](mailto:donnelly6132b@aol.com)

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

#### Ambassador

Dianne Blain Williamson-Huntsville-AL

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

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

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

### Arizona

#### Phoenix Area Support Group Leaders

Angela Li-Peoria, AZ

(847) 505-4325

E-mail: [angelali1010@gmail.com](mailto:angelali1010@gmail.com)

Mary Fuchs- Casa Grande, AZ

(480) 212-6425

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

Facebook Group:

[www.facebook.com/groups/arizonaataxia/](https://www.facebook.com/groups/arizonaataxia/)

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

#### Ambassador

Bart Beck-Tucson, AZ

(520) 885-8326

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

### Arkansas

#### Ambassadors

Judy and David King-Hot Springs Village, AR

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

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

### California

#### Los Angeles Area Support Group Leaders

Lora Morn-Santa Monica, CA

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

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

Harvey Kahn-Whittier, CA

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#### N. California Area Support Group Leaders

Brian Wong - Santa Clara, CA

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Fernando & Rocy Wu-Danville, CA

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Sacramento Area Representatives

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Teresa Bredberg-Sacramento, CA

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S.G. Website: [norcalataxia.org](http://norcalataxia.org)

Facebook Group:

<https://www.facebook.com/groups/592006361008986/>

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

#### Orange County Area Support Group Leaders

Cindy De Mint-Yorba Linda, CA

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Daniel Navar-Montebello, CA

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S.G. Website: <http://orangecountyataxia.org/>

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

Facebook Group: <https://www.facebook.com/groups/1980393985511432>

#### Palo Alto Support Group Leaders

Victoria Tanoury, RN, CNRN - Stanford, CA

(650) 736-1399

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Sarah Kahn-Stanford, CA

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

#### Ambassadors

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

### Colorado

**Greater Denver Area Support Group Leader**  
Charlotte DePew-Aurora, CO  
(720) 379-6887  
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# 2017

# Ataxia Calendar of Events

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

## Why Attend an Ataxia Support/Social Group?

Many of you may ask, "Why should I attend a support group meeting?"

Support groups can remind us that we are not alone and that while each individual may experience Ataxia in a different way, together we have many things in common. A benefit of attending a support group is simply to have a chance to talk with others and learn how different people deal with the same disease.

Attending a support group meeting may give you a glimpse into the many different stages and types of the disease. This can help by using some of the strategies that have been beneficial to others in order to avoid and/or plan for some of the same challenges that others have faced in the progression of their Ataxia.

Hopefully attending a support group meeting will leave you with a sense of hope and inspiration, knowing that if others can cope, so can you. **Come. Learn. Share. But most of all, know that you are NOT alone.**

## SUPPORT GROUP MEETINGS

**Wednesday, October 4, 2017**

### Western PA Ataxia Support Group Meeting

Time: 7 p.m.-9 p.m.

Location: Bethel Park Community Center, 5151 Park Avenue, Pittsburgh, PA

More Info: Ed Schwartz - 724-941-2210 or [eds@ataxia.org](mailto:eds@ataxia.org)

**Saturday, October 7, 2017**

### Rhode Island Ataxia Support Group

Time: 11 a.m.-2 p.m.

Location: Bristol Community Center, 101 Asylum Road, Bristol, RI.

More Info: Anabela Azevedo - 401-297-8627 or [azevedo70anabela@gmail.com](mailto:azevedo70anabela@gmail.com)

### Treasure Coast Ataxia Support Group Meeting

Time: 1 p.m.-4 p.m.

Location: PSL Community Center, 2195 SE Airoso Blvd, Port St. Lucie, FL 34984

More Info: Lisa Cole - 772-370-3041 or [lisacoleataxia@gmail.com](mailto:lisacoleataxia@gmail.com)

### Willamette Valley Ataxia Support Group Meeting - Portland Location

Time: 3 p.m. - 4 p.m.

Location: The Capitol Hill Library, 10723 SW Capitol Hwy, Portland, OR 97219

More Info: Jason Wolfer at 503-502-2633 or [wolferjason@gmail.com](mailto:wolferjason@gmail.com)

**Wednesday, October 11, 2017**

### Willamette Valley Ataxia Support Group Meeting - Albany Location

Time: 11:30 a.m.-1 p.m.

Location: Albany Hospital, 4th Floor Conference Room, 1046 6th Avenue SW, Albany, OR 97321

More Info: Jason Wolfer - 503-502-2633 or [wolferjason@gmail.com](mailto:wolferjason@gmail.com)

**Saturday, October 14, 2017**

### Tampa Bay Ataxia Support Group Movie Night

Location: AMC-Westshore, 210 Westshore Plz, Tampa, FL, 33609

Details: Movie and time TBD

More info: Darlene Harris at 813-431-2859 or [msdee0004@yahoo.com](mailto:msdee0004@yahoo.com) / Linda Farrow - [Indfrw2@gmail.com](mailto:Indfrw2@gmail.com)

### Central Minnesota Ataxia Support Group Meeting

Time: 10 a.m.-12 p.m.

Location: 1038 Sunset Ridge Road, St. Cloud, MN 56303

More Info: Marsha Binnebose at 320-248-9851 or [mbinnebose@hotmail.com](mailto:mbinnebose@hotmail.com)

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

Time: 10 a.m.-12 p.m.

