The National Ataxia Foundation is pleased to report that 21 outstanding ataxia research studies were awarded funding in late December 2012. With support from NAF’s generous partners and donors, NAF committed $1 million in research dollars for fiscal year 2013.

There were 35 reviewers assigned to evaluate the 53 research applications NAF received from scientists around the world. Each application was assigned two to three independent peer reviewers, along with a review from NAF’s Scientific Review Panel. After a careful and thorough review of each application was concluded, recommendations were given to NAF’s Board of Directors for the final funding decision.

Ataxia scientists from around the world were awarded funding through NAF’s five research programs: five researchers were awarded the NAF Research “Seed Money” Award, five were awarded the NAF Post Doc Fellowship Award, three were awarded the NAF Young Investigator Award, four received the $50,000 Young Investigator-SCA Award, and four were awarded the $100,000 Pioneer SCA Translational Research Award. The summaries of these important studies are included in this expanded issue of Generations.

The National Ataxia Foundation gratefully acknowledges all who supported this year’s funded ataxia research studies. Thank you to our anonymous donor who so generously supported this year’s research studies through a three-year $1.5 million dollar research commitment, to the Michael and Patricia Clementz Family Fund for SCA3 Research for their continued financial commitment, the Angeldance Fund in Memory of Sue Cowles Shoup of the Dallas Foundation for their most generous gift, the Gordon and Marilyn Macklin Foundation’s continued...
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The deadline for the Summer issue of Generations (mailed in late June) is May 17
support and generous $150,000 matching research gift.

Thank you to each individual and family who gave so generously in supporting NAF’s 2012 annual ataxia research drive and to those who supported NAF throughout the year. A special thank you to the families, individuals, support groups, chapters, and ambassadors who conducted and supported events. Thank you as well to our corporate and foundation friends. Thank you to all of you for giving researchers the tools to help end ataxia.

NAF Funded Research for FY 2013

Pioneer SCA
Translational Grant Awards

Tetsuo Ashizawa, MD
University of Florida, Gainesville, FL

Natural History of and Genetic Modifiers in Spinocerebellar Ataxias

Spinocerebellar ataxias (SCAs) 1, 2, 3, and 6 are the four most common SCAs that are caused by expansion of CAG repeats. Elongated poly-glutamine (polyQ) repeats resulting from the repeat expansion in these disorders renders the protein products of the respective genes toxic to the cell. Research supported by NAF and NIH made the mechanisms of the toxicity increasingly clear in these disorders. The advances in understanding the disease mechanism have brought a hope for testing novel treatments in the near future. These treatments are expected to slow down or stop the progression of the disease and eventually reverse the disease process. However, without knowing how fast each of these disorders progresses, it is extremely difficult to determine whether a drug is actually improving the course of the disease. Obtaining quantitative data on the natural progression of the disease is, therefore, critical for designing clinical trials that can unequivocally show the efficacy of treatments that are designed to alter the disease course. Without knowing the natural history, we may falsely rule some effective treatment useless and vice versa. Not all patients progress at an equal rate even when they have the same disease. The size of the CAG expansion and other genetic modifiers influence the progression rate. Once the genetic modifiers are defined, they can be used to identify a population of patients who have a comparable genetic background. Identification of genetically sorted patient populations can make the design of clinical trials simpler and the data analysis straightforward. Such “stratification” of study populations can reduce the number of patients required for studies, providing an important advantage in clinical research of rare disorders like SCAs. Additionally, if we identify genetic modifiers that slow the progression of the disease, such information can be used to develop therapeutic drugs to slow the disease progression. Finally, it is important to store DNA and serum from the blood, cerebrospinal fluid, and cell lines such as skin fibroblasts from patients. Stem cells that mimic human embryonic stem cells can be generated from the skin fibroblasts which bypass the ethical issue of using human embryos. These resources are invaluable in further studies of disease mechanisms and development of new treatments. Furthermore, they are essential for the development of biomarkers, which will be useful for confirming that the
drug is doing what it is supposed to do and the patient’s body is biochemically and physiologically responding to the drug in expected ways in clinical trials.

**Puneet Opal, MD, PhD**  
Northwestern University, Chicago, IL  
**VEGF as Therapy for SCA1**

Spinocerebellar Ataxia Type 1 is a relentless and fatal genetic disease that affects the cerebellar region of the brain. This disease is caused by a glutamine repeat expansion in the protein ataxin-1. Recently, we made the unexpected discovery that ataxin-1 directly suppresses the expression of the angiogenic and neurotrophic cytokine VEGF in the SCA1 mouse brain. Following up on this observation, we discovered that genetic replacement of VEGF levels mitigates the SCA1 phenotype in SCA1 knock-in mice. (SCA1154Q/2Q; Q=glutamine), the best existing mouse model of SCA1. We have also demonstrated in preliminary proof-of-principle experiments that pharmacologic replenishment of VEGF (by intraventricular delivery) improves the cerebellar aspects of the SCA1 phenotype, specifically the hallmark ataxia and the cerebellar dendritic pathology. We would like to pursue additional experiments to test the therapeutic potential of VEGF. These studies will help design clinical trials for patients with SCA1 and other ataxias.

**Harry T. Orr, PhD**  
University of Minnesota, Minneapolis, MN  
**Small Molecule Inhibitors of PKA: A Therapeutic Strategy for SCA1**

Spinocerebellar ataxia-type (SCA1) is a progressive lethal neurodegenerative disorder. In SCA1, the protein affected is Ataxin-1 has a region within it that typically contains 35 or fewer glutamine residues in individuals not affected with SCA1. Individuals with SCA1 have a genetic mutation that leads to ataxin-1 protein containing greater than 40 (and as many as 83) glutamine amino acid residues. As a result of this mutation, the normal function of the protein is compromised. Ataxin-1 is expressed in the Purkinje neurons of the cerebellum, the brain cells that coordinate balance and movement. Expression of mutant Ataxin-1 leads to degeneration of Purkinje neurons, and subsequent loss of motor and balance coordination. Recently, an amino acid residue found in both normal and mutant Ataxin-1, designated serine 776, was found to undergo a chemical modification termed phosphorylation, that is crucial for disease progression. In transgenic mice studies, phosphorylation of serine 776 was found to be necessary for mice to get the disease. Mice expressing a continuously phosphorylated form of normal Ataxin-1, showed the same pathological and behavioral symptoms as mice expressing the mutant Ataxin-1 protein. These studies indicate that molecules that inhibit phosphorylation at serine 776 have therapeutic potential for SCA1. To begin to find potential...
inhibitors, we screened several compounds to find inhibitors of Ataxin-1 serine 776 phosphorylation in a cell-free assay. The molecules discovered in these initial screens now need to be optimized chemically and analyzed in progressively more complex model systems in an effort to find a small molecule inhibitor of Ataxin-1 serine 776 phosphorylation that has the potential of becoming an effective drug.

Henry L. Paulson, MD, PhD
University of Michigan Medical School, Ann Arbor, MI

Novel Cell-Based Screens for Therapeutic Compounds in SCA3

Despite recent progress in defining the underlying disease mechanisms, no preventive treatment exists for any of the nine known polyglutamine disorders including Spinocerebellar Ataxia Type 3 (SCA3). In this application to continue the second year of a Pioneer Award (which had been submitted last year as a two-year proposal), we seek to develop preventive therapy for SCA3, building on our longstanding expertise in SCA3 and preliminary results obtained in drug screens employing cell-based assays. The overall objective is to identify compounds that slow or prevent disease in SCA3, a fatal and untreatable disorder. The proposed studies take advantage of two newly developed, complementary cell-based assays that target proximal steps in the pathogenic cascade. These assays are designed to identify compounds that either reduce total levels of the toxic disease protein ataxin-3, or inhibit its oligomerization, which is likely a key biochemical step in SCA3 and other polyQ diseases. Initial compound screens in both assays (and carried out, in part, in the first year of funding) have identified over 30 compounds, including various proteostasis modulators, that reduce levels of expanded ataxin-3 or early oligomer formation. In this second year of the two year proposal, we will build from successful compound identification to in vivo testing in a murine model of disease. New Aim 1 will confirm the activity of identified compounds in a novel cerebellar organotypic culture system derived from SCA3 transgenic mice. Aim 2 will test whether a promising compound from among those identified in year 1 and evaluated to have acceptable pharmocokinetic properties, can mitigate disease in a mouse model of SCA3 that expresses the full human disease gene and recapitulates features of the human disorder. Our expectation is to identify at least one or more compounds that hold promise as potential therapeutic agents for humans who suffer from SCA3.

Description of Relevance

The proposed research uses newly developed cell-based assays to screen drugs in order to identify possible preventive therapy for the degenerative brain disease, SCA3, an untreatable and fatal disorder. A drug identified in our screens will then be tested for its effectiveness in slowing disease in a mouse model that faithfully mirrors many aspects of the human disease.

Dr. Henry L. Paulson

ShopNAF
Looking for that perfect gift or items for your everyday needs? Shop online through MarketAmerica's NAF shopping portal, www.ShopNAF.org. Each purchase made through this website will help support the National Ataxia Foundation.
Young Investigator Awards

Christopher P. Baines, PhD
Univ. of Missouri-Columbia, Kansas, MO

Development of New Mouse Models of Friedreich’s Ataxia

Mouse models of Friedreich’s Ataxia (FA) have provided important test systems for the development of potential therapeutic agents for treatment of this disease. However, the FA-like disease that develops in these animals is either too severe or too mild. Moreover, the genetic changes required to generate and maintain these mice are very complex thus making their use very time-consuming and laborious. Our studies, therefore, propose to generate a new mouse model of FA that will ideally would fall somewhere in between these existing systems, both in terms of disease progression and in ease of use. Should this approach be successful, this new mouse model would represent a significant addition to our arsenal in the study of FA and the development of therapeutics to treat this disease clinically.

Brent Fogel, MD, PhD
UCLA, Los Angeles, CA

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

Impaired balance and coordination, or ataxia, arises from damage to the cerebellum. In some cases, chronic progressive cerebellar damage occurs slowly over time due to genetic errors in a patient’s DNA. Although we know of many genetic errors that cause ataxia, and continue to find more each year, diagnosing the correct gene in a patient is difficult because the individual diseases can look very similar amongst each other and can also appear very different from person to person.

Although disease in roughly half of all families can be explained by testing the most common five genes, this still leaves hundreds of thousands of individuals worldwide without a diagnosis. The remaining dozens of the known genes are each very rare (contributing to about 1% of all genetic ataxia at best) and there are likely many more genes still waiting to be discovered. Recently, a process called “next-generation sequencing” has emerged which is capable of rapidly and
cheaply sequencing all genes known to be expressed in the human genome (called the “exome”). With the support of the National Ataxia Foundation Young Investigator Award, we are using this technology to assess patients for mutations in known ataxia genes and identify new genes which cause cerebellar ataxia.

Aim 1) To augment the work currently underway, we will incorporate additional methods to improve identification of causative genetic mutations in additional multi-generation dominant ataxia families using identity-by-decent (IBD) mapping, followed by exome sequencing. IBD mapping will improve identification of mutations, and allow detection of pathogenic DNA rearrangements not normally found by exome sequencing alone.

Aim 2) We will expand our search for novel genes using exome sequencing by examining recessive ataxia families. Family selection will be based on early age of disease onset, patients having unaffected parents and affected siblings, and negative screening for common autosomal recessive ataxias.

Aim 3) To determine how newly identified genes contribute to cerebellar ataxia, we will search for additional mutations within our ataxic patient population. We will also examine control samples to verify observed changes are not simply benign but rare. We anticipate discoveries stemming from this work will improve the ability of physicians to diagnose more patients with genetic ataxia, as well as contribute new knowledge to our current understanding of how the dysfunction of certain genes results in cerebellar disease. As a Young Investigator Award, this project will also allow the principal investigator to continue to develop his active research program in the study of genetic cerebellar ataxia and further contribute new information for patients and their families to better understand these devastating illnesses and hopefully, someday soon, reach a cure.

Jiaxin Hu, PhD
University of Texas Southwestern Medical Center at Dallas, TX

RNA-based Therapy for Spinocerebellar Ataxia 3 and Dentatorubral-pallidoluysian Atrophy

There are nine CAG repeat expansion diseases including Huntington’s disease, spinocerebellar ataxia 3 (SCA3) and dentatorubral-pallidoluysian atrophy (DRPLA). They are autosomal dominant neurodegenerative disorders and are caused by the prolonged CAG repeats on their mutant genes. We have developed a new strategy to treat the Huntington’s disease: targeting the expanded CAG repeats by nucleic acids and selectively inhibiting the mutant huntingtin (HTT) production without reducing the wild-type protein. We have developed several classes of selective inhibitors including antisense oligonucleotides, duplex RNAs, and chemically modified single-stranded RNAs (ssRNA). Some of the compounds are currently being tested in HD mouse model and preliminary results are promising. Our approach can also be applied to treat other CAG repeat expansion diseases such as SCA3 and DRPLA.

