Generations

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National Ataxia Foundation Commits Funding for 19 Research Studies

In 2011 a total of 90 research proposals were submitted to the National Ataxia Foundation, up from 39 proposals submitted in 2010. A total of 48 leading ataxia scientists from around the world completed the review process under the leadership of Harry Orr, PhD, NAF's research director, and Laura Ranum, PhD, a member of NAF's Medical Research Advisory Board. The scores were then reviewed by the scientific committee who made recommendations to the NAF Board of Directors for final approval.

In December 2011, NAF made a funding commitment of more than $825,000 to fund 19 research studies. New in 2011, because of the generosity of an anonymous donor, the Foundation expanded its research program to include an emphasis on research in spinocerebellar ataxia by adding two new research programs – the Young Investigator Award for SCA Research and the Pioneer SCA Translational Research Award.

In addition, the National Ataxia Foundation continued to provide direct funding of ataxia research studies that focus on a better understanding of disease mechanism and progress towards finding treatments and a cure for all forms of ataxia in three research programs – the Research Grant, Young Investigator Award, and Post-Doc Research Fellowship Award.

In 2011 the Foundation continued funding the tools needed to move basic science and translational research into the clinical research arena which included funding a Tissue Donation Program, Patient Registry and Data Base.

NAF continues to be a world leader in ataxia research funding. Your continued contributions and fundraising efforts make that happen. Thank you.

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The deadline for the Spring issue of Generations is May 11, 2012.

Share Your Story in *Generations*

Generations is published quarterly by the National Ataxia Foundation to inform others of the latest research, ataxia chapters and support groups, events and other topics related to all the forms of ataxia. Personal stories from those affected by ataxia are an important part of the publication. Stories submitted should be no longer than 1,200 words. If possible, tell how NAF has made an impact in your life or situation. Submit stories to *liz@ataxia.org* to be considered for publication.

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Pioneer SCA Translational Grant Awards

Albert LaSpada, MD, PhD
University of California, San Diego

Development of Ataxin-7 Knock-down Therapies to Treat SCA7

Spinocerebellar ataxia type 7 (SCA7) is a dominantly inherited neurological disorder. SCA7 patients develop ataxia due to degeneration of the cerebellum and the brainstem, and also suffer from visual difficulties due to a form of retinal degeneration, resulting in blindness in many patients, especially patients who present before the age of 30. SCA7 is caused by a CAG trinucleotide repeat expansion in the ataxin-7 gene. The CAG repeat tract is translated into a series of glutamine amino acid residues that occur in a consecutive row in the ataxin-7 protein. The presence of an expanded tract of glutamines in the ataxin-7 protein causes the protein to adopt an aberrant conformation; hence, production of the mutant ataxin-7 protein is the first step in a pathogenic cascade that culminates in neurological disease and vision loss.


Dr. Albert LaSpada

SCA7 is one of nine so-called CAG-polyglutamine repeat diseases, and these disorders belong to a broad category of neurodegenerative diseases involving proteins that misfold. As production of the altered protein is the crux of the pathology in all such diseases, numerous studies have tested the hypothesis that reduced expression of the disease protein can yield improvements in disease pathology and progression. To achieve a reduction in the expression of the mutant protein, a number of strategies have been devised. Many of these strategies target the messenger RNA (mRNA), which provides the template for encoding of the disease protein. One strategy with enormous potential, known as the antisense oligonucleotide (ASO) approach, is to chemically produce a stretch of nucleotides that match a sequence of the mutant messenger RNA. The binding of the ASO to the mRNA yields a duplex that is then recognized by the enzyme RNase H. Upon recognition, RNase digests the duplex, resulting in destruction of the mRNA.

We have been working with a company, ISIS Pharmaceuticals, to create ASOs directed against ataxin-7, and have now validated a set of ASOs that can destroy the ataxin-7 mRNA and thereby reduce the expression of ataxin-7 protein. In this project, we propose to produce high quality ASOs, test them for toxicity effects in mice, and then use them to treat SCA7 retinal degeneration in mouse models that recapitulate the exact SCA7 retinal disease phenotype. If these "preclinical trials" are successful, we would be in a position to file an application with the FDA for permission to attempt this therapy in human SCA7 patients. This would also set the stage for using ASOs to treat SCA7 brain disease.