Location: Ben Washington Baptist Church - Rev Jr Sheppard Educational Center, 615 Davis St, Irving, TX 75061

Details: There is lots of parking and it is handicap accessible. The meeting room is in a separate bldg from the church.

More Info: David Henry at [cheve11e@sbcglobal.net](mailto:cheve11e@sbcglobal.net)

### **Northern California Ataxia Support Group Meeting**

Time: 11 a.m.-3 p.m.

Location: Our Savior's Lutheran Church, 1035 Carol Ln, Lafayette, CA 94549

Details: You can RSVP to the meeting directly from the group website below and then clicking on the meetings and entering your name and the number in your party.

<http://www.norcalataxia.org>

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

Time: 12 p.m.-2 p.m.

Location: Northeast Library, 6000 Wilson Rd, Kansas City, MO 64123

Details: Stephanie Wilkins at 816-623-3318 or [sfwilkins@yahoo.com](mailto:sfwilkins@yahoo.com)

### **Denver Area Ataxia Support Group Meeting**

Time: 1 p.m. - 4 p.m.

Location: Swedish Medical Center, 501 E. Hampden Avenue, Englewood, CO 80113. 2nd Floor Conference Rooms.

More Info: Charlotte DePew at 720-379-6887 or [cldepew77@comcast.net](mailto:cldepew77@comcast.net)

### **Saturday, October 21, 2017**

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

Time: 2 p.m.-4 p.m.

Location: Orange Coast Memorial Hospital, 18111 Brookhurst St, Fountain Valley, CA 92708. Pacific Coast Room.

More Info: Cindy DeMint at [cindyocataxia@gmail.com](mailto:cindyocataxia@gmail.com)

#### **Twin Cities Ataxia Social Group**

Time: 10 a.m. - 12 p.m.

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

Details: Family and friends of an afflicted individual are always welcome! Please join us and make new connections!

More Info: Lenore Healey Schultz at 612-724-3784 or [Schultz.lenore@yahoo.com](mailto:Schultz.lenore@yahoo.com)

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

Time: 11 a.m. - 1 p.m.

Location: Hide A-way Grill, 744 W Park Street, West Point, NE.

More Info: Linda Snider at 402-212-3060 or [lindasnider@cox.net](mailto:lindasnider@cox.net)

### **NCASG - Sacramento Area Ataxia Support Group Meeting**

Time: 1 p.m. - 4 p.m.

Location: Sutter Roseville Medical Center - Meeting Room 8, 1 Medical Plaza Drive, Roseville, CA 95661.

More Info: Teresa Bredberg at 916-215-2686 or [tbredberg@sbcglobal.net](mailto:tbredberg@sbcglobal.net)

### **Saturday, October 28, 2017**

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

Time: 10 a.m.-2 p.m.

Location: Covenant Presbyterian Church, Homewood, AL

More Info: Beck Donnelly at [donnelly6132b@aol.com](mailto:donnelly6132b@aol.com) or 205-987-2883

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

Time: 1 p.m.-3 p.m.

Location: Davie Medical Center, 329 NC Highway 801 NC

More Info: Ron and Donna Smith at 919-779-0414 or [rsmith@sacherokee.com](mailto:rsmith@sacherokee.com) or [dsmith@sa-pr.com](mailto:dsmith@sa-pr.com)

#### **Central Pennsylvania Ataxia Support Group Meeting**

Time: 11 a.m.-1 p.m.

Location: Muhlenberg Community Library, Laureldale, PA

More Info: Mike Cammer at 610-996-5814 or [michael.cammer62@hotmail.com](mailto:michael.cammer62@hotmail.com)

### **Wednesday, November 1, 2017**

#### **Western PA Ataxia Support Group Meeting**

Time: 7 p.m.-9 p.m.

Location: Bethel Park Community Center, 5151 Park

Avenue, Pittsburgh, PA

More Info: Ed Schwartz at [eds@ataxia.org](mailto:eds@ataxia.org) or 724-941-2210

### **Saturday, November 4, 2017**

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

Time: 1 p.m.-3 p.m.

Location: Emory Rehabilitation Hospital, 1441 Clifton Road, NE Room 101, Atlanta, GA 30322

More Info: [atlantaataxia@gmail.com](mailto:atlantaataxia@gmail.com) or 404-822-7451

#### **Los Angeles Ataxia Support Group Meeting**

Time: 2 p.m.-4 p.m.

Location: Veterans Memorial Complex, 4117 Overland Ave, Culver City, CA 90230

More info: Lora Morn at [loramorn@gmail.com](mailto:loramorn@gmail.com) or Harvey Kahn at 562-686-9720

### **Wednesday, November 8, 2017**

#### **Willamette Valley Ataxia Support Group Meeting - Albany Location**

Time: 11:30 a.m.-1 p.m.

Location: Albany Hospital - 4th Floor Conference Room, 1046 6th Ave SW, Albany, OR 97321

More info: Jason Wolfer at [wolferjason@gmail.com](mailto:wolferjason@gmail.com) or 503-502-2633

### **Thursday, November 9, 2017**

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

Time: 6:30 p.m.-8:30 p.m.