To find the best candidates for clinical development. My proposal has three aims. In Aim 1, I will develop more potent and selective duplex RNAs and ssRNAs to inhibit the mutant ataxin-3 protein production for SCA3. In
In collaboration with ISIS Pharmaceuticals and Alnylam Pharmaceuticals, we will test chemically modified RNAs with novel designs and ssRNAs. We hope to identify candidate compounds with improved potency and selectivity. In Aim 2, I will screen our best agents including duplex RNAs, ssRNAs and antisense oligonucleotides to reduce the mutant atrophin-1 production for DRPLA. In Aim 3, I will develop induced pluripotent stem cells (iPSCs) as a novel screening assay to evaluate the biological effects of selective reducing the mutant protein. iPSCs can be transformed from patient fibroblast cells and developed into neurons. iPSC technology is very useful because people can screen drug candidates and test their effects in human neuronal cells, which is more relevant for neurodegenerative disorders such as SCA3 and DRPLA. Developing selective inhibitors of mutant ataxin-3 and atrophin-1 would widen the therapeutic potential of the anti-CAG approach and may lead to development of a single drug for treating several different CAG repeat expansion diseases.

Machado-Joseph disease or spinocerebellar ataxia type 3 (MJD/SCA3) is a genetic neurodegenerative disorder originally described in people of Portuguese descent, and the most common of the dominantly inherited ataxias worldwide. MJD is associated with expansion of the number of CAGs within the coding region of the causative gene - MJD1/ATXN3. The abnormal over-repetition of the CAG trinucleotide is translated into an expanded polyglutamine (polyQ) tract within ataxin-3 (Atax3), a protein involved in deubiquitination, resulting in severe clinical features and leading inevitably to death. No treatment is available. We and others have shown that MJD pathogenesis is associated with calpain-mediated proteolysis of mutant ataxin-3 (Haacke et al 2006, Koch et al 2011, Simões et al 2012 Brain). Calpains are activated by calcium whose levels in neurons rise upon glutamate receptors excitation. Since caffeine (a non-selective adenosine receptor antagonist) and selective adenosine A2A receptor (A2AR) blockade modulates glutamatergic overexcitation, we propose to investigate caffeine-mediated alleviation of MJD. Our preliminary data suggest that caffeine and A2AR inactivation decrease MJD associated neuropathology and motor behavior impairments.
which paves the way to consider A2AR as novel therapeutic target to manage MJD, an approach that could be brought to patients in a short time frame.

Satyan Chintawar, PhD
Université Libre de Bruxelles – Erasme Hospital, Belgium

Generation of Peripheral Sensory Neurons from Friedreich’s Ataxia Human iPS Cell Lines

Friedreich’s ataxia is an inherited neurological disorder characterized by progressive damage to the nervous system accompanied by gait abnormalities, visual loss and speech problems. Disease can also lead to heart problems and diabetes. Currently, there is no universal treatment option available to cure the disease or to significantly ameliorate the symptoms. Most of the research efforts to understand the disease process have so far been attempted on animal models recapitulating some features of the disease or patient’s blood or skin cells. All existing models have limitations as animal models do not display all disease characteristics and accessible patient cells, such as blood and skin cells are not affected by the disease even though they carry same genetic mutation of affected brain cells. New stem cell technology allows us to transform skin cells to brain cells, such as neurons, principle cell type vulnerable in FRDA. We have undertaken an effort to generate specific neuronal types, such as peripheral sensory neurons from patients’ skin cells. This approach will provide us disease-affected human cells in a dish and offer the opportunity to understand disease mechanism and screen potential therapeutic molecules for their safety and toxicity assessment.

Diane M. Papazian, PhD
University of California–Los Angeles, Los Angeles, CA

Development of Knock-In Mouse Models for Early- and Late-Onset SCA13

Spinocerebellar ataxia type 13 (SCA13) is a rare genetic disease in humans characterized by atrophy of the cerebellum, which is the part of the brain that controls movements, and loss of coordination. SCA13 is caused by mutations in the KCNC3 gene, which encodes the voltagegated Kv3.3 potassium channel. Voltage-gated channels such as Kv3.3 control the passage of ions across cell membranes. In the nervous system, voltage-gated channels are responsible for producing action potentials, which are very rapidly moving electrical signals that transfer information over long distances. The KCNC3 gene is prominently expressed in neurons of the cerebellum, where Kv3.3 channels regulate the rate at which action potentials are produced. Mutations that cause SCA13 alter the function of Kv3.3 channels and are likely to disrupt the ability of cerebellar neurons to produce action potentials in the normal pattern and at the normal frequencies. How these changes in neuronal function give rise to the symptoms of

Continued on page 10
SCA13 is unknown. Intriguingly, different mutations in KCNC3 give rise to distinct clinical forms of SCA13. In one form, the disease is evident in infancy or early childhood. Affected children are delayed in acquiring motor skills and have persistent coordination problems and intellectual disability. In this form of SCA13, the cerebellum does not develop normally and is shrunken in size. In the other form of SCA13, the disease emerges during adulthood. Affected individuals experience movement difficulties that increase in severity as time passes. In parallel, the cerebellum shrinks due to the process of neurodegeneration. Although SCA13 is a rare disease, it provides a novel opportunity to determine how changes in action potential firing affect motor coordination and neuronal viability during development and aging. Insights gained from studying SCA13 will provide new understanding of other diseases in which action potential firing is altered. To identify the mechanisms by which mutations in KCNC3 cause two clinically distinct forms of SCA13 and to develop new therapies, animal models for the disease are necessary. The long term goal of this project is to develop genetically modified mice that contain a mutation that causes either infant- or adult-onset SCA13 in place of the normal gene. The goal of the present application is to modify mouse genomic DNA to contain one or the other SCA13 mutation and to generate embryonic stem cells that contain the modified DNA. These cells are essential for making genetically modified mice.

Andrew Singleton, PhD
National Institute of Aging, Bethesda, MD

Exome Sequencing to Identify New Ataxia Genes

We are planning to use a new technique to identify the genetic abnormalities that cause ataxia in a small population. The identification of the genetic background of ataxia will help to better understand the mechanisms of the disease and develop new therapies to treat it.

Jeremy Schmahmann, MD
Massachusetts General Hospital, Harvard University, Boston, MA

Prospective Evaluation of the Sensitivity and Specificity of Cognitive Tasks for the Diagnosis of the Cerebellar Cognitive Affective Syndrome

It has long been thought that the role of the cerebellum is confined to the coordination of movement. Patients with ataxia are well acquainted with the incoordination, gait disturbance, and difficulties with fine motor control. Ataxia patients have also long known that intellectual and emotional functioning can be impaired by disorders that affect the cerebellum. Whereas ataxia doctors and researchers have only recently become familiar with these non-motor manifestations of cerebellar damage, patients and their families live with and deal with the consequences of cognitive and emotional difficulties in the setting of ataxia disorders. A major development in the evolution of the understanding of these disorders is the identification of genetic abnormalities that cause ataxia.
of the functions of the cerebellum was our discovery at the Massachusetts General Hospital (Schmahmann and Sherman, 1997, 1998) of a clinical syndrome affecting higher function resulting from lesions confined to the cerebellum. In our patients with lesions confined to the cerebellum there were deficits in language, spatial processing, working memory, and affective regulation. The clinical presentation was consistent across subjects, and we called this constellation the cerebellar cognitive affective syndrome (CCAS). It produces problems with planning, abstract reasoning, working memory, and visuo-spatial processing as well as language difficulties and personality changes. We subsequently showed that disorders of mental function such as anxiety, depression and social skill set can also be affected by diseases of the cerebellum (Schmahmann et al 2009). This determination of the neuropsychiatry of the cerebellum has an impact on our understanding of the role of the cerebellum in mental illness. One difficulty with reaching a diagnosis of CCAS is that it rests on the determination of deficits in the domains of executive function, visual spatial processing, linguistic skill, as well as emotional dysregulation, which are not evaluated by doctors in routine tests of cognition function such as the Mini Mental State Examination. It is therefore likely that the CCAS is missed in patients who have cerebellar lesions but only minimal or no motor manifestations. Second, the CCAS was defined in patients with disease confined to the cerebellum. We presently do not know how much the cerebellum contributes to the cognitive problems that a patient with a cerebellum-plus syndrome is experiencing. This is important because most of the spinocerebellar ataxias, and other conditions such as Friedreich’s Ataxia and Ataxia Telangiectasia, as well as ataxia oculomotor apraxia and other disorders, affect not only cerebellum, but other brain areas as well. In this study, therefore, we will evaluate groups of patients with conditions that affect the cerebellum only (e.g., following stroke), the cerebellum as well as other brains areas (e.g., Machado Joseph disease), and those with non-cerebellar brain illness (e.g., Alzheimer’s and Parkinson’s disease). Our tests of cognitive function evaluate the CCAS as well as other deficits not usually seen following cerebellar lesions. By using this approach in the different groups of patients, we will be able to determine which cognitive problems stem from the cerebellum and which arise from damage to non-cerebellar areas. The results of these studies have the potential to provide a new level of sensitivity and specificity to the cognitive evaluation of patients with cerebellar and non-cerebellar disorders.

Young Investigator for SCA Research Awards

Dong-Hui Chen, MD, PhD
University of Washington, Seattle, WA

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

Spinocerebellar ataxia (SCA) is a group of neurologic disorders caused by degeneration or malfunction of the cerebellum and the spinal cord. Poor coordination of movement is a common symptom of all the SCAs. The SCAs are hereditary and some can be passed from one generation to the next in an autosomal dominant transmission pattern. At least 30 genetically different forms of autosomal dominant SCA
have been described, including SCA14. SCA14 shares many clinical and pathologic features with other autosomal dominant SCAs, but may also included myoclonus (spasmodic jerky contraction of muscles) and a variety of cognitive impairments. We previously discovered that SCA14 is caused by mutations in the protein kinase C gamma (PKC) gene and now we plan to study how these mutations lead to neuronal death and how the disease develops. Because PKCg is primarily present in one cell type (Purkinje cells) only in the cerebellum, study of disease development is not possible in humans. An animal model of SCA14 would be invaluable for such investigations. We have created mouse lines that have either normal or a mutated form of the human PKCg gene. The mice with the mutant human PKCg develop abnormalities in their brains, including aggregations of the mutant protein, but do not have problems walking. We propose to modify these mouse models so they have the same phenotype of incoordination and neuronal loss as seen in people with SCA14. We can learn more about the functions and effects of the mutant proteins and the course of the disease, and potentially discover new therapeutic interventions by studying the behavior and nerve cells of these animals.

Francesca Maltecca, PhD
Università Vita-Salute San Raffaele, Milan, Italy

Unraveling the Mitochondrial Conundrum at the Basis of Spinocerebellar Ataxia Type 28 and its Novel Therapeutic Approaches

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

Thorstien Schmidt, PhD
University of Tuebingen, Germany

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

Spinocerebellar ataxia type 3 (SCA3) or Machado-Joseph disease (MJD) is caused by the expansion of tandem repeat of the three DNA elements CAG within the so called ataxin-3 gene. This means that everybody in the general population has between 12 and 40 repetitions of CAG in one’s own ataxin-3 gene. This means that everybody in the general population has between 12 and 40 repetitions of CAG in one’s own ataxin-3 gene. SCA3 patients, however, have more than 62 of these CAG repeats. Everybody has two copies of the ataxin-3 gene, one inherited by the mother, one inherited by the father. However, only one of these two copies contains the expanded CAG repeat and the second copy contains a CAG repeat in the normal size range. Statistically, more repeats lead to an earlier onset of symptoms while patients with less repeats get first symptoms at much older age. However, this is a statistically correlation and it is not possible to predict the exact age at onset from just the number of CAG repeats. For examples, a SCA3 patient with 71 CAG repeats may get first symptoms as early as with 25 years or not until 60 years or age. In order to improve the prediction when first symptoms may occur, we analyzed whether additional variation of the ataxin-3 gene – beside the CAG repeat – influence the age at onset. We observed that each patient has a specific combination (a so called haplotype) of these different variants both in the normal and the expanded ataxin-3 copy. Interestingly, 2% of the European patients with one specific haplotype had a much later (five years later) onset of symptoms.

Within the first year of this project, we discovered that the variations of ataxin-3 modify important cellular processes causing the disease symptoms including the formation of so called protein aggregates. Interestingly, the non-affected copy of ataxin-3 with the normal CAG repeat seems to modify these processes.

We now apply to extend our successful project to another year. In this second year we plan to include further variations in our study, to find out why and how the second copy is able to influence the affected copy and which additional disease-causing processes are influenced by these variations. Our project will help understanding the processes which lead to SCA3, may lead to a better prediction of the age at onset and may point to novel targets for a possible future therapeutic intervention.

Continued on page 14
Sokol Todi, PhD
Wayne State University School of Medicine, Detroit, Michigan

Mechanisms of Neuroprotection in SCA 3/MJD

Spinocerebellar Ataxia Type 3 (also known as Machado-Joseph Disease; SCA3/MJD) is perhaps the most common dominantly inherited ataxia in the world. SCA3/MJD is a progressive loss of full control of bodily movements. It arises from the expansion of a region of the ataxin-3 protein beyond normal levels from 12-42 to over 60 repeats of the amino acid glutamine. Such expansions affect several areas of the brain and the spinal cord. It is unknown how mutations in ataxin-3 cause SCA3/MJD. Currently there is no cure for SCA3/MJD.

We have identified eight proteins that reduce degeneration from disease-causing ataxin-3. Through the research proposed here, we seek to understand how these proteins regulate cell death caused by ataxin-3. Our short-term goal is to isolate new therapeutic targets for SCA3/MJD. Our long-term goal is to develop successful therapies for this debilitating inherited disease.