Puneet Opal, MD, PhD
Northwestern University, Chicago, IL

Exploring the Therapeutic Potential of VEGF in SCA1

We are studying a genetic disease called Spinocerebellar Ataxia Type 1 that affects the cerebellar region of the brain. This is a relentless and uniformly fatal disease with no current cure.

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Dr. Puneet Opal

Our hypothesis is that the vascular growth factor VEGF is decreased in SCA1 cerebella and that some aspects of the disease could be reversed by replenishing VEGF. We are currently focusing on using mouse models in SCA1. However, we hope that our studies will provide the impetus to initiate clinical trials for patients with SCA1 and perhaps other ataxias.

Harry Orr, PhD

University of Minnesota, Minneapolis, MN

Small Molecule Inhibitors of PKA: A Therapeutic Strategy for SCA1

This Pioneer SCA research grant was jointly funded by NAF and the Bob Allison Ataxia Research Center (BAARC).

Spinocerebellar ataxia-type 1 (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 normal individuals. Individuals with SCA1 however, often have a genetic mutation that leads to ataxin-1 protein containing greater than 35 (and as many as 200) 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 undertook a large drug screen of 225,000 small molecules compounds to find specific inhibitors of ataxin-1 serine 776 phosphorylation. The molecules discovered in the drug screen 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 being an effective drug.

Dr. Harry Orr

Henry Paulson, MD, PhD

University of Michigan, 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 Spino-▸▸

cerebellar Ataxia Type 3 (SCA3). We seek to develop preventive therapy for SCA3, building on the investigators' 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, ataxia-3, or inhibit its oligomerization, which is likely a key biochemical step in SCA3 and other polyQ diseases. Initial screens in both assays have identified 22 compounds that reduce levels of expanded atain-3 or early oligomer formation. The project is a two year proposal with three aims, building from compound identification (year 1) to in vivo testing in a murine model of disease (year 2). Aim 1 will confirm the activity of compounds identified in our initial screens in secondary assays employing neural cell lines and cerebellar organotypic cultures derived from SCA3 transgenic mice. Aim 2 will utilize these same cell-based primary and secondary assays to screen a small, customized library of proteostasis modulators and a much larger, diverse collection of natural products. From Aims 1 and 2, several compounds are expected to show efficacy and have desirable chemical and pharmacokinetic properties that justify further in vivo testing. Aim 3 will test whether a promising compound identified in aims 1 and/or 2 mitigates 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 a potential therapeutic agents for humans who suffer from SCA3.

Description of Relevance

The proposed research will use 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 screen will then be tested for its effectiveness in slowing disease in a mouse model that faithfully mirrors many aspects of the human disease.

Young Investigator Research Grant Award

Brent L. Fogel, MD, PhD
University of California, Los Angeles

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 the 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 the disease in roughly half of all families can be explained by testing the most common 5-10 genes, this still leaves hundreds of thousands of individuals worldwide without a diagnosis. The remaining dozens of the known genes are each very rare (maybe 1% of all genetic ataxia at best) and there are likely many more genes waiting to

Dr. Brent L. Fogel

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be discovered. Often, physicians have to resort to large screening tests which include many genes, but as the numbers of genes increase, these tests become more costly to patients and less useful. New technology provides a way to achieve a better result less expensively through a process called "next-generation sequencing" which is capable of sequencing a person's entire genome in a fraction of the time and cost of current sequencing methods. At present, sequencing of the genes known to be expressed in the human genome (called the "exome"), costs about $1000 per individual and can be obtained in about four weeks. We propose to use next-generation sequencing to A) develop a new way of testing for known ataxia genes and B) identify the genetic cause of cerebellar ataxia in a series of families whose cause is currently unknown. To do this we will select five families with undiagnosed cerebellar ataxia. To insure the ataxia is genetic and due to a single gene, we will only select families which show autosomal dominant disease, e.g. where multiple individuals, both men and women, in successive generations have cerebellar ataxia. We will then comprehensively evaluate the exome of a single patient for genetic variants. The goals of this work will be to 1) develop a method for efficiently analyzing the exome sequence to determine if a patient possesses a mutation in a known ataxia gene, and 2) to develop an effective strategy to identify new ataxia-causing genetic variations using exome information from a minimum of family members. We anticipate these new methods will improve the ability of physicians to rapidly and accurately diagnose patients with genetic ataxias at a fraction of the current cost, as well as contribute new knowledge to our understanding of how the dysfunction of certain genes results in cerebellar ataxia. As this is a Young Investigator award, this project will also serve as a springboard for the principal investigator to develop an active research program in the study of genetic cerebellar ataxia to further contribute to helping patients and their families now and in the future.