Location: Mount Sinai Beth Israel Medical Center - Phillips Ambulatory Care Center - 2nd Floor, Conference Room, 10 Union Square East, New York, NY

More info: Kathleen Gingerelli at [kgingerelli@msn.com](mailto:kgingerelli@msn.com)

### **Saturday, November 11, 2017**

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

Time: 10 a.m.-12 p.m.

Location: 1038 Sunset Ridge Rd, St. Cloud, MN 56303

More info: Marsha Binnebose at 320-248-9851 or [mbinnebose@hotmail.com](mailto:mbinnebose@hotmail.com)

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

Time: 10 a.m.-12 p.m.

Location: Ben Washington Baptist Church - Rev Jr Sheppard Educational Center, 615 Davis St, Irving, TX 75061

Details: There is lots of parking and it is handicap accessible. The meeting room is in a separate bldg from the church.

More info: David Henry at [cheve11e@sbcglobal.net](mailto:cheve11e@sbcglobal.net)

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

Time: 11 a.m.-2 p.m.

Location: St. Vincent Fishers Hospital, 13861 Olio Rd., Fishers, IN 46037

Details: Join our support group for Ataxians and families. 1st meeting - get to know each other. Bring something to share for lunch plus your own drink. Paper goods supplied. We will meet in Conference Room #A & B (Park & enter at entrance One - follow the hallway to the right).

More info: RSVP Amy Draves: 765-610-2866 [amy4kids@msn.com](mailto:amy4kids@msn.com) or Teresas Cocco: 317-439-2512 [tcocco12@gmail.com](mailto:tcocco12@gmail.com)

### **Saturday, November 18, 2017**

#### **Nebraska Ataxia Support Group Social Outing**

Location: Climbing Gym tentatively scheduled.

More info: Linda Snider at 402-212-3060 or [lindasnider@cox.net](mailto:lindasnider@cox.net)

#### **Twin Cities Ataxia Social Group**

Time: 10 a.m.-12 p.m.

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

Details: The Twin Cities Ataxia Support Group meets once a month. Family and friends of an afflicted individual are always welcome! We meet on the third Saturday of every month. We wanted to provide a central location that it easy to access which is why we picked this place. Please join us, and make new connections!

More info: Lenore Healey Schultz at 612-724-3784 or [schultz.lenore@yahoo.com](mailto:schultz.lenore@yahoo.com)

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

Time: 12 p.m.-3 p.m.

Location: Mass General Hospital in the Yawkey Building - Yawkey 4 room 820, 55 Fruit Street, Boston, MA 02114

**Details:** There is a garage underneath that building but I find that parking in that garage a bit difficult, it may be easier for people to use the garages in front of the hospital. Parking stickers will be available that can be used to comp the parking price. Stickers are good for max of 4 hours. There will be a light lunch and drinks provided donations are welcome to our Sunshine Fund. Please feel free if you like to bring a sweet.

**More info:** John Mauro at [john@ataxia.org](mailto:john@ataxia.org) or 508-736-6084

### **Tampa Bay Ataxia Support Group Meeting**

**Time:** 12:30 p.m.-3 p.m.

**Location:** University of South Florida - Morsani Center, 13330 Laurel Dr #1013, Tampa, FL 33612

**Details:** Guest Speaker, Uriel Riley, Personal Trainer and Exercise Therapist

**More info:** Darlene Harris [msdee004@yahoo.com](mailto:msdee004@yahoo.com) 813-431-2859 or Linda Farrow at [Indfrrw2@gmail.com](mailto:Indfrrw2@gmail.com)

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

**Time:** 1 p.m.-3 p.m.

**Location:** Ability 360, 5025 E Washington Street, Phoenix, AZ 85034

**More info:** Mary Fuchs at 480-212-6425 or [mary11115@msn.com](mailto:mary11115@msn.com)

### **NCASG - Sacramento Area Ataxia Support Group Meeting**

**Time:** 1 p.m.-4 p.m.

**Location:** Sutter Roseville Medical Center - Meeting Room 8, 1 Medical Plaza Dr, Roseville, CA 95661

**More info:** Teresa Bredberg at 916-215-2686 or [tbredberg@sbcglobal.net](mailto:tbredberg@sbcglobal.net)

### **Saturday, December 2, 2017**

#### **Orange County Ataxia Support Group Holiday Party**

**Time:** 1 p.m.-4 p.m.

**Location:** TBD

**More info:** Cindy DeMint at [cindyocataxia@gmail.com](mailto:cindyocataxia@gmail.com). <http://orangecountyataxia.org/>

### **Treasure Coast & Tampa Bay Joint Ataxia Support Group Meeting**

**Time:** 10:30 a.m.-1 p.m.

**Location:** Southwest Library-Community Room, 7255 Della Drive, Orlando, FL

**More info:** Lisa Cole at 772-370-3041/[lisacoleataxia@gmail.com](mailto:lisacoleataxia@gmail.com), Darlene Harris [msdee004@yahoo.com](mailto:msdee004@yahoo.com)/813-431-2859 or Linda Farrow at [Indfrrw2@gmail.com](mailto:Indfrrw2@gmail.com)

### **Mid-Atlantic Ataxia Social Group Holiday Party**

**Location:** BWI Marriott Hotel, Linthicum Heights, Maryland

**Details:** Please join us for our 3rd Annual Ataxia Network Holiday Party! There will be lunch and other fun activities. This will be a great opportunity to meet other people living with ataxia and make new friends! Optional: bring a gift, between \$5-\$10, for a holiday gift exchange. Registration is free, but required. Please register by November 17 at the website provided below.