Clare Louise Van Eyk, PhD
The University of Adelaide, Australia

A Role for ADAR and TDP-43 RNA Binding Proteins as Key Mediators of Toxicity in the Autosomal Dominant Spinocerebellar Ataxias

The spinocerebellar ataxias (SCAs) are a group of diseases characterized by progressive degeneration, primarily in a region of the brain called the cerebellum; a part of the hind-brain that controls motor coordination, balance and muscle tone. At present, there are 28 known SCAs with an autosomal dominant pattern of inheritance, meaning that they equally affect males and females and that the gene with the disease-causing mutation dominates over the unaffected copy of the gene. Of those for which the causative mutation is known, more than half are caused by a special type of mutation involving and increase in the number of repeats of a sequence in the DNA. This type of mutation is also responsible for a number of other diseases, including Huntington’s Disease and Myotonic Muscular Dystrophy. The repeating sequence is present in a different gene in each disease, however there are a number of common features: the diseases are all degenerative, they generally show symptoms later in life and they all involve the...
formation of aggregates in cells. This has led to the hypothesis that there may be common cellular mechanisms involved in these distinct diseases, however the pathway leading from the initial mutation to disease symptoms is still not fully understood.

In order to address the gap in understanding of the mechanisms involved in the SCAs and other diseases caused by this type if mutation, we have developed disease models in the fruit fly. In this model, introduction of repeat sequences similar to those found in SCA affected individuals results in morphological and behavioral changes in flies. We are then able to genetically alter these flies and observe the effects on their morphology and behavior and thereby gain information about the steps in the disease pathway.

In this research project, we will be investigating the effect of the repeating sequences on the structure of RNA and how this might be involved in disease. RNA is the intermediate molecule which gives a read-out of the DNA code, generally allowing the message it carries to be converted to a working protein. Where there is a repeating sequence in the DNA, this means that the RNA which gets produced also contains a repeating sequence and it is thought that in the case of diseases such as he SCAs, this repeating sequence causes the RNA to fold up in an incorrect way. This folding results in the RNA interacting inappropriately with other cellular factors. We have identified two candidate proteins which have reduced function or altered localisation in neurons from SCA patients and therefore are excellent candidates for a role in SCA pathology.

In this project, we investigate whether these proteins directly interact with RNAs containing repeating sequences in fly models and what effect this has on localization of the RNA and the protein. We will genetically test the ability of altering levels of these proteins to modify morphological and behavioural changes in our fly models and therefore determine whether these proteins may be good candidates for the development of therapeutics. Findings from these fly models will then be verified by looking for similar cellular changes in human tissue samples. We aim to ultimately use the validated fly models as a screening tool for identifying compounds which can reduce or delay pathology to treat these devastating diseases.

Tyisha Hathorn, PhD
University of Florida, Gainesville, FL

SCA5: Molecular Effects and Reversibility of Mutant-III Spectrin

Spinocerebellar ataxia type 5 (SCA5), a disabling genetic disease that causes trouble with walking, speech and hand coordination. We have made a mouse model to study this disease and show that these mice have specific changes that affect neurons in the brain which are also affected in patients with this disease. The first aim of this proposal is to test if these mice will recover from the disease after the SCA5 gene we put into these mice is turned off. These experiments are important because they will help us determine if SCA5 causes permanent changes to the brain or if the disease is potentially reversible. In the second aim, I will characterize a large number of newly identified mutations located in different parts of the SCA5 gene to test if these changes also cause ataxia. These experiments will help us better understand how this gene works and which of these potential mutations cause disease and
which do not. This aim will directly benefit families with confirmed mutations because it will allow for more accurate diagnosis and family planning.

Fang He, PhD
University of Michigan Medical School, Ann Arbor, MI

Determination of the Toxic Species in Fragile X-Associated Tremor Ataxia Syndrome

Expanded DNA repeat sequences are a common cause of cerebellar ataxia. These repeats can elicit cerebellar degeneration as either RNA or as protein, but the relative contributions of each toxic species to the development of disease in patients is unknown. Fragile X-associated Tremor Ataxia Syndrome (FXTAS) is an inherited cause of cerebellar ataxia that results from such a repeat. To date, most studies have focused on how the FXTAS repeat as RNA can elicit neurodegeneration. However, our group has now found that the repeat can also be translated into a potentially toxic protein. This grant will explore the relative contributions of the toxic RNA and protein species to neurodegeneration using fly models of the disease. The findings from these studies will help identify the appropriate therapeutic targets in FXTAS and should provide important insights into the relative contributions of RNA and protein species to all the repeat-associated cerebellar ataxias.

Robert F. Moccia, MD, PhD
Massachusetts General, Harvard University, Cambridge, MA

Investigation of Stress Granule Dynamics and Functional Consequences of Expanded Ataxin-2 in iPS-Derived Neurons From SCA2 Patients

Spinocerebellar ataxia type 2 (SCA2) is a neurodegenerative disease caused by an abnormal increase in the size of a specific part of the protein called ataxin-2. The expanded part of the protein consists of a single repeated amino acid called glutamine. SCA2 is one of a number of neurological diseases that share these so-called polyglutamine expansions. While we have learned much about the disease since the discovery of this mutation, there is still much more we need to know about the normal function of ataxin-2 in neurons and how this polyglutamine expansion disrupts that to cause disease. Through the work of several research groups we are now aware that ataxin-2 very likely interacts with mRNA, the template for making proteins that our cells need to survive.

The types of proteins our cells need to make can be quite different depending on their circumstance, for example when they are under stress or injured. We believe that proteins like ataxin-2 somehow help guide this decision to ensure the correct proteins are made in these situations. A dramatic example of this occurs when cells are stressed, such as when they are deprived of nutrients or energy. In these circumstances, a group of proteins gather up all of the mRNA that is not needed at that moment and form
small structures called stress granules. Ataxin-2 is one of the proteins that participates in this process, but we do not yet know how the disease-causing mutations impact it.

Ataxin-2 also interacts with another protein called PABP which itself is very important in stabilizing certain mRNAs and increasing the amount of protein made from them. Interestingly, it appears that abnormally high levels of ataxin-2, such as has been reported in patients with SCA2, can cause decreases in the amount of PABP. This is a second way in which ataxin-2 might interfere with the normal activities of protein production in neurons, but it has not yet been directly studied.

A major limitation in unraveling these cellular events has been our inability to address them directly in living diseased human neurons. A recent technological advance called induced pluripotent stem cells (iPS) now makes it possible for patients with a disease to provide researchers with a tiny sample of their skin which can then be used to make living neurons in a laboratory. Because these neurons were made from the patient’s own cells, they have all of the same genetic material that led to the disease. Our group routinely uses this method to study neurological disease and we will now apply it to SCA2. Importantly, this enables us to determine which observations about ataxin-2 are most critical to dying human neurons. In the long term it will also provide a tool for screening new drugs that might help these cells to survive.

Spinocerebellar Ataxia Type 3 (also known as Machado-Joseph Disease; SCA3/MJD) is a devastating neurodegenerative disease caused by the expansion of a region of the ataxin-3 protein beyond normal levels. SCA3/MJD is a progressive loss of body movement and affects several areas of the brain as well as the spinal cord. It is not known how ataxin-3 mutations cause SCA3/MJD. Because it is important that we understand the normal functions of disease proteins in order to comprehend the diseases they cause, in this application I propose to study the normal functions of ataxin-3. I will investigate how ataxin-3’s interaction with its protein partners controls its biological function and how ataxin-3’s roles are regulated during the stress.

Ataxia Investigators Meeting

The National Ataxia Foundation will host the 5th International Ataxia Investigators Meeting on March 18-21, 2014, just prior to the Annual Membership Meeting.

Over 100 ataxia researchers from around the world will gather to address the multi-disciplinary nature of ataxia, to define better the pathogenic basis of ataxia and to explore routes to therapy for this largely untreatable disease.

Clinical and academic ataxia investigators are invited to submit abstracts to be considered for presentation at the meeting. Harry Orr, Ph.D. and David Lynch, M.D., Ph.D. are the lead organizers of this scientific meeting.

For more information, please send an e-mail to susan@ataxia.org.
The 2013 Annual Membership Meeting (AMM) was hosted by NAF’s Ataxia Support Groups in the Northeast Region. These support groups did a great job coordinating this event and the National Ataxia Foundation would like to congratulate them on hosting such a successful meeting. More than 320 attendees came for the three-day event. Attendees came from 31 U.S. states and from international countries including Canada, India, Hong Kong, and the United Kingdom.

Thursday, March 14 was the major arrival day for most attendees and the day kicked off with registration and getting familiar with the GM Renaissance Center. Pre-conference activities for attendees included picking up their conference materials in the registration area, viewing the NAF information tables, attending the fundraising for NAF session, and meeting up with friends. Thank you so much to the Mauro Family for donating the bottled water and providing the St. Patrick’s Day cookies for the welcome bags.

Friday morning started out with the general session program. Camille Daglio, NAF’s Board Vice-President and Carolyn Davis, representative of the NE ataxia support groups, gave a welcome announcement which was followed by an overview of ataxia patient care services and research available in Michigan by Dr. Henry Paulson. Dr. Paulson also took on the MC duties Friday morning which involved introducing other ataxia medical professionals. Their presentations gave attendees information about the impact of genetics on ataxia research, how...
understanding the function in neurons is promising for developing treatments of ataxias, how genetic mutations are inherited and cause disease, the biological systems that contribute to balance, and new findings in SCA3 research.

Friday afternoon gave attendees the opportunity to meet others with the same type of ataxia or the same role in the life of a person with ataxia through the very popular Birds of a Feather session. These small group sessions gave attendees the opportunity to share experiences and ask questions of medical professionals and researchers who were circulating among the groups.

On Friday and Saturday attendees were able to observe and try the Nintendo Wii game system, get a NAF temporary tattoo, try coloring as a therapy for handwriting, participate in wheelchair Yoga, and listen to poetry in the Activity Room. Thank you to Heather Evans for facilitating the Activity Room activities again this year.

Friday evening was the “Get to Know Your Neighbor” Welcome Reception. Everyone gathered in the region of their home state to network with other attendees. Many new connections were made at the reception. It was common to hear throughout the reception, “I had no idea someone else lived so close to me.” The delicious food and great company were enjoyed by all. During the reception a presentation was shown of the fundraisers held in 2012 that supported the important work of NAF. These events raised over $285,000! Thank you to all the supporters and organizers of these events!

Nintendo Wii tennis was just part of the fun had in the Activity Room during the AMM.

Northeast region attendees enjoying Friday night’s Welcome Reception at the AMM.

Saturday continued with the general session program with both new and familiar medical professionals and researchers presenting ataxia related information. Laura Rice-Oeschger, LMSW kicked off the sessions by talking about how to nurture well-being by embracing and caring for the one life we have to live. Throughout the day attendees heard about devices to improve balance, therapy strategies for speech and swallowing, physical therapy, financial planning, stem cell research and much more. Thank you Joe DeCrescenzo for MCing Saturday’s General Sessions. Saturday also included the silent auction bidding which raised more than $3,200. Thank you to everyone who participated and donated items for this event. The NAF AMM Business Meeting included the election of the NAF Board of Directors.

The Silent Auction on Saturday raised more than $3,200. Thank you to all who bid!
Annual Meeting Review
Continued from page 19

Saturday evening’s “Motown” Banquet was a fun-filled experience for all in attendance.

During the presentation portion of the evening Joseph DeCrescenzo, Arnie Gruetzmacher, and John Mauro, Jr. each received the, “I am the Strength Behind Ataxia” award for their contributions to the ataxia community. These awardees are featured on page 30. The 50/50 raffle raised $2,100 and the winner generously donated back the winnings. A lucky first-time AMM attendee won a drawing for a beautiful 2013 AMM afghan made by NAF President Char Danielson. Thank you to Jonas Cepkauskas who provided such wonderful dancing music and the Mauro Family for the hip centerpieces!

The Sunday morning general session program included informative presentations on emerging research and medical strategies, NAF research advancements, and gluten ataxia among others. Dr. Sarah Ying gave the closing presentation of the conference with a summary of the various topics and presentations from the weekend. Thank you Joe Cox for MCing Sunday’s General Sessions.

Each days’ general session presentations were followed by a question and answer session. Please watch future issues of Generations for publication of various presentations. You can view the presentation slides on NAF’s website www.ataxia.org. Audio presentations synched with PowerPoint presentations can be purchased online at www.dcprovidersonline.com/naf. An order form appears on page 24.

A Special Thank You

The National Ataxia Foundation would like to extend a special thank you to all the attendees, speakers, facilitators, exhibitors and the numerous volunteers of the NAF 2013 “Driving Together Towards A Cure” NAF Annual Membership Meeting held in Detroit, MI. This conference would not have been possible without the time, contributions, and efforts given by so many. Thank you much for the wealth of information and knowledge that was brought to the conference by all the speakers, facilitators and exhibitors. The information and skills taken away from this conference by the attendees is

NAF Board of Directors: (back row) Dr. Harry Orr, Sam Kirton, Bill Sweeney, Joe DeCrescenzo, Camille Daglio, Char Danielson, David Zilles, Dr. Laura Ranum, Harold Crawford, and Dr. Larry Schur; (front row) Earl McLaughlin and Denise Drake. Not pictured: Arnie Gruetzmacher, Jeff Storms, Julie Schuur, and Dr. Susan Perlman.
invaluable and worth more than any words can say. It was a pleasure working with the Support Group Leaders of the Northeast Region. We would like to thank Becky Dunlop, RN, for volunteering as our on-site nurse at the conference. We would also like to thank Randy Dombrowski for taking such memorable pictures of this year’s event.