Research Grant Awards

David Chan, MD, PhD

Howard Hughes Medical Institute and California Institute of Technology, Pasadena, CA

Identifying Proteins Regulated by AFG3L2 by Quantitative Proteomics

Spinocerebellar ataxia (SCA) is a type of inherited brain disorder. There are over 20 different subtypes of SCAs and they are caused by mutations in different genes. Patients with SCA primarily suffer progressive incoordination of walking, but they may have additional neurological problems depending on the subtype of SCA which they have. There is currently no cure for SCAs.

Dr. David Chan

One of the SCA subtypes is called SCA28, which is caused by mutation in a gene named AFG3L2. The product of this gene is the AFG3L2 protein, which functions inside cellular organelles called mitochondria. AFG3L2 is a "protease," and the function of proteases is to degrade other proteins. There are many different proteases inside the cell, and different proteases are often responsible for degrading different sets of proteins.

In mitochondria, there are approximately one thousand different types of proteins. These proteins work in many important pathways, and the levels of these proteins can alter depending on the need of the cell. Some of these proteins ⏩

would require the function of AFG3L2 when they need to be degraded. However, when AFG3L2 is not functioning, as in the case for SCA28 patients, proteins that need to be degraded are no longer degraded, thus causing perturbations to pathways which they function in, and ultimately leading to dysfunction of mitochondria.

Therefore, to understand factors that contribute to SCA28, we need to know what proteins require AFG3L2 for their degradation, and what pathways are affected when AFG3L2 no longer functions. We have recently established a method that can answer these questions, and we propose to use this method to identify proteins and pathways that require AFG3L2. Having this information may point towards novel therapeutic targets for treating SCA28.

Beverly Davidson, PhD
University of Iowa, Iowa City, IA

RNA Interference Therapy for Spinocerebellar Ataxia 7 (SCA7)

Spinocerebellar ataxia 7 (SCA7) is an autosomal dominant disease and one of the nine polyglutamine expansion diseases. It is characterized by ataxia and retinal degeneration. SCA7 is caused by mutations in the gene, ataxia-7. Currently, there are no effective treatment strategies for SCA7. Previously, we have shown that RNA interference (RNAi) therapy provides therapeutic benefit in a mouse model of Huntington's disease (HD), another model of the dominantly inherited polyglutamine expansion diseases. We hypothesize that SCA7 cerebellar and retinal degeneration can also be alleviated using RNAi-based gene silencing therapies, and will test two different approaches. One approach targets only the mutant human transgene that is expressed in the mouse model. This is known as allele-specific silencing. The second approach tests RNAi reagents that cannot distinguish between the mutant and the normal genes. This is known as non-allele specific. If the latter works, it would be useful for all types of patients with SCA7. If allele-specific approaches are required, we will need to develop personalized RNAi therapies, because most patients will have different alterations in their SCA7 gene which would be needed for targeting the RNAi therapy only to the mutant gene.

Our proposal has 3 aims. The first is to work in collaboration with Dr. Arlene Drack, an ophthalmologist at the University of Iowa, and Dr. Al LaSpada, a SCA7 researcher at the University of California San Diego, in characterizing the retinal and cerebellar phenotypes in a new SCA7 mouse model. We have already made progress on characterizing the ataxia phenotypes, and will finish that work and learn about the retinal phenotypes. The second aim is to develop RNAi sequences that can be used in our allele-specific and non-allele specific gene silencing experiments. We need to identify several sequences for each approach, and confirm their activity in tissue culture cells before we move into our mouse model. We have already made progress on this aim, and have several candidate sequences ready for