**More info:** Donna Neuworth at [ddeleno1@jhmi.edu](mailto:ddeleno1@jhmi.edu) or 410-616-2811. <https://tinyurl.com/y7bz8mch>

### **Wednesday, December 6, 2017**

#### **Western PA Ataxia Support Group Meeting**

**Time:** 7 p.m.-9 p.m.

**Location:** Bethel Park Community Center, 5151 Park Avenue, Pittsburgh, PA

**More info:** Ed Schwartz at [eds@ataxia.org](mailto:eds@ataxia.org) or 724-941-2210

### **Friday, December 8, 2017**

#### **Alabama Ataxia Support Group Social**

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

**More Info:** Becky [Donnelly6132b@aol.com](mailto:Donnelly6132b@aol.com) or 205-987-2883

### **Saturday, December 9, 2017**

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

**Time:** 10 a.m.-12 p.m. **Location:** Ben Washington Baptist Church - Rev Jr Sheppard Educational Center, 615 Davis St, Irving, TX 75061

**Details:** There is lots of parking and it is handicap accessible. The meeting room is in a separate bldg from the church.

**More info:** David Henry at [chevelle@sbcglobal.net](mailto:chevelle@sbcglobal.net)

### Central Minnesota Ataxia Support Group Meeting

Time: 10 a.m.-12 p.m.

Location: 1038 Sunset Ridge Rd, St. Cloud, MN 56303

More info: Marsha Binnebose at 320-248-9851 or [mbinnebose@hotmail.com](mailto:mbinnebose@hotmail.com)

### Kansas City Ataxia Support Group Meeting

Time: 12 p.m.-3 p.m.

Location: Northeast Library, 6000 Wilson Rd, Kansas City, MO 64123

More info: Stephanie Wilkins at 816-623-3318 or [sfwilkins@yahoo.com](mailto:sfwilkins@yahoo.com)

### Greater Atlanta Ataxia Support Group Christmas Potluck

Time: 1 p.m.

Location: 328 Mell Ave, Suite B, Atlanta, GA 30307

More info: [atlantaataxia@gmail.com](mailto:atlantaataxia@gmail.com) or 404-822-7451

### Wednesday, December 13, 2017

#### Willamette Valley Ataxia Support Group Meeting - Albany Location

Time: 11:30 a.m.-1 p.m.

Location: Albany Hospital - 4th Floor Conference Room, 1046 6th Ave SW, Albany, OR 97321

More info: Jason Wolfer at [wolferjason@gmail.com](mailto:wolferjason@gmail.com) or 503-502-2633

### Saturday, December 16, 2017

#### Twin Cities Ataxia Meeting

Time: 10 a.m.-12 p.m.

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

Details: The Twin Cities Ataxia Support Group meets once a month. Family and friends of an afflicted individual are always welcome! We meet on the third Saturday of every month. We wanted to provide a central location that it easy to access which is why we picked this place. Please join us, and make new connections!

More info: Lenore Healey Schultz at 612-724-3784 or [schultz.lenore@yahoo.com](mailto:schultz.lenore@yahoo.com)

### Nebraska Ataxia Support Group Social Outing

Time: 11 a.m.-1 p.m.

Location: Creighton Prep High School, 7400 Western Ave, Omaha, NE

Details: Guest speaker TBA

More info: Linda Snider at 402-212-3060 or [lindasnider@cox.net](mailto:lindasnider@cox.net)

### NCASG - Sacramento Area Ataxia Support Group Meeting

Time: 1 p.m.-4 p.m.

Location: Sutter Roseville Medical Center - Meeting Room 8, 1 Medical Plaza Dr, Roseville, CA 95661

More info: Teresa Bredberg at 916-215-2686 or [tbredberg@sbcglobal.net](mailto:tbredberg@sbcglobal.net)

## REMEMBERING THE NAF IN YOUR WILL

Throughout the years, individuals have named the National Ataxia Foundation as a beneficiary in their wills. Their thoughtfulness and foresight has enabled the NAF to provide more research studies, more services to patients and families and more education and ataxia awareness to the public. We are grateful for the impact that has been made by these compassionate acts. If this is something you would like to consider, please contact Joel Sutherland at [joel@ataxia.org](mailto:joel@ataxia.org) or call (763) 231-2748.