We would also like to thank this year’s sponsors Athena Diagnostics, the FA Project, and MetLife Center for Special Needs Planning. Thank you to the Detroit Convention and Visitors Bureau for the welcome bags and local information provided for this year’s meeting. Thank you to the Detroit Marriott at the Renaissance Center Hotel for their service and hospitality throughout this event.

First Annual Florida Ataxia Awareness Cruise Is a Big Success

By Emily Medina

In November of 2012, I went on the First Annual Florida Ataxia Awareness Cruise, which was organized by the West Central Florida Support Group and Royal Caribbean. The cruise started in Tampa, FL, sailed to Cozumel, Mexico and ended in Tampa, FL.

I had a great time, hanging out with fellow ataxians, spreading the word on what ataxia is and creating ataxia awareness, trying new things, and having fun in the sun!

In January 2014 there will be the Second Annual Ataxia Awareness Cruise. It will be a five-day cruise that departs from Ft. Lauderdale, FL travels to both Faimouth, Jamaica, and Labadee, Haiti, and then returns to Ft. Lauderdale, FL. Even though it is so far in the future, I am already very excited and looking forward to going and having a great time. I hope you will join me on the cruise!

See the Events Calendar at www.ataxia.org for more information.
NAF Merch — ATAXIA RESOURCES —

Healing Wounded Doctor-Patient Relationships
by Linda Hanner with contributions by John J. Witek, M.D. and doctors and patients around the nation
This book is packed with information that anyone who ever goes to a doctor for any reason deserves to know and that every professional who wants to maximize his or her healing power must understand. $10

Living with Ataxia: An Information and Resource Guide
by Martha Nance, M.D.
This illustrated book provides a compassionate, easy to understand explanation of ataxia with ideas on how to live well with ataxia. It is an excellent tool for building awareness for those who do not know what ataxia is or how it affects a person who has ataxia. This second edition was published in 2003. $14

Managing Speech and Swallowing Problems: A Guidebook for People with Ataxia
by G.N. Rangamani, Ph.D. with contributions from Douglas E. Fox, M.S.
This 60-page booklet is an excellent resource for those who struggle with speech and/or swallowing problems. It is an easy to understand booklet with straight-forward and realistic suggestions for speech and swallowing management. This second edition was updated in 2006. $7.50

— FICTION & PERSONAL STORIES —

Ten Years to Live
by Henry J. Schut
The story of the Schut’s family struggle with hereditary ataxia and the impact it had on this extended family. It is dedicated to the author’s brother, Dr. John W. Schut, who was committed to the cause of finding a cure for ataxia, which claimed his life. $8.75

There’s Nothing Wrong with Asking for a Little Help … and Other Myths
by Dave Lewis
The story about one man’s experiences in living with Friedreich’s ataxia. Dave spent the last three years of his life writing his memoir to provide information and inspiration to countless others. Proceeds from the book purchased through NAF will be used to support promising Friedreich’s ataxia research. $15.95

— COOKBOOKS —

Recipes and Recollections by Kathryn Hoefer Smith
Dedicated to the memory of her daughters who had Friedreich’s ataxia, Kathryn Hoefer Smith has taken the handwritten cookbook her mother-in-law made for her sons and their families and duplicated it in 2003. It is full of delicious recipes and recollections. Perfect for FRDA research fundraisers. $10

Cooking for a Cause
by Julie Karjalahti for FRDA research
This 177-page cookbook has kid’s recipes, fun craft recipes, along with the usual desserts, breads, beverages and other recipes you would expect from a good cookbook. $12

— VIDEO/CD —

Ballads of a Family Man CD
10 songs in memory of Billa Ballard. SALE — $5

“Together There is Understanding” VHS or DVD
Discussion of ataxia. 50 minutes. VHS $20; DVD $25

Shop for NAF Merchandise online at http://tinyurl.com/nafstore
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<td>Limited years and sizes available. You pick the size and we’ll pick the AMM.</td>
<td><strong>SALE!</strong> $1 each while supplies last!</td>
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<td>White. New design. Sizes small to XXX-large.</td>
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**To place your order, call (763) 553-0020, fax (763) 553-0167, mail a copy of this form to National Ataxia Foundation, 2600 Fernbrook Lane, Suite 119, Minneapolis, MN 55447 or visit http://tinyurl.com/nafstore**

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National Ataxia Foundation

56th Annual Membership Meeting - Recordings
March 15-17, 2013 - Detroit Marriott Hotel - Detroit, MI

*SPECIAL* A limited number of FREE recorded sessions from this year’s Conference will be available after the Annual Meeting online at: www.dcprovidersonline.com/naf/

The free sessions are available for “view only” while purchased sessions are downloadable.

SESSIONS OFFERED FOR FREE:

- **Friday:** Welcome by Camille Daglio, The Michigan Experience, and Overview of Mechanism of Disease in Ataxia
- **Saturday:** The Four Components of an Effective Physical Therapy Program for Ataxia, and Cerebellum and Cognition: New Information, New Implications
- **Sunday:** NAF Research Advancements - Progress To Therapies, NAF Update, and What We Have Learned

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Digital Conference Providers, Inc. 100 S. Cass Ave., Suite 200, Westmont IL, 60559
Phone (630) 963-8311 Fax (630) 963-8312 Customersupport@dcproviders.com
The NAF Board of Directors along with the Western Regional Support Groups would like to invite you to attend the

National Ataxia Foundation
57th Annual Membership Meeting
March 21-23, 2014

Bally’s Las Vegas is pleased to provide the facilities for the 2014 AMM.

— RESERVATION INFORMATION WILL BE ANNOUNCED SOON —

For more information on Las Vegas visit www.lvcva.com. For the latest information on conference registration, program schedule, and area information, keep checking the National Ataxia Foundation website, www.ataxia.org.

2014 NAF AMM “Support Our Conference” Campaign
https://naf.myetap.org/fundraiser/14AMM/
NAF Annual Membership Drive Begins in May

Why become a member of the National Ataxia Foundation? Membership is a partnership between you and NAF. As a member you are a stakeholder in the organization, investing in NAF’s capacity to provide important programs and services to the ataxia community. As a member you are strengthening the organization’s ability to provide important ataxia publications, to maintain the NAF’s web site, and to create ataxia awareness.

Your membership support brings world-class researchers together through programs such as the Ataxia Investigators Meeting (AIM) and provides a multi-day ataxia conference through the Annual Membership Meeting. Membership support also helps in the printing and distribution of Generations, the development of local support groups, and the expansion of ataxia social networking sites.

In return for your membership contribution, or gift contribution, you can be assured that you are an active participant in finding the answers to end ataxia.

Please support the 2013 Annual Membership Drive and please ask others to become NAF members. Thank you!

Regional Concept for NAF Annual Membership Meetings

The National Ataxia Foundation offers its members an annual membership meeting to provide the latest information on ataxia research and topics of concern and interest within the ataxia community. These meetings also provide a setting for sharing, learning, and networking. The conferences are hosted each year by an NAF chapter or support group(s) that helps in the planning, provides volunteers, acquires donated items, and raises funds in support of the meeting.

These conferences have seen continued growth over the years in terms of expanded programs, exceptional speakers, and number of attendees. To help address the continued expansion and costs of these meetings, a concept was developed called “The Regional Concept” to help bring in additional support groups and chapters in co-hosting these meetings. Additionally, these groups will have a larger window to assist in raising funds to help underwrite part of the costs of these conferences to help ensure continued quality programs and affordability to our attendees. A further enhancement of this program is to provide more participation opportunities to potential attendees by diversifying the location of these conferences.

The 2013 NAF Annual Membership Meeting (AMM) was an example of how well the Regional Concept is moving forward in meeting these goals, including increasing the number of participants who have never attended an AMM. More than 40% of this year’s meeting attendees were first-timers. In addition, the region in which the conference was held had a significantly higher proportion of attendees. This diversity of locations allows the opportunity for those who may not have been able to attend a previous...
AMM because of location.

As announced in the 2013 Annual Membership Meeting Program, the following is a listing of the states in each region and the tentative year that the AMM will be held in that region:


**North Central Region 2015** — Colorado, Illinois, Iowa, Kansas, Minnesota, Nebraska, North Dakota, Missouri, Montana, South Dakota, Wisconsin, and Wyoming.

**Southeast Region 2016** — Alabama, Florida, Georgia, North Carolina, South Carolina, and Tennessee.

**South Central Region 2017** — Arkansas, Louisiana, Mississippi, New Mexico, Oklahoma, and Texas.

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**Swim Team Supporting Ataxia Research Has Strong Motivation**

A high school swimming team in a Syracuse, NY suburb is doing its part to help raise funds for Ataxia research, but it is more than a public service project. One team member has a special reason for taking part.

The 32-member Liverpool High School Boys Varsity Swim Team has been collecting cell phones for recycling for two years. Proceeds from recycling 70 phones collected this season are again earmarked for the National Ataxia Foundation.

For 16-year-old junior Marc Alessi, the fundraiser has added meaning. Marc’s father died two years ago from ataxia.

At a recent 2013 season swim meet, Marc made a moving address to the parents and students watching the event. He shared his feelings about what it meant to collect the cell phones, and how his father’s death affected him.

The idea for the cell phone collections was generated locally by Mary Jane Damiano, head of the Central New York Ataxia Support Group. Her efforts attracted the attention of swim team coach Mike Ferrell.

Damiano, who has Friedreich’s Ataxia, said she is grateful for the efforts of individuals and groups, such as the Liverpool Boys Varsity Swim Team. She acknowledged that the money raised means a lot to her and the thousands of people affected with some form of ataxia. She said she hopes that one day the research will yield medications that will help ataxia sufferers, and lessen the impact of the disease.
Walk n’ Roll for Ataxia
The ultimate finish line ... a cure for ataxia

What is Walk n’ Roll for Ataxia?
The Walk n’ Roll for Ataxia program is the National Ataxia Foundation’s largest national grassroots fundraising event. Walk n’ Roll for Ataxia currently takes place in cities across the United States.

Since its inception in 2007, Walk n’ Roll for Ataxia has raised more than $700,000 thanks to the support and tireless commitment of walkers, rollers, runners, volunteers, donors, and sponsors.

Why Walk or Roll?
So that you can be a part of helping to find the answers to cure ataxia. Thousands of families, friends, co-workers, neighbors, and communities come together each year to support the Foundation’s fight to improve the lives of people affected by ataxia and their families. Make a difference by joining them!

How Can I Participate?
For more information about joining or starting a Walk n’ Roll for Ataxia event in your community, please contact Lori Shogren, NAF Special Projects Coordinator, at (763) 553-0020 or lori@ataxia.org.

Currently scheduled 2013 Walk n’ Roll events and locations:
• June 17 – Gilbert, SC
• September 8 – Denver, CO
• September 14 – Detroit, MI
• September 14 – St. Louis Park, MN
• September 21 – Auburn, MA
• September 21 – Duluth, GA
• September 28 – Lafayette, CA
• September 28 – Long Beach, CA
• September 28 – San Diego, CA

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

[Photos of Walk n’ Roll events]
For several years NAF has been recognizing International Ataxia Awareness Day with Walk n’ Roll events around the country. Last year there were 10 actual Walk n’ Rolls and a virtual Walk n’ Roll which raised more than $200,000.

Walk n’ Rolls come in different sizes. Some are very large with speakers, T-shirts, silent auction items, gift baskets, food and festivities as well as the actual walk. Some are done on a smaller scale.

As the number of Walk n’ Rolls continues to grow, an Ad Hoc committee was created to enhance the existing events and also encourage other Chapters, Support Groups and Ambassadors to join in the fun and help raise Ataxia awareness and funds.

*Friends Asking Friends* (FAF) was selected as the software program for NAF’s Walk n’ Rolls. *Friends Asking Friends* will provide fundraising function and capability and utilize social media to reach out and generate awareness as well as donations. This will allow individuals or support groups to create an online site with information about their own event and use the *Friends Asking Friends* software to reach out to their family and friends about ataxia and encourage them to participate in the Virtual Walk n’ Roll.

The Atlanta Support Group held their first Walk n’ Roll in 2010 using the Virtual Walk n’ Roll site to learn what interest there would be in a Walk n’ Roll. This was simple and did not require anything but setting up the group in the virtual Walk n’ Roll site and then sending letters out to family and friends. The first year they raised $4,000. Because of the success of this experience, the group decided to conduct an actual event the next year at a local park that had a 1.25-mile walking trail and a pavilion. By keeping the event simple, starting at 9 a.m. with registration, refreshments, and the actual walk and concluding at 11:30 a.m. with a celebration of the event, the group raised $7,000 in 2011 and $10,000 in 2012.

The new software will allow each Support group the opportunity to have a team page. On this website you can tell everyone about your support group and include pictures or video as well as your special message. (See the homepage at left.) This home page will show the progress toward reaching your goal as well as a listing of the top contributors and teams. There is also information about your actual event and a place for people to donate or register for your event. This software system will provide a reporting function that gives you up-to-the-minute information on registrants and donors which allows you to print reports for check-in and manage the event on the day of the Walk n’ Roll.

This year we are asking you to consider participating in the virtual Walk n’ Roll or conducting your own virtual Walk n’ Roll. More information will be available in May when the final software is installed at NAF. A demo will be available at [www.ataxia.org](http://www.ataxia.org) to view the new capabilities and see how easy it is to set up a Virtual Walk n’ Roll using *Friends Asking Friends*. Stay tuned for more information.
“I am the Strength Behind Ataxia” Award Recipients Announced

Each year the National Ataxia Foundation recognizes individuals at the annual membership meeting for their outstanding achievements. In 2011, the National Ataxia Foundation established a new award called the “I am the Strength Behind Ataxia” Award to recognize those who have made a significant impact within the ataxia community. The first award was given to DeNiece Roach, the long standing President of the National Ataxia Foundation.