# Upcoming Informational, Awareness Events, and Fundraisers

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

**Saturday, October 7, 2017**



## Fort Wayne Walk n' Roll to Cure Ataxia

**Time:** 9 a.m.-1 p.m.

**Location:** Foster Park, 3900 Old Mill Rd, Ft. Wayne, IN 46807

**Details:** Registration: 9:00am and Walk n' Roll: 10:00am. No Registration Fee - Donations Gladly Accepted. Event T-shirt for participants that attend available on a first-come; first-serve basis while inventory and sizes last. All proceeds benefit the National Ataxia Foundation. **To volunteer or for more information:** Contact Jessica Lebrato EM: [jclebrato711@gmail.com](mailto:jclebrato711@gmail.com) or 260-609-6690 [www.ataxia.org/walk/fortwayne](http://www.ataxia.org/walk/fortwayne)



## Saturday, October 7, 2017 New Hampshire Walk n' Roll to Cure Ataxia

**Time:** 9 a.m.-1 p.m.

**Details:** Aviation Museum of New Hampshire, 27 Navigator Rd, Londonderry, NH 03053  
**Details:** Come and learn about ataxia while having fun raising funds for NAF. FREE, FAMILY, FUN! Entertainment and Raffle following Walk n' Roll No Registration Fee - Donations Only. All proceeds benefit the National Ataxia Foundation. **More information:** Jane Jaffe at 619-286-9745 or [sicilianmother@cox.net](mailto:sicilianmother@cox.net) [www.ataxia.org/walk/newhampshire](http://www.ataxia.org/walk/newhampshire)

## Italian Night for a Cure

**Time:** 5 p.m.-8 p.m.

**Location:** Floridino's, 590 N Alma School Rd, Chandler, AZ 85224

**Details:** Join us for an evening of pasta, wine, and fun to raise funds for NAF! This event is a dinner with a raffle and guest speaker Joel Sutherland, NAF's Executive Director. Participants are

welcome and encouraged to raise support of this event by sharing their personal fundraising pages that are generated during registration for this event. The registration fee is \$25. Visit the event website to donate in support of this event, register for this event, start or join a team, set a goal, and begin raising money in support of NAF! All proceeds benefit the National Ataxia Foundation. **More information:** Mary Fuchs at 480-212-6425 or [mary11115@msn.com](mailto:mary11115@msn.com) <https://ataxia.donorpages.com/2017ItalianNightForACure/>

## Tea Time to Cure Ataxia

**Time:** 11 a.m.-3:30 p.m.

**Location:** Aubrey Rose Tea Room, La Mesa, CA  
**Details:** Due to the overwhelming popularity of this tea, this year you will again have a choice of sitting at 11:00 am - 1:00 PM or 1:30 P.M. - 3:30 P.M. Both sittings are sold out, but donations are still being accepted.

**More information:** Jane Jaffe at 619-286-9745 or [sicilianmother@cox.net](mailto:sicilianmother@cox.net)

## Friday, October 13- Saturday, October 14, 2017 MSA Coalition Patient & Family Conference

**Time:** 5 p.m.-8 p.m.

**Location:** Nashville Airport Hotel, 2200 Elm Hill Pike, Nashville, Tennessee, 37214

**Details:** Seating is limited - event registration is required so we may reserve your spot at the conference. (Only those planning to attend in person are to register. The live stream at MSA's website is open to everyone). **To volunteer or for more information:** <https://www.multiplesystematrophy.org/newsroom/annual-conference>

**Thursday, October 26, 2017**

### **University of Pittsburgh Brain Day**

**Time:** 10 a.m.-5:30 p.m.

**Location:** University Club, 123 University Place, Pittsburgh, PA 15213

**Details:** This free event will feature interactive scientific poster sessions highlighting the depth and range of neuroscience research at Pitt, a luncheon to foster relations between our experts and Advocacy Group members, and a keynote session on Alzheimer's Disease. Visit the event website to register.

**More information:** <https://www.pittbrainday.site/luncheonregistration>

**Friday, October 27-Sunday, October 29 2017**

### **Bay Area Abilities Expo**

**Location:** San Mateo County Event Center

**Details:** Abilities Expo has been the go-to source for the Community of people with disabilities, their families, seniors, veterans and healthcare professionals. Every event opens your eyes to new technologies, new possibilities, new solutions and new opportunities to change your life.

**More information:** <http://www.abilities.com/bayarea/>

**Saturday, October 28, 2017**

### **JHU Ambassadors - Arts for Ataxia**

**Time:** 10:30 a.m.-2:30 p.m.

**Location:** JHU - Levering Great Hall - Homewood Campus, South Garage, Bowman Drive, Baltimore, MD 21218

**Details:** Join us in raising awareness for Ataxia! This event includes a speaker panel, Music, and food. including a panel of people with ataxia and care partners from the Johns Hopkins Ataxia Center Advisory Board and Amanda Therrien, PhD, Center of Movement Studies Kennedy Krieger Institute will be speaking on "New Developments in Ataxia Research". RSVP at the website provided.

**More information:** <https://tinyurl.com/ybylch2v>

**Friday, December 1-Sunday, December 3, 2017**

### **DC Metro Abilities Expo**

**Time:** 10:30 a.m.-2:30 p.m.

**Location:** Dulles Expo Center

**Details:** Abilities Expo has been the go-to source for the Community of people with disabilities, their families, seniors, veterans and healthcare professionals. Every event opens your eyes to new technologies, new possibilities, new solutions and new opportunities to change your life.

**More information:** <http://www.abilities.com/dcmetro/>

**Friday, October 13 - Sunday, October 15, 2017**



### **Let's Stop This Thief! - 60 for 60 to Cure Ataxia**

**Location:** Atwater, MN

**Details:** Executive Director Joel Sutherland, along with teammates Vince Kelly, Mark Melles, and Mark Koller, will begin their 60 mile walk to raise funds to stop this thief.

**More Info:** Joel Sutherland at 763-553-0020 or [joel@ataxia.org](mailto:joel@ataxia.org)



### **Tampa Bay Ataxia Group 60 for 60 Walk n' Roll to Cure Ataxia**

**Location:** Carol and Frank Morsani Center for Advance Healthcare, 13330 USF Laurel Drive, Tampa, FL, 33613

**Details:** To donate or join the team, go to <https://ataxia.donorpages.com/201760For60/TampaBayAtaxiaSupportGroup/>

**More Info:** Darlene Harris at 813-431-2859 or [Msdee004@gmail.com](mailto:Msdee004@gmail.com)

### **The Ataxia Community is always looking for great ideas to share in *Generations*.**

If you have Pearls of Wisdom or a personal story you would like to share in a future issue of *Generations*, please submit it to Stephanie at [stephanie@ataxia.org](mailto:stephanie@ataxia.org). Please keep your "pearls" short and personal stories to 1000 words or less.

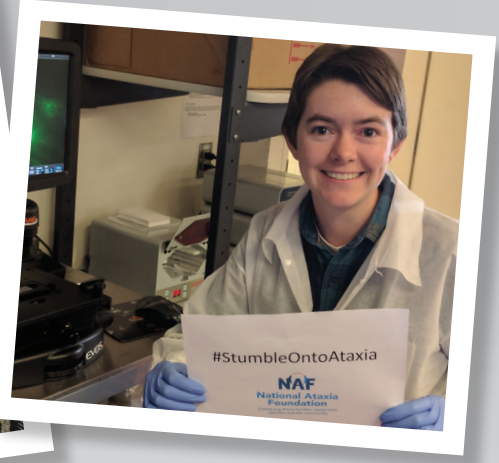
Those submitting a personal story are asked to please include a photo or two and a brief author bio (1-2 sentences).



# International #StumbleOntoAtaxia Campaign Takes Off

## Hundreds Participated - Tens of Thousands Reached

NAF rolled out its first-ever coordinated awareness campaign on social media to lead up to International Ataxia Awareness Day (IAAD) this year. The campaign aimed to shed light on Ataxia symptoms and how they impact a person's life. The campaign slogan, Stumble Onto Ataxia, gave a nod to one of the most common symptoms (trouble walking) while encouraging others to learn about the disease. The campaign featured an entire month's worth of social media posts centered around Ataxia symptoms and how they affect a person's life. People of all walks of life sent in their #StumbleOntoAtaxia photos to be a part of the campaign. Thank you to all of the participants and supporters! Not only did NAF receive submissions from across the country - but international as well - with photos from Japan, the UK, and Canada to name a few. Take a look at some of the great NAF supporters who joined in on this initiative.



## Memorials and In Your Honor

The National Ataxia Foundation is grateful to those who have made contributions in memory of or in honor of their friends and families whose names are listed below. This list reflects contributions made in May 2017 through July 2017. 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 always let us know if the contribution is a memorial or in honor of their friend or family member.

Debbie Adair	Louise Estabrook	Larry Klotz	Rick Roemke
Christian Agostini	Jeanette Eustache-	Klotz Family	Mary Romero
Matthew Agostini	Thaman	Jamie Kosieracki	Johnny Rorrio
Jason Aiello	Mary Farley	Karin Koski	Edward Scheffler
Wilber Allen	Pauline Farley	Karen Kraynak	Derek Semler
Barbara Almeida	Michael Fiorentino	Jesse Kuenzi	Richard Shute
Diane Anderson	Kevin Fleming	Langley Family	Sybil Sibley
David Ashley	Fred Flory	Dr Michael Lawlor	Charles Sink
Bruce Backens	Bob Flynn	Lawlor Family	Deborah Snyder
Sharon Baggett	Terrence Fort	Jenny Leader	Joseph Stamer
James Baldwin Jr.	Albert Frei	Rita Lobascio	Linda Steffan
Jennifer Bellini	Ben Frei	Brad Machado	Robin Stevenson
Lopamudra Bhaduri	Bernard Frei	Lawrence Mandela	Irwin Streickler
Mark Binnebose	Jolene Glueckert	Chip Masamitsu	Kelly Tambourino
Sheila Bredberg-Ballek	Marc Gokenbach	Massanova Family	Will Thornton
Angela Brown	Katherine Gorman	Brett Masserant	Aymee Torres
Clete Brunnert	Rege Gottschalk	Evelyn McClory	Margaret Tseng
Bill Buckley	Ricardo Guerrero	Robert McClory	Robert Tucci
William Buckley	Teresita Guerrero	Greg McGuire, Sr.	John Turnbull
Jacob Bunnell	Sarah Hale	Charlie McLaughlin	Margaret Uhland
Katie Campbell	Susan Hammett	Devon McMillon	Terry Underwood
Paul Canfeild	David Hankins	Robert McMurtry	Jacob Van Buren
Kenny Canter	Janet Hannaford	Amy Messigian-Legault	Antoinette Varron
Eric Christian	Vicki Hardy	Christy Meyers-Plotnick	Patty Walshaw
Cameryn Cobb	Susan Harmer	Kimberly Michael	Barry Washburn
Marcia Cox-Vaughey	Darlene Harris	Mitchell Family	Phil Wauben
Patricia Crandall	Bernice Hartley	Edward Noel	Marvin Way
JT De Mint	Marge Heer	John O'Brian	Sheila Weiss
Peter De Mint	Kassi Henderson	Dr Harry Orr	Weiss Family
Tim De Mint	Helen Henry	Ronald Peabody	Leroy Wernsing
Mary Dean	Shari Hinojosa	John Pellegrino	Wernsing Family
Ora Dean	Johnny Hogan	Peterson Family	Olive Westhoff-
Robert Debartolo	Jordan Hubbard	Antonio Pimentel	Derrington
Joseph DeCrescenzo	Sydney Hubbard	Christine Plotnick	David Westrick
Marika Devan	Charlene Hughes	Frank Poli	Mary Whaley
Jack Dewitt	Krista Humes	Nello Poli	Thomas Williams, Jr.
Becky Donnelly	Lisa Jaffe	Kim Poor	Pearl Workley-Straub
Fred Donnelly	Kerry Johnson	Brad Radford	Michelle Zhang
Rick Donnelly	Terry Johnson	Patrick Reed	Rudy Zhang
Teresa Donnelly	Marvin Kamen	John Riberio	Jonathan Zilles
Terri Donnelly	Nadine King	Maria Rideout	
Arlo Drury	Denise Kipley	Janet Riley	
Sara Dykstra	Donna Klotz	Patti Riley	