This past year, NAF invited and received more than 20 nominations for the “I am the Strength Behind Ataxia” Award from throughout the U.S. and other countries. We congratulate all of the nominees for their stellar work within the ataxia community.

For 2013 three nominees were selected. Congratulations to this year’s award recipients.

**Joseph DeCrescenzo**

Joe is the Delaware Ataxia Support Group Leader and Treasurer of the Chesapeake Chapter of NAF. Joe was diagnosed with SCA 2 almost a decade ago. Since that time he has fought his disease with strength, dignity, courage, leadership, and determination.

From the very beginning of this journey Joe felt he was given ataxia for a purpose: to raise ataxia awareness, to help people through educating and supporting them, and to raise funds for research to help find a cure. In 2012, Joe chaired a raffle fundraiser and a Walk, Roll n’ Run fundraiser. Combined, these events raised more than $25,000 to support the 2013 NAF Annual Membership Meeting. Joe gives his all in raising ataxia awareness and in raising funds to support NAF’s efforts… and does so from his heart.

Joe is hailed by his family as an amazing dad, grandpa, husband, brother, uncle, and friend who always helps others. Joe was just elected to the NAF Board of Directors and we warmly welcome him. Congratulations, Joe!

**Arnie Gruetzmacher**

Arnie Gruetzmacher has been on the National Ataxia Foundation’s Board of Directors since 1971. In 1972-1977, Arnie served as the President of the Board and has been on the NAF Executive Committee since its formation in the mid-1970’s.

In addition, Arnie has served as the volunteer National Chair of the annual membership meetings since 1980. The AMM has become a centerpiece of NAF due to the hard work of Arnie. His vision and leadership over the years in formatting the AMMs has created a program which provides a variety of opportunities for attendees each year to network with one another as well as researchers, clinicians, medical specialists, and others.

Arnie has spent countless hours each and every year to help the Foundation. His service to NAF has been exceptional and his commitment has never wavered. He has authored a Financial Planning Fact Sheet specifically for persons with ataxia and their families, and has advised...
countless families in financial planning.

Ataxia impacted his life when he was very young. Arnie saw firsthand the affects of ataxia through his family: his aunts, uncles, and cousins were affected by ataxia. He has brought this experience with him in serving on the Board and he has had a major impact in charting the course in the Foundation’s efforts to provide meaningful and compassionate programs.

John Mauro Jr.

John is the Central Massachusetts Ataxia Support Group Leader. John was diagnosed in 2009 with Sporadic Unknown Ataxia. John’s awareness and fundraising initiatives for NAF began in 2009 with the Ride for John. This event has become an annual event now known as the Auburn Walk n’ Roll for Ataxia. In 2012, John’s ataxia awareness activities also included partnering with Massachusetts Senator Michael Moore and Representative Paul Frost to pass a resolution recognizing September 25th as “International Ataxia Awareness Day” in the State of Massachusetts.

This past year John made several media appearances to help raise ataxia awareness including a radio interview on the Jordan Levy Show and two TV interviews on the Hank Stoltz show and local Channel 3 News. John has a passion to educate people about ataxia and is always looking for opportunities to raise awareness about ataxia. He is the “idea” man and has countless great ideas on how to get the word out.

John also wants to be a role model to others on staying active. John has gone parasailing, taken adaptive skiing lessons, and is always looking for a new adventure. John inspires others through his positive attitude, never gives up, and never lets his limitations get the best of him. His family describes him as the “Energizer Bunny!” John is surrounded by the love and support of his wife Dana and children Nick and Zach. Thank you, John!

Getting Married?

If you are getting married, you can support the National Ataxia Foundation by registering with the I Do Foundation. From honeymoons to invitations to wedding gifts to charitable wedding favors, the I Do Foundation allows couples and their guests to make wedding-related purchases that generate donations for charity. The I Do Foundation’s Charity Registry service also makes it easy for guests to make donations in lieu of gifts. All of these services are available free of cost at www.IDoFoundation.org. Check it out today, and be sure to select NAF as your beneficiary.

John Mauro Jr. at the Auburn Walk n’ Roll for Ataxia.
Awakening Others About the Challenges of Having a Disability

By Jon Rodis

One thing that helps me awaken family, friends and my colleagues to what it is like to live day to day in this body is something I came up with back in 2001 when I was filing for disability. I have shared this story in my presentations at past Conferences and by phone or e-mail conversations, but it bears repeating it in written form.

Deciding to file for disability was one of the most difficult decisions I have ever had to make. It was hard enough to have to give up my career but I knew that my health was getting much worse the longer I continued to work. When I decided it was time, I began the process. One of the first steps to apply was to fill out the social security application forms. I could have applied over the phone but I chose to go to the office in person and sit down with one of the SSA representatives.

Here is what happened:

As I walked towards the representative’s desk, he looked at me and asked, “You’re disabled?”

WOW! I couldn’t believe what I just heard. My first reaction, other than my jaw hitting the floor, was to hit the guy as hard as I could and knock him over his desk. However, I knew that wouldn’t help my approval chances so I took a deep breath and said the following to him:

“Let me tell you just part of what makes me disabled. Think about the last time you had a bad cold. Perhaps your whole body hurt, you were probably pretty weak and possibly had some dizziness and, in general, you felt like crap. Correct?”

I gave the guy a few seconds to think about it and then I went on to say, “That is how I feel two to three days of the week.”

I gave him a few more seconds and I then went on to say, “Now think about the last time you had a bad flu.”

I gave a few more seconds and added, “You not only hurt from head to toe; you most likely were extremely weak, had bouts of dizziness and getting out of bed was nearly impossible. You definitely were not able to do the smallest chores, never mind go to work.”

I gave a few seconds more and said, “That is how I feel four to five days a week!”

At this, his face was completely red and he asked me in a very solemn tone to please sit down. He hadn’t understood what an “invisible” disability was and I gave him a crash course. The meeting went very well from then on and I gave him more of the specific medical reasons as to why I could no longer stay employed.

I hope my story can assist you, and everyone,
with helping people relate to what we go through by sharing experiences that they themselves can relate to. Everyone has had a cold and flu.

Another suggestion: the next time one of your relatives or friends or whoever doesn’t understand your disability is sick with a cold or flu, call them and ask them why they are not at their job or in school. In a nice way, tell them that they are feeling like you feel on most days.

Also, for those of you who have disability placards for your vehicles; if someone comes up to you and tells you that the space is reserved for a disabled person, tell him or her that you are disabled and explain why you use an accessible parking space. Their face will probably drop. People need to realize that having a disability does not necessarily require a wheelchair or crutches. This will be a great opportunity to raise awareness for the disorder or disease that you have.

I hope that my experience and suggestions will help you in trying to get people to understand your situation. It has helped me, not only, in dealing with my friends and family but also in educating medical professionals on what it is like to have an invisible disability.

As always, feel free to contact me for more information, support and answers to your questions about applying for SSDI.

---

**Rare Disease Day 2013**

* Submitted by Carolyn Davis

A rare disease affects fewer than 200,000 individuals in the United States. However, as many as 25 million people in the United States and up to eight percent of the global population may be affected by one of about 7,000 genetic and acquired rare diseases. Around 4,500 of these diseases have genetic testing available, but the large majority have no treatments and none have effective cures.

For Rare Disease Day 2013 the National Institutes of Health hosted a two-day symposium celebrating research efforts on rare diseases across NIH, the federal government, and the advocacy community.

In his keynote address, Dr. Christopher Austin, a neurologist who is Director of NIH’s National Center for Advancing Translational Sciences, gave an overview of collaborative rare diseases research activities at NIH. He acknowledged the fantastic efforts of individual researchers but warned we won’t win without a team effort.

Within the NIH research budget, 11.38 percent is spent for rare diseases research. NIH has 9,400 research projects studying 2,137 rare diseases. Research projects studying orphan drugs numbers 1,650.

NIH is fostering collaborative efforts especially in the goal of re-purposing drugs. They are bringing pharmaceutical companies and academics together to test 58 compounds for different diseases. In coordination with the International Rare Diseases Research Consortium, the goal is 200 new drug therapies by 2020.

Increased interest in rare diseases and orphan products is fueled by media interest, an increase in research investigators, public-private projects, interest in re-purposing drugs, patient registries to identify research subjects, and better models for research design with small patient populations.

Collaboration was an underlying theme of the symposium as speakers from various institutes, agencies, and organizations presented updates and information on their research and programs.

Jon Rodis is a volunteer for the National Ataxia Foundation who has had to navigate the process to receive Social Security Disability himself. He now helps people all over the United States who are disabled with getting approved for social security disability benefits. He is willing to answer any questions you may have about the process. His e-mail address is WSALMGCDJM@aol.com or you may call him at (617) 846-4975. He does not charge a fee for his service.
NAF Represented at Brain Health Fair

Submitted by Jane Jaffe

The Brain Health Fair was held in San Diego, CA, at the Hilton Bayfront Hotel, on Saturday, March 16. The National Ataxia Foundation was one of the exhibitors at the Brain Health Fair.

Volunteers for the day were, Pat Ward and H. Ward, Ron Rogers, Jane and Larry Jaffe.

The many visitors who stopped by the NAF exhibit were very interested in ataxia.

Of course, the first question is, “What is ataxia?” It was a great opening for all of the volunteers to explain ataxia to the general public.

It was a beautiful day in sunny California and the fair was well attended.

(Left to right) Larry Jaffe, Ron Rogers, Jane Jaffe, Pat Ward and H. Ward at the Brain Health Fair in San Diego.

The volunteers all agreed it was a very rewarding day, and look forward to next year.
Living with Ataxia – A Challenge to Me and My Family

By Roy Camero, Lifetime Member of the NAF

My story begins in 1994. That year began the onset of my present condition – ataxia. That summer, while my wife and I were bowling with friends, I began falling with no apparent reasons and also started knocking over my drinking glass on the table while I was eating at home. My wife told me that something was wrong, so she made an appointment with our family doctor.

After several tests, my doctor referred me to a neurologist who ordered scans and MRIs. The neurologist found abnormality in my cerebellum but his diagnosis was inconclusive on what was causing the degeneration. So he made me an appointment with a neurologist at Virginia Mason Clinic. After going through rigorous tests, the diagnosis was that I have a form of ataxia – a word that I have never heard before. I’m not even sure if it’s listed in the English Dictionary.

In order to determine the exact form of ataxia, I was referred to see Dr. Larry J. Schut at the Mayo Clinic in Minnesota. That was in 1995. After a team of doctors had examined me, Dr. Schut made the diagnosis that I have a non-hereditary form of ataxia which is called Sporadic Ataxia.

This was a great relief to my family, especially to my kids who were concerned that they would get my disease. Still it was bad news though, since there is no known cure or treatment. Dr. Schut did prescribe for me a bunch of vitamins and supplements to help with my therapy for the various symptoms of ataxia that I am living with now. I will be 68 years old next February. Thankfully my ataxia is slow in progression. I retired on disability after working for 25 years with the federal government in 1996.

Before ending my story, I would like to share some humorous experiences of having ataxia and how I solved my problem at meals. To solve this problem, my wife or kids place a straw in my drinks so I don’t have to hold the glass or soda can. And I don’t use a fork because I might poke my face. Also my caregiver tells me to rest my elbows on the table while eating.

Now for two funny stories:

I was still working and able to drive to work. I usually parked my car at the lot across my office building so I would walk with my briefcase to my office. My officemates who were looking out the window said, “Look, it’s early morning and Roy is already drunk.” When I mentioned this to my wife, she said to forget my pride and start using a cane. And so I did and since then my officemates started to ask, “What’s wrong?” instead.

Another incident was on Thanksgiving Day. My wife asked me to go to the liquor store to pick up some wine. After a long wait, it was my turn to pay. The clerk asked me if these were all that I was buying. I said yes, but with noticeably slurred speech. The clerk told me that he could not sell me the liquor because I was already drunk. I tried to explain that I have an ataxia.

The clerk said, “Yes, I will call a taxi.”

Without a word, I left the store and pretended that I had not heard what people said behind me. When I got home I told my wife all about it and she laughed and thought it was funny ... to me, I wasn’t so sure.
Over the Mountains and Through the Desert

By Mary Fuchs, Arizona Ataxia Support Group Co-Coordinator

On October 22, 2012, four members of the Arizona Ataxia Support Group and a member of the Denver Area Ataxia Support Group went to the Ataxia clinic at UCLA to see Dr. Susan Perlman. Mary Fuchs, AASG co-coordinator, changed the words to the well-known poem below to reflect this trip.

Over the mountains and through the desert to UCLA we go. Dr. Perlman knows the way for us to go.

Over the mountains and through the desert to UCLA we go. Get stuck for blood, cheeks swabbed, and over to Maria we go.

Over the mountains and through the desert to UCLA we go. Maria makes us do pegs, eye chart, and big questionnaire.

Over the mountains and through the desert now to Dr. Perlman’s office we go. Do the tap tap tap, finger to nose, ting a ling of the tuning fork on our toes.

Over the mountains and through the desert to UCLA we go. She looks at our MRIs for white matter and cerebellum size.

Over the mountains and through the desert to UCLA we go. We won’t stop till they find an ATAXIA cure.

Over the mountains and through the desert back home we go. Thank you Dr. Perlman and Staff.