# So you have a genetically confirmed form of Spinocerebellar Ataxia?

**Invitae is looking for individuals with specific genetically confirmed forms of SCA: SCA7, SCA10, SCA12 or DRPLA who are willing to provide saliva sample and a copy of their genetic test results.**

Invitae is a diagnostic testing company whose mission is to make genetic testing more widely accessible and affordable, especially to individuals with a rare disease who often face difficulty obtaining a diagnosis.

Next-generation sequencing panels have benefitted many rare disease communities, but due to the inherent technical difficulties, a reliable, low-cost, comprehensive pane has yet to be developed for Spinocerebellar Ataxia.

## **Invitae is offering \$200 for your participation.**

If you have a genetically confirmed diagnosis of one of these Ataxias and are interested in participating, please contact Invitae Genetic Counselor Hannah White at [Hannah.white@invitae.com](mailto:Hannah.white@invitae.com) or (415) 231-5648 for more information.



## **Tissue donations for research in Friedreich Ataxia**

If you have been diagnosed with Friedreich Ataxia and wish to contribute to its eradication by helping research, please consider donating your tissues after death. To do so, contact Dr. Arnulf H. Koeppen for detailed information. Tissues affected by Friedreich Ataxia are brain, eyes, spinal cord, dorsal root ganglia, sensory peripheral nerves, heart, and the insulin-producing beta-cells of the pancreas.

Arnulf H. Koeppen, MD • Professor of Neurology and Pathology

Research Service (151) • VA Medical Center

113 Holland Ave, Albany, NY 12208

Tel. 518-626-6377 • FAX 518-626-5628

E-mail: [arnulf.koeppen@va.gov](mailto:arnulf.koeppen@va.gov) or [akoeppen@mail.amc.edu](mailto:akoeppen@mail.amc.edu)

## Gift – Honor – Memorial

A contribution given in memory of a friend or relative is a thoughtful and lasting tribute, as are gifts to honor your friends or family. A Gift Membership is a wonderful gift to a friend or relative for special occasions like birthdays, graduations, anniversaries, and holidays. NAF will acknowledge your gift without reference to the amount. Simply fill out this form and mail with your check or credit card information to the National Ataxia Foundation. Honor/Memorial envelopes are available free of charge by writing or calling NAF.

My contribution is:     In Memory  In Honor  Gift Membership

Name \_\_\_\_\_

Occasion \_\_\_\_\_

Send Acknowledgment Card to:

Name \_\_\_\_\_

Address \_\_\_\_\_

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

From:

Name \_\_\_\_\_

Address \_\_\_\_\_

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

## Membership

**Yes**, I want to help fight Ataxia! Enclosed is my membership donation.

(Gifts in U.S. Dollars)

Lifetime membership - \$500

Annual Memberships:

Patron membership - \$100-\$499     Professional membership - \$65

Individual - \$40 Household - \$60     Addresses outside the U.S. please add \$15

### Recurring Gift Membership Program:

If you wish to contribute monthly or quarterly, please consider the Recurring Gift Membership Program. For more information contact the NAF office or visit

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

Name \_\_\_\_\_

Address \_\_\_\_\_

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

Phone \_\_\_\_\_

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

Yes, sign me up for NAF e-mails

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## PAYMENT INFORMATION

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

Check. Please make payable to the NAF.