(Left to right) Denise Laundy (AZ), Corinne Laundy (AZ), Charlotte DePew (CO), Rita Garcia (AZ), and Mary Fuchs (AZ) after arriving at UCLA.

PATIENTS with EARLY SYMPTOMS of FRIEDREICH’S ATAXIA

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

at the Center for Magnetic Resonance Research at University of Minnesota

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

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

If you are interested or have questions, please call Diane Hutter @ (612) 625-2350 or e-mail hutte019@umn.edu.
From the Desk of the Executive Director

It was so wonderful to see so many of you at the 2013 NAF 56th Annual Membership Meeting (AMM) in Detroit, Michigan on March 15-17, 2013. This year’s conference attendees included 40% who were first-timers and was hosted by the Northeast Region. We are pleased that you were able to attend and are hopeful that you found the conference informative and had the opportunity to network and meet new friends. A special thank you to all the members of the Northeast Region who volunteered, participated in the planning of the meeting, and raised funds for the conference.

Plans have already begun for the 2014 NAF AMM, which will be held in March 2014 in Las Vegas, Nevada at Bally’s. The 2014 AMM will be in conjunction with the NAF’s 5th International Ataxia Investigators Meeting (AIM). With the success of the 2012 AIM, where researchers and families met through a poster session, we will again offer meeting attendees the opportunity to meet with world leading ataxia investigators. More information about the 2014 AMM will soon be available on NAF’s web site, E-Blasts, Facebook, and future issues of Generations. We look forward to seeing you in Las Vegas.

The National Ataxia Foundation is a membership supported nonprofit organization, which offers members a discount in the annual membership meeting registration fees. Membership also provides you with the quarterly news publication, Generations. Membership support allows NAF to provide important programs for the ataxia community as well as representation as various medical conferences and Ability Expos. Membership support is far reaching in the development of publications and in providing current and accurate information through print, in-office and electronic media.

Become an NAF member today and ask others to join as well. This year’s NAF Annual Membership Drive will begin in May 2013. We ask that you please renew your membership and invite a friend, co-worker, or relative to also become an NAF Member. If each of us would ask one other person to join … think what we could accomplish for the ataxia community. Please look for the 2013 NAF Annual Membership Drive letter in the mail in May 2013. You may also renew your membership on the back page of this issue of Generations. Membership expiration dates are shown on the address label. Thank you for your continued support through membership.

You will see in this expanded issue of Generations a listing and the summaries of the research studies funded in late December 2012 for fiscal year 2013. Through your support and our partners, the Foundation was able to fund 21 promising ataxia research studies totaling $1,000,000. I cannot tell you how thankful we are for your support of these important research efforts and the profound impact your generosity made in allowing NAF to support these world-class ataxia research studies. Your generosity is giving researchers the tools to find more answers to help end ataxia. Thank you!
Our next meeting will be on April 27 from 10:00 a.m. until 2:00 p.m. in Homewood, AL.

**Greater Atlanta Ataxia Support Group**

*By Dave Zilles*

The Greater Atlanta Ataxia Support Group continued to be active through the winter. We are truly blessed to have such a wonderful group of individuals that genuinely care for each other and have developed lasting friendships.

Our speaker at the November 10 meeting was Susan Wilson from Canine Assistants. Susan brought with her an assist dog in training. She and the dog provided some demonstrations as how a dog may assist an individual. She also discussed the process of applying and obtaining an assist dog. The presentation was very informative and well received.

Our annual Christmas party was held on December 8. We had a potluck dinner with lots of delicious dishes brought by our members. After stuffing our bellies we had a white elephant gift exchange. This gift exchange is always fun to see who steals what gifts and what someone...

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**Alabama Ataxia Support Group**

*By Becky Donnelly*

The year 2012 ended with a big bang for the Alabama Ataxia Support Group when we met at the Creekside Tavern in Hoover, AL, with 30 people in attendance. Two couples in our group planned the Christmas social event and tables were decorated with lighted wine bottles which were gifts, along with homemade cookies, for each family. Two new members attended and joined the group.

The new year began with a meeting and luncheon on January 26 at Covenant Presbyterian Church. Our speaker was Ms. Glenda Duman of Hoover, AL, who presented the book by Scott Coleman, “Best When Broken,” a story of courage and determination after a horrible ski accident and how he became an overcomer of life’s misfortune. After a business meeting and cell group reports on members, the group broke into break-out sessions, with the caregivers group being led by Alan English, those with ataxia by Becky Donnelly. This is always a favorite time for our group members.
ends up with. Our Christmas party is one of our favorite events. It’s so popular that we’re looking for a larger location in 2013.

The Abilities Expo was in Atlanta February 8-10. The Abilities Expo is a great trade show for the disability community with lots of information and resources. Several of our support members volunteered to work the NAF table distributing ataxia information, answering questions about ataxia, and creating ataxia awareness. We also met a few individuals with ataxia who were not aware of our support group and are new members now.

On February 23 the speaker for our meeting was Ellen Sichel. Ellen has trained extensively in the area of transforming stress and pain into productive, life-enhancing solutions. She is the author of “Splash Into Calm” and consults at the Cancer Support Community, Weinstein Adult Day Program, and businesses. She provided instruction on breathing techniques and other methods for dealing with stress. Her presentation was interactive and ignited some lively discussion among the group.

Upcoming spring events are a support group meeting on May 18 and our spring picnic at Lake Lanier on June.

**Denver Area Support Group**

*By Charlotte DePew*

About 35 people attended the January 19 meeting with three new members present. Prior to the speaker, everyone introduced themselves and related something of their choosing about their ataxia experiences. This is always very interesting, especially when humor comes out.

Our 3rd Annual RWnR will be held Sunday, September 8 in Denver City Park, the same location as the past two years.

We had a dynamic speaker on life care-planning when a disabled family member of any age is in the picture. Our speaker was Mary Beth Leitzmann, care coordinator for an elder and disability law firm. Mary Beth briefly outlined many payment resources for medical and long-term care before describing various care levels that range from in-home family care provider to skilled nursing home. For some, especially when the disabled person is young, special needs trusts can protect assets and assure adequate funds for future care.

The take-home messages: 1) We are all going to use benefits (disability, Medicaid, Medicare, private insurance, or other) to pay for some level of care at some time. 2) Start financial planning early/now for a continuum of care. 3) Protecting assets is necessary but complex with numerous “tricks-of-the-trade” not well known or advertised. One support group couple related their unexpected rehab-facility experience thinking they had an adequate financial plan. They soon found the financial process more complex and demanding. Mary Beth guided them through the maze and reduced their stress.

Additionally, Mary Beth brought handouts on Medicare, Medicaid, community resources, information on special needs trusts, and much more. Also included was a magnetized medical history kit to place on the refrigerator. This is the first place EMS looks for medical history and is also one less stressor on the family in the event of medical emergencies.

**India’s Seek A Miracle Ataxia Group (SAMAG)**

*By Swasti Wagh, SAMAG Indore Chapter President*

An International conference on Recent Advances in Molecular Mechanisms of Neurological Disorders was organized by the Society of Neurochemistry, India and All India Institute of Medical Sciences (AIIMS), New Delhi during February 21-23.

The significant feature of this conference was that patients were invited to present their views.

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As an ataxia patient I gave a presentation on “Psychological, Behavioral, Social and Ethical Aspects Related to Ataxia Patients.” In this talk I added my views on ataxia research and how research in different disciplines can be beneficial for ataxians. The presentation was much appreciated in the conference. The abstract of my talk is printed in the proceedings of conference.

On behalf of SAMAG, I thank Dr. Rajeshwari, the organizing secretary of the conference, for giving me this opportunity to put my views in the conference.

By Dr. Yasmin Sultana,
SAMAG Delhi Chapter President

An International conference on Recent Advances in Molecular Mechanisms of Neurological Disorders was organized by Dr. Moganty R. Rajeshwari, Professor, Department of Biochemistry, All India Institute of Medical Sciences (AIIMS) on February 21-23, at JLN Auditorium, AIIMS. The highlights of the conference were the recent developments in molecular mechanisms of many neurological disorders including Alzheimer, Huntington disease, Spinocerebellar ataxias, Friedreich Ataxia, Parkinson, Epilepsy, and many others.

Ms. Swasti Wagh, SAMAG Indore Chapter President, and a patient with Friedreich’s ataxia, presented the social, behavioural, psychological aspects of living with ataxia. Dr. Rao, Advisor, Department of Biotechnology, and Chief Guest of Valedictory function of the conference, praised the organizer of the conference, Dr. Rajeswari, for bringing a patient with a neurological disorder to the conference thereby bridging the gap between the researchers and the patients. He also emphasized that more community-focused work must be done by Government Agencies in this regard.

At the personal level, I am thankful to Dr. Rajeswari for giving me an opportunity to stay informed about the recent developments in the area of neurosciences. As a patient of Friedreich’s ataxia also I have gained a lot of information on topics of my interest.

Use the following link to view pictures of the event: https://picasaweb.google.com/samataxiagroup/SAMAGIndoreDelhiChaptersAtSNCINewDelhiConferenceFromFebruary21stTo23rd2013?authuser=0&feat=directlink.

Kansas City Support Group
By Lois Goodman

This is the beginning of our 23rd year meeting at the same library – although we have outgrown the small room. We are now in the large room and have access to a small kitchen. We have coffee, drinks and snacks at each meeting.

We had 20 attend our February meeting. That was a good turnout for February. Twenty-six people attended the December Christmas party. Our dinner was catered in by one of the member’s daughter and granddaughter. We had lots to eat and a good time was had by all. It is so good to get together with fellow ataxia people. We shared stories and it was good to laugh together. We are among friends who share the same problems. Our group is wide spread in distance and age. Some come from over 100 miles and from different directions. Our age group is from the 40’s to late 80’s.

None of us will be attending the convention (Annual Membership Meeting). Our prayers are with all to have a good time and safe trip.

We’ll meet again in April and every other month there after. We hope to have special speakers at some of our meetings.

Northeast Florida Ataxia Support Group
By Mac Kelso

The Northeast Florida Ataxia Support Group met at Baptist South Hospital on February 16 at 1:45 p.m. with 17 attendees. John Richwine opened the meeting by introducing Cory. 
Cory opened his first meeting by telling how he had contracted Legionnaires Disease that shut down most of his major organs except for his heart and caused him to go into a coma. When he awoke from the coma, his speech was slurred and he had other symptoms of ataxia. A speech therapist heard Cory speaking nearby and that is when Cory first met our guest speaker, Ceil Brooks. She worked with Cory to help him with his speech.

Ceil Brooks is a Certified Speech-Language Pathologist. She has been a practicing Speech Pathologist for over 30 years and currently she is employed by Brooks Rehabilitation Center. Ceil gave a 45-minute presentation on dysphagia to our group. She started with a self-test for swallowing disorders to determine if there were swallowing issues. Ceil then discussed the signs and symptoms, for example a wet or gurgly sounding voice when eating. Then she briefly talked about how a diagnosis is made through a swallowing evaluation and medical history. Ceil elaborated on some of the special tests used for evaluating swallowing issues, such as Modified Barium Swallow Study and Fiberoptic Endoscopic Evaluation of Swallowing (FEES). She also cited several treatments available ranging from tongue resistance exercise, proper positioning while eating, to adding thickeners to liquids and foods, etc.

For more information, Ceil recommended these web sites: www.nlm.nih.gov/medlineplus and www.webmd.com.

She closed by taking questions from the group. The group gave Ceil a big round of applause for her great presentation. Next the group turned its focus to upcoming events.

The following events are in the planning stages: Dr. Subramony to talk to the group either at the Movement Disorder Center or on Skype; a dentist to teach/demonstrate a method for ataxians to brush their teeth; Walk-Roll-Wobble for International Ataxia Awareness Day on September 25 that will include a silent auction. Special recognition goes to Sonia Hannan for the healthy snacks she served up. They were a big hit! She plans on serving healthy eats at each meeting.

Cory also announced that the Tampa Ataxia Group has a picnic planned on March at Lake Seminole. All are invited. Additionally, the Tampa Group has scheduled another Ataxia Cruise for 2014 on Royal Caribbean. Finally, he announced that NAF has allocated new funds for SCA3 research.

The next proposed meeting will be May 11 at 1:45 p.m. in the Azalea, Begonia and Camellia Rooms at Baptist South, unless we decide to have a meeting sooner offsite. All members were invited to come to Applebee’s after the meeting for supper and casual conversation.
We had 20 attend our meeting with one new guest who has Friedreich’s ataxia. Welcome Rachel.

Dr. Richard Ivry, a professor of psychology and neuroscience at UC Berkeley spoke to us about his lab. He is recruiting ataxic patients for motor and cognitive research. His post-doc students are gaining insights about how the cerebellum works. He has grant money that is used to develop motor and cognitive tasks. Individuals who participate are compensated for their time. The sessions are about two hours each. This is research only, not a clinical assessment of your skills. Anyone with SCA who is interested may contact Rich at ivry@berkeley.edu or (510) 642-7146.

Our second speaker was Janet Schmidt, a PT who specializes in treating neuro patients, fall prevention and evaluation. Janet works for Kaiser Permanente which offers free fall prevention classes for KP members. Janet brought a packet of exercises to help us improve our muscle tone. It is so important to keep working our muscles in our legs and our core. We are not exercising to build our muscles as much as we working to maintain movement and flexibility. I have extra packets from Janet. I will have them at our April meeting.

Our next meeting is April 13. Dr. Sharon Sha from UCSF Aging and Memory Center and her Research Coordinator, Gabriela Sastri will be our guest speakers. They will be telling us about all that is going on at the new neuroscience building on the Mission Bay campus.