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

Card:     Visa     MasterCard

Discover     AMEX

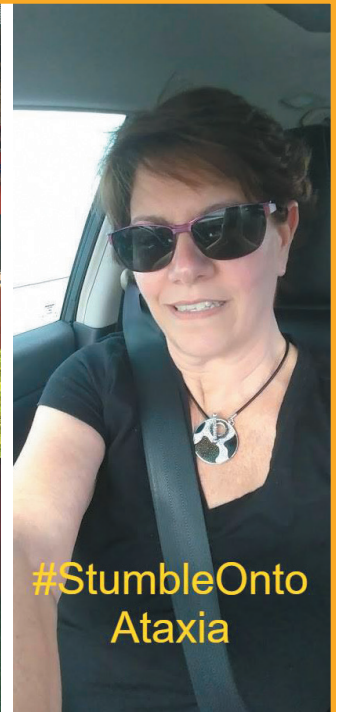
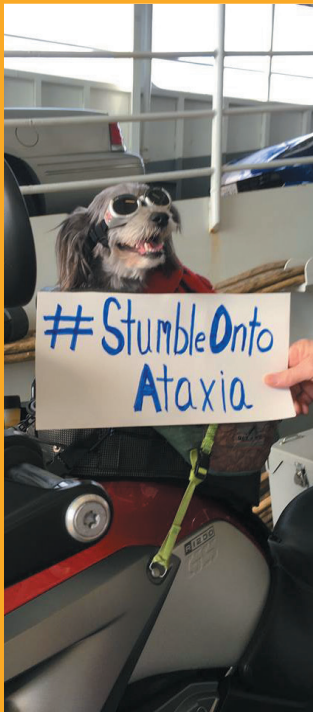
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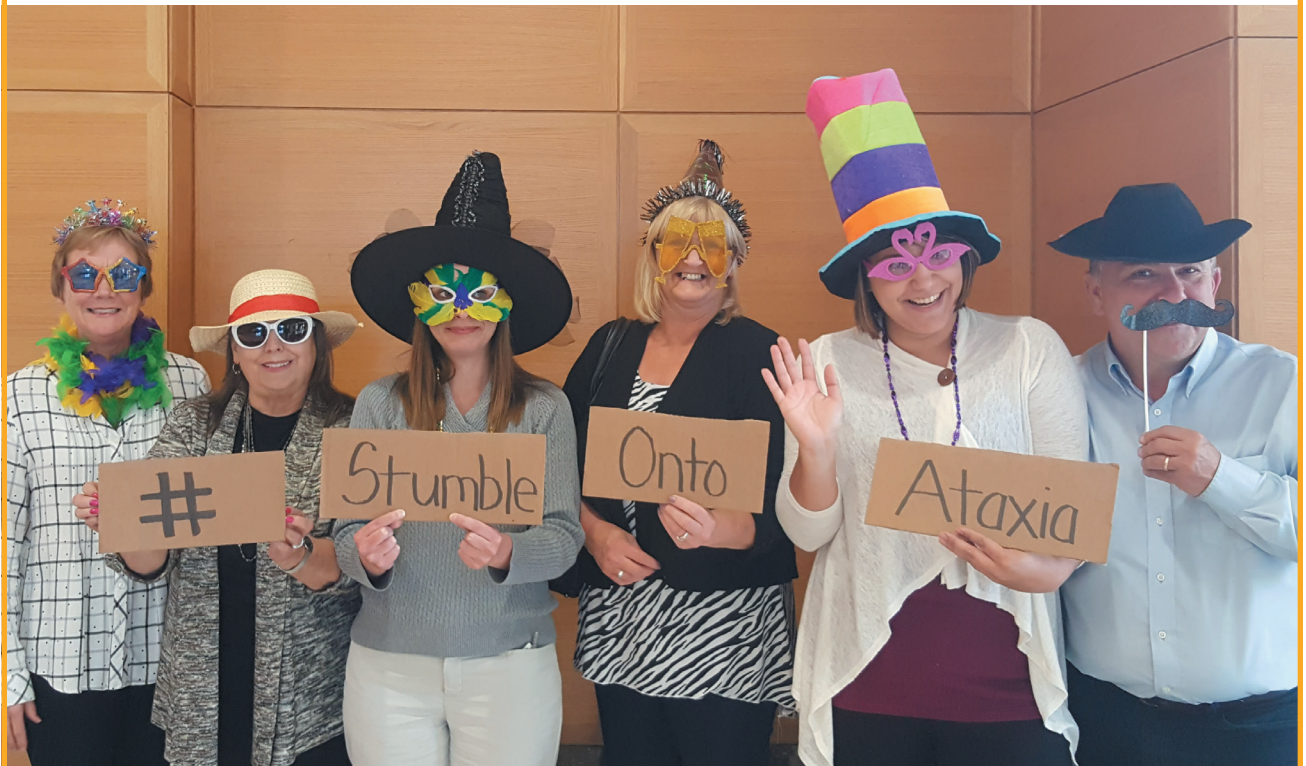
Exp. Date \_\_\_\_\_ CVV # \_\_\_\_\_

Signature \_\_\_\_\_

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



Check out the  
**#StumbleOntoAtaxia**  
Awareness Campaign on Page 47



**Ataxia Research Drive**

Oct 15th - Dec 15th

**Details on page 30**

[www.ataxia.org/ResearchDrive](http://www.ataxia.org/ResearchDrive)

The National Ataxia Foundation  
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