New Hampshire Ataxia Support Group
By Jill Porter

In December we met at The Puritan Backroom, a popular restaurant in Manchester, NH. Everyone enjoyed getting together for a meal and again, we had someone new join us.

Our first meeting in 2013 was our largest turnout to date. John Mauro, Leader of the Central Massachusetts Support Group and his wife Dana, joined us to get acquainted with the NH group. It is encouraging to also see family members and friends start to attend as well.

Looking forward this year we plan to push forward to have the State of New Hampshire recognize International Ataxia Awareness Day.

We are open to new ideas for meetings, welcome newcomers and enjoy sharing and helping each other. All of our support group information is posted on the NAF website. Please contact me if you are interested in more information about our group.

Northern California Ataxia Support Group
By Joanne Loveland

We began the meeting with homemade chili and cornbread made by Shirley Hanks. Yum!
92708, from 1:30 to 4:00 p.m.

We had five support group meetings in 2012. We had a few new members that joined us and some new people that contacted us but have not made it to the meetings yet.

On December 8, 2012, the Los Angeles Ataxia Support Group sponsored and hosted a few members of OCASG and held a special presentation with Dr. Tom Clouse, MD. His main focus was to work with individuals with ataxia who can still walk. He has ataxia himself and his presentation was very interesting to observe, as he has taught himself some physical exercises to counteract ataxic symptoms; and he walks about showing no symptoms of ataxia. It was quite remarkable.

For more information on Dr. Clouse, please visit www.walkingwithataxia.com and also www.youtube.com/watch?v=Br72k-LLXsc.

On December 29, we held our Holiday Party to celebrate Christmas and New Year’s.

For more information about the Orange County Ataxia Support Group, please visit www.ataxia.org/chapters/OrangeCounty/default.aspx.

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Tri-State Ataxia Support Group

By Kathleen Gingerelli

November 15, 2012, was our final meeting of the year, so we decided to have some fun. The night started off with our normal introductions and we welcomed our new arrival, Daniel, who is doing some work with Dr. Hunt. The important part was next... ordering pizza!

While we waited for the food to arrive, the group munched on some snacks and talked about our meeting dates for 2013 and I shared some ataxia merchandise – awareness bracelets and magnets – ordered from the NAF website.

I also told everyone about a fundraiser I was hosting at my house sponsored by Lia Sophia Jewelry. A portion of my proceeds from this night are being donated to the National Ataxia Foundation under the general research heading.

Right now, the NAF is sponsoring the Ataxia Research Matching Gift Challenge. All donations received by December 15, 2012, marked for general research will be doubled. My party was on November 17 and was a success! All who came were educated about ataxia and had fun buying some cool jewelry. It was a great night and I was able to make a wonderful donation to the NAF that will be doubled.

After the pizza and garlic knots arrived and everyone was settled we started our main event... watching the movie “Rock of Ages.” The movie received a “thumbs-up” from the group. We all said good night after the movie and headed out.

Remember to spread the awareness about ataxia to all you can! Check out the website at www.ataxia.org, register, “like” their Facebook page and become a member in order to receive the Generations newsletter.

Welcome to year number six! Wow, I can’t believe it’s 2013 and here we are going into our sixth year of meetings. We have had so many new faces over the years, along with our loyal returnees, each with a story about living with all types of ataxia. Even though everyone is not able to attend every meeting we always have an interesting group to discuss topics. I hope we continue to reach new members for each meeting date in 2013 and continue to come up with new and interesting ways to “Spread the Awareness.”

At our first meeting of 2013 we celebrated the New Year with our annual potluck dinner. We started off the night at 6:30 p.m. with quick hello’s and welcome’s to everyone including our newest attendees, Antonio, who does not have a definitive ataxia diagnosis yet, and his charming mother, Karin. Anyone who did not have a list was given a list of all our meeting dates for 2013. Again, I talked about how positive it is to become a member of the NAF. Remember, it’s
easy: visit www.ataxia.org and for a $35 fee you can stay linked and receive all the updated information pertaining to ataxia through e-mail, related websites and the quarterly newsletter, Generations (the official publication of the National Ataxia Foundation).

We then moved onto the eating portion of our night. Yum, yum, yum! As always, we had excellent food brought by all our members including the cookies for dessert sent by proxy from our very own Dr. Ann Hunt, who was missed during the evening. There was the normal talking and visiting while everyone was eating and a lot of laughter could be heard throughout the night. (Along with everyone trying to figure out the secret ingredient in David’s chicken!) Thanks to everyone for an awesome night!

Please join us for our next meeting on March 14 ... same bat time (6:30-8:30 p.m.) and same bat place (2nd floor conference room). (I like Batman.)

West Central Florida Ataxia Support Group
By Linda Farrow

Cindy Steever-Ziegler welcomed everyone to our first meeting of 2013 on January 12 at Marsoni Hall on the University of Southern Florida campus in Tampa, FL. After we all ate, she introduced our speaker, Dr. Michael Sosa, from Maximized Living.

Dr. Sosa spoke about how Maximized Living takes in all areas of our lives. There are five essentials of Maximized Living that address the cause of our health problems so that we can live a better life. The five essentials are: 1) maximized minds; 2) maximized nerve supply; 3) maximized quality nutrition; 4) maximized oxygen and lean muscle; and 5) minimized toxins.

Dr. Sosa went on to describe each essential.

His daughter was aiding him in his presentation. We were then given the opportunity to be put on a contact list and she circulated around the room getting people’s email addresses. He, also, gave us the chance to get a complete x-ray of our spine.

Our next order of business was Cindy and Jessica announcing the next “Cruising to Create Ataxia Awareness.” It will be on January 27, 2014. It will be five nights on the Liberty of the Seas, Royal Caribbean sailing from Ft. Lauderdale. We will be visiting Jamaica and Labadee (RC’s private island).

Members of the Twin Cities Ataxia Support Group at their holiday party on Saturday, December 15, 2012.

CFC Number

The mission of the Combined Federal Campaign (CFC) is to promote and support philanthropy by providing federal employees with an effective workplace giving program.

The National Ataxia Foundation’s CFC number is 10752. This program provides a convenient way to donate to the Foundation, and provides great benefit to those with ataxia.

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

by Dr. Abigail Collins

I grew up in a house of dancers. My brother was extraordinarily talented – he could pick up any dance move from MTV, was the star of his high-school musical “Grease,” and went on to become a professional ballet dancer. My younger sister did the jazz-ballet-tap circuit as a child until she found her true love in salsa dancing. She even judges local dance competitions, because she really is that good. I, on the other hand, have always been clumsy – I walked into walls, dropped my plate and spilled my milk. My nickname growing up was “Grace” for my obvious lack thereof in a house of ridiculously coordinated siblings. When I tried to dance, it wasn’t very pretty. So when I decided to sub-specialize my neurology practice in movement disorders, my mother thought the idea was brilliant because, as she put it, “you’ll be able to identify.”

I knew that there was a dance after the banquet at the National Ataxia Foundation annual membership meeting, and although this was my third meeting, I had never joined in previously. Perhaps it was PTSD sustained from harrowing high-school dances, fatigue from being at the meeting all day long, or simply insecurity. In truth, I like to dance, but have always been self-conscious about my inherent lack of ability and my all-around clumsiness. But Charlotte DePew, the coordinator of our Denver NAF support group chapter, informed me that she wanted to dance. “Coordination,” she said, “is relative,” and in a conference room full of people with ataxia, I looked like Balanchine.

Out on the dance floor, we held hands in a circle. Ataxians and people who love them alternating, people standing, people in chairs and scooters. We twisted, we swayed, we shimmied and shook. Charlotte danced without holding on. Mary drove in circles and Donavon popped a wheelie. Kids in manual chairs figured out how to slow dance. I decided on a very liberal interpretation of “doctor’s orders” and started informing people that their presence was required on the dance floor, even if they weren’t “my” patients. Even if all they could do was drive their electric chair back and forth or put their hands in the air. Because when I grabbed that hand, it was frankly hard to turn me down, or escape for that matter. We danced for hours to all kinds of music, not wanting it to end. We boogied around the room and tried to do the electric slide. We kept demanding just one more until we eked out seven or eight “last songs.” I have never had so much fun or felt so at home dancing as I did at the NAF dance. Our smiles and joy lit up the room. And although from the outside looking in, it might not have been very pretty in the traditional sense, from the inside-out, from that dance floor, it truly was a thing of beauty. So get your dancing shoes or wheels on, because I can’t wait to see you back on the dance floor in Vegas, baby!
The National Ataxia Foundation has a large network of volunteers who serve as support group leaders, chapter presidents, and ambassadors for our organization. These volunteers help identify important local resources and professional care for people with ataxia and their families.

If you or a family member or friend has been newly diagnosed with ataxia, please contact the NAF leader nearest you. If there is not a group in your area, we encourage you to visit our online social networks. You may also consider starting a support group in your area or becoming an NAF ambassador. If you are interested in these volunteer positions please contact Lori Shogren at lori@ataxia.org or (763) 553-0020.

The use of these names and contact information for any purpose other than requesting information regarding NAF or joining a chapter or support group is strictly prohibited. Thank you.

### Social Networks

**NAF BULLETIN BOARD**  
Moderator – Attila and Bear  
www.ataxia.org/forum/toast.asp

**NAF CHAT ROOM**  
Moderator – Della (ddpokernut@yahoo.com)  
www.ataxia.org/connect/chat-rooms.aspx

**NAF FACEBOOK GROUP**  
www.facebook.com/group.php?gid=93226257641

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

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

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Continued on page 50
NAF Directory
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Calendar of Events

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

SUPPORT GROUP MEETINGS

— Saturday, April 27, 2013 —
Alabama Ataxia Support Group Meeting
Time: 10 a.m. – 2 p.m.
Location: Covenant Presbyterian Church, Homewood, AL
Details: For more information contact Becky Donnelly at (205) 987-2883 or donnelly6132b@aol.com.

Central PA Ataxia Support Group Meeting
Time: Noon – 2 p.m.
Location: Muhlenberg Community Library, 3612 Kutztown Rd., Laureldale, PA
Details: For more information, contact Chris Rakshys at (610) 395-6905 or rakshys@ptd.net.

Detroit Area Ataxia Support Group Meeting
Time: 1 – 4 p.m.
Location: The Barbara Ann Karmanos Cancer Institute at Wayne State University in the Warts Classroom, 4100 John R St. Detroit, MI 48201
Details: For more information contact Tanya Tunstull at (313) 397-7858 or tinyt48221@yahoo.com.

New Hampshire Ataxia Support Group Meeting
Time: 10 a.m. – noon
Location: The Stop & Shop Conference Room, 7 Kilton Rd., Bedford, NH 03110
Details: For more information contact Jill Porter at (603) 626-0129 or jilleporter@comcast.net.

— Saturday, May 4, 2013 —
Tarheel Ataxia Support Group Meeting
Time: Noon – 3 p.m.
Location: White Deer Park – Nature Center, 2400 Aversbooro Rd., Garner, NC
Details: For more information or to RSVP contact Jerry Hauser at deaconwfu@msn.com.

West Central FL Ataxia Support Group Meeting
Time: 12:30 – 3 p.m.
Location: The Morsani Center, 13330 USF Laurel Dr, #1013, Tampa, FL 33612
Details: For more information contact Cindy Steever-Ziegler at (239) 878-3092 or csteever@msn.com.

— Wednesday, May 8, 2013 —
Willamette Valley Ataxia Support Group Meeting
Time: 11:30 a.m. – 1 p.m.
Location: Albany General Hospital, 1046 6th Ave SW, Albany, OR
Details: For more information contact Ivy Stilwell at (541) 812-4162 or istilwell@samhealth.org.

— Thursday, May 9, 2013 —
Tri-State Ataxia Support Group Meeting
Time: 6:30 – 8:30 p.m.
Location: Beth Israel Medical Center, Phillips Ambulatory Care Center, 1 Union Square East, New York, NY, 2nd Floor Conference Room (room #3)
Details: For more information, please contact Denise Mitchell at markmeghan2@gmail.com or Kathy Gingerelli at kgingerelli@msn.com.

— Saturday, May 11, 2013 —
Central MN Ataxia Support Group Meeting
Time: 10 a.m. – noon
Location: Liberty Savings Bank (1st Floor Community Room), 111 7th Ave. S, Saint Cloud, MN. Entrance in rear of building for mobility issues.
Details: For more information please contact Marsha Binnebose at (320) 248-9851 or marsha.binnebose@yahoo.com.

North Texas Ataxia Support Group Meeting
Time: 10 a.m. – noon
Location: Las Colinas Cancer Center, 7415 Las Colinas Blvd., Irving, TX. The parking is free and the building is handicap accessible.
Details: For additional information contact David Henry Jr. at cheve11e@sbcglobal.net.

Northeast Florida Ataxia Support Group Meeting
Time: 2 – 4 p.m.
Location: Baptist South Hospital. Azalea, Begonia and Camellia conference rooms.
Details: For more information contact Steve and Carole Brown at (352) 591-5095 or bike4brown@aol.com.

— Saturday, May 18, 2013 —
Greater Atlanta Ataxia Support Group Meeting
Time: 1 p.m.
Location: Emory Center for Rehabilitation Medicine, 1441 Clifton Rd. NE, Room 101, Atlanta

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Details: For more information contact the Greater Atlanta Ataxia Support Group at atlantaataxia@gmail.com.

Twin Cities Ataxia Support Group Meeting
Time: 10 a.m.
Location: Langton Place in Roseville at 1910 W. Cty. Rd. D., Roseville, MN
Details: For more information contact Lenore Healey Schultz at (612) 724-3784 or cshultz.lenore@yahoo.com.

— Saturday, June 8, 2013 —
Central MN Ataxia Support Group Meeting
Time: 10 a.m. – noon
Location: Liberty Savings Bank (1st Floor Community Room), 111 7th Ave. S, Saint Cloud, MN. Entrance in rear of building for mobility issues.
Details: For more information please contact Marsha Binnebose at (320) 248-9851 or marsha.binnebose@yahoo.com.

Kansas City Ataxia Support Group Meeting
Time: 2 p.m.
Location: The Northeast Library, 600 Wilson Rd, Kansas City, MO
Details: For more information contact Lois Goodman at 816-257-2428 or Jim Clark at 816-468-7260 or clarkstone9348@sbcglobal.net.

North Texas Ataxia Support Group Meeting
Time: 10 a.m. – noon
Location: Las Colinas Cancer Center, 7415 Las Colinas Blvd., Irving, TX. The parking is free and the building is handicap accessible.
Details: For additional information contact David Henry Jr. at cheve11e@sbcglobal.net.

— Wednesday, June 12, 2013 —
Willamette Valley Ataxia Support Group Meeting
Time: 11:30 a.m. – 1 p.m.
Location: Albany General Hospital, 1046 6th Ave. SW, Albany, OR
Details: For more information contact Ivy Stilwell at (541) 812-4162 or isterwell@samhealth.org.

— Saturday, June 15, 2013 —
Orange County Ataxia Support Group Meeting
Time: 2 – 4 p.m.
Location: The Orange Coast Memorial Medical Center, Breast Center Building, Room 1A, 9900 Talbert Ave., Fountain Valley, CA
Details: For more information contact Daniel Navar at (323) 788-7751 or danieln27@gmail.com.

Twin Cities Ataxia Support Group Meeting
Time: 10 a.m.
Location: Langton Place in Roseville at 1910 W. Cty. Rd. D., Roseville, MN
Details: For more information contact Lenore Healey Schultz at (612) 724-3784 or cshultz.lenore@yahoo.com.

— Saturday, June 22, 2013 —
Central New York Support Group Meeting
Time: 1 – 3 p.m.
Location: North Syracuse Community Center, 700 South Bay Rd., North Syracuse, NY
Details: For more information contact Judy Tarrants at (315) 683-9486 or jtarrants@aol.com.

JHU Ataxia Support Group Meeting
Time: Noon – 2 p.m.
Location: Johns Hopkins at Green Spring Station Pavilion II, 1st floor conference room behind the café, 10753 Falls Rd., Lutherville, MD
Details: For more information contact Bailey Vernon, Health Educator at (410) 616-2811 or bvernon1@jhmi.edu. Please RSVP if attending.

— Saturday, June 29, 2013 —
Detroit Area Ataxia Support Group Meeting
Time: 1 – 4 p.m.
Location: The Barbara Ann Karmanos Cancer Institute at Wayne State University in the Warts Classroom, 4100 John R St., Detroit, MI
Details: For more information contact Tanya Tunstull at (313) 397-7858 or tinyt48221@yahoo.com.

New Hampshire Ataxia Support Group Meeting
Time: 10 a.m. – noon
Location: The Stop & Shop Conference Room, 7 Kilton Rd., Bedford, NH.
Details: For more information contact Jill Porter at (603) 626-0129 or jilleporter@comcast.net.

Thank You NAF Chapters, Support Group Leaders, and Ambassadors!
Please submit your meetings and event listings to lori@ataxia.org.
INFORMATIONAL AND AWARENESS EVENTS
— April–October, 2013 —

One Mountain At A Time
Details: This year, from April through October, I, Alana Moehlman, will be attempting what is called a “thru-hike” of the Pacific Crest Trail (PCT) to raise awareness and funds for the National Ataxia Foundation. The PCT is a long-distance hiking and equestrian trail closely aligned with the highest portion of the Sierra Nevada and Cascade mountain ranges to the east of the U.S. Pacific coast. The trail is approximately 2,663 miles long and passes through 25 national forests and seven national parks. Please join me on my journey from the deserts of southern California north to the Cascades of Washington state and into Canada. What a difference we could make if everyone contributed one penny per PCT mile, amounting to $26.63 per individual contribution! I will be keeping a journal along the way which can be found at www.trailjournals.com/alanamoehlman. Please pass this information on to friends and family to help get the word out and help raise funds for NAF! https://naf.myetap.org/fundraiser/13mountain/

— Friday, May 3-5, 2013 —

Abilities Expo
Location: New Jersey Convention and Expo Center, Edison, NJ
Details: http://www.abilitiesexpo.com

— Saturday, May 11, 2013 —

An Ataxia Dance Celebration!
Time: 7 – 9 p.m.
Location: The Church, 1160 Lincoln St., Denver, CO 80203; (303) 832-3528

— Sunday, June 9, 2013 —

Dancing for a Cause – 37th Annual Dayton Dance Conservatory Late Spring Recital
Time: 1 p.m.
Location: The Victoria Theatre, Dayton, OH
Details: The National Ataxia Foundation was chosen by our ballet dance instructor, Miss Margarita Martinez. The concept and choreography of the pieces by Martinez, danced by her beginner and beginner/advanced ballet classes, will be related specifically to the NAF cause. The classes will also be collecting donations and raising awareness about ataxia for the remainder of the season. For more information about attending or supporting this event, contact the Dayton Dance Conservatory at (937) 236-6011 or contact dayondance@gmail.com. www.dayondanceconservatory.com

— Friday, June 28-30, 2013 —

Abilities Expo
Location: The Renaissance Schaumburg Convention Center, Chicago, IL
Details: www.abilitiesexpo.com

— Saturday, June 29, 2013 —

Dewayne’s Walk, Run n’ Roll for Ataxia
Time: 8 a.m.
Location: First Baptist Church, 441 Lewie St., Gilbert, SC 29054
Details: Dewayne Hite was healthy and robust during childhood and young adulthood. In high school he was the strongest kid on the weight team. In his late 20s he became clumsy, unable to keep balance on his feet and unable to perform his job. At age 30 he was diagnosed with the rare genetic disease, ataxia. Funds from Dewayne’s 5K will go to the National Ataxia Foundation for research to find new treatment and a cure for SCA2. For more information please call Anna Hite at (803) 532-2447 or send an e-mail to DocA35@ATT.net. https://naf.myetap.org/fundraiser/13dewaynewrr/

Study Participants Needed

Patients with SCA 1, SCA2, SCA3, SCA6 and MSA-C are needed for an MRI study to evaluate the chemistry of the brain in ataxias at the Center for Magnetic Resonance Research at University of Minnesota.

You will lie in the scanner for about 1.5 hours while listening to music of your choice. Expenses will be covered and you will be reimbursed for your time.

If you are interested or have questions, please call Diane Hutter at (612) 625-2350 or e-mail hutte019@umn.edu.
Memorials and In Your Honor

The National Ataxia Foundation is grateful to those who have made contributions in memory or in honor of their friends and families whose names are listed below. This list reflects contributions made in November 2012 through February 2013. We are sorry that we cannot separate the memorial contributions from those made in honor of someone, as sometimes the person making the contribution does not let us know if the contribution is a memorial or in honor of their friend or family member.

Jason Aiello  Patricia Clementz  Rita Garcia  Richard Knapp
Sunan Ajharn  The Coffey Family  Kathy Gardner  Fred Konkel
M/M A. Alibria  Julie Cole  Ryan Gibbons  Jamie Koslieracki
Michelle Alioto  Lou Coletti  Kathleen Gingerelli  M/M J. Kremzien
Jack Anderson  Roger Cooley  Christine Goar  M/M J. Laird
Nancy Anderson  Joan Costello  Anna Godsoe  Soula Lane
K. Arnauld  Pat Crandall  Jacob Goldman  Jen Leader
Sharon Baggett  Patricia Crandall  Michele Goldman  Michael Leader
M/M Bagwell  Bertie Crane  Mary Golinksy  Chui Lee
Sister Mary Baker  Becky Crutchfield-Long  Penny Golminas  Johna Leidholt
James Baldwin Family  Grant Curtis  Mark Graham  Viola Lembke
Tracey Balis  Bud Davies  Matt Gras  Ellen Lembke-Mourton
Daniel Balogh  Kennon Davis  Larsen Gregory  Carole Linden
Jay Bambery  Paige Davis  Richard Gregory  Joyce Lokken
Jeremy Barbeau  Anthony DeAngelis  Lawrence Gronenthal  Sophie Lott
Jeffery Barberi  J.T. DeMint  Donna Gruetzmacher  Cindy Lozano
Mary Barros  Peter DeMint  Stephanie Hales  Michael Lundquist
Frank Basso  Tim DeMint  Evelyn Hankins  Greg Lunzer
Subhash Batra  Alex Detschermitsch  Jim Hankins  M/M R. Macedonid
Bart Beck  Bruce Devan  Jimmy Hankins  Gordon Macklin
Betty Beck  John DiMonte  Sue Hargett  Marilyn Macklin
Clair Beck  The DiMonte Family  David Henry Jr.  Cathy Mak
Cheryl Belsly  Paul Dolan  Cristina Hernandez  Rebecca Mandernach
Erling Bengtsson  Fred Donnelly  Arlene Hersh  Michael Massanov
Theodore Benson  Rick Donnelly  Jason Hinkle  The Massanov Family
Giovanni Bertussi Jr.  Alice Draft  Ruth Hinsdale  Brent Masserant
E. Birdsong  Carolyn Draft  Gene Hoffman  Brett Masserant
Fred Blasberg  Chris Draft  Louis Howe Jr.  The Masserant Family
Bruce Bollinger  CarolynDraftFamily  Krista Humes  Candice Matykowski
Muriel Breland  Larry Ehrhardt  Howard Hunnius  John Mauro
Angela Brown  David Erkens  Violette Jacobs  Margaret McCrory
Carole Brown  John Erkens  Jane Jaffe  Maury McDonald
Kim Brown  Heather Evans  Larry Jaffe  M/M J. McDonough
Paul Caparelli  Joseph Falcon  Lisa Jaffe  Charley McLaughlin
James Carr  Katherine Falcon  Betty Jones  Earl McLaughlin
Richard Carr  Trinity Falk  Jeff Kahn  Linda Meier
Robert Carr  Alex Faulkner  Marianne Jones  Jack Moore
Karen Carrick  Sara Ferrarone  Kar Kee Ng  Raymond Morris
Terrance Carrol  Charlie Fisher  Denis Kelly  Patricia Muscarelli
Maureen Carter  Angela Fleischman  Lisa Kelso  Robert Muscarelli
Kristen Cayias  Ann Foster  Cindy Kern  Martha Myers-Makohon
M. Charlton  Lisa Fountain  M/M W. Kern  Alan Nadeau
C. Cheung  Joe Frei  Erin Kiernan  Michael Nagle
William Chwec  Albert Frei Sr.  Major Young Kim  Ray Nauman
JoAnn Ciecierski  Mark Frykman  Virginiia Kincaid  Daniel Navar
MaryJean Clark  Richard Gallmeyer  Joshua Kirschbaum  Justin Nelson
Remembering NAF in Your Will

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

Over the years these individuals have given anywhere from a few thousand dollars to nearly one million dollars. Their forethought and benevolence has enabled NAF to support promising ataxia research and provide meaningful programs and services to ataxia families. It is because of these quiet heroes that many research studies and programs have been funded.

Please consider remembering NAF in your will. Thank you.
Is your address correct? Are you receiving more than one issue of Generations? If there are any changes that need to be made, please call NAF at (763) 553-0020 or e-mail naf@ataxia.org. Thank you!

**GIFT – HONOR – MEMORIAL**

A contribution given in memory of a friend or relative is a thoughtful and lasting tribute, as are gifts to honor your friends or family. A Gift Membership is a wonderful gift to a friend or relative for special occasions like birthdays, graduations, anniversaries, and holidays. NAF will acknowledge your gift without reference to the amount.

Simply fill out this form and mail with your check or credit card information to the National Ataxia Foundation.

Honor/Memorial envelopes are available free of charge by writing or calling NAF.

My contribution is:

- [ ] In Memory  
- [ ] In Honor  
- [ ] Gift Membership

Name ________________________________
Occasion _____________________________

Send Acknowledgment Card to:
Name ________________________________
Address ______________________________
City/State/Zip __________________________

**MEMBERSHIP**

Yes, I want to help fight ataxia! Enclosed is my membership donation. *(Gifts in US Dollars)*

- [ ] Lifetime membership $500
- [ ] Annual memberships:
  - [ ] Patron membership $100-$499
  - [ ] Professional membership $55
  - [ ] Individual $35
  - [ ] Household $55
- [ ] Addresses outside the U.S. please add $15

Name ________________________________
Address ______________________________
City/State/Zip __________________________
Phone ________________________________
E-Mail ________________________________

- [ ] Yes, sign me up for NAF e-mails

**PAYMENT INFORMATION**

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

- [ ] Check. Please make payable to the National Ataxia Foundation.

Total Amount Enclosed $ ________________

Credit Card:  
- [ ] Visa  
- [ ] MasterCard  
- [ ] Discover

Name on Card __________________________
Card # ________________________________
Exp. Date ________________ CVV # ______

From:
Name ________________________________
Address ______________________________
City/State/Zip __________________________
Phone Number _________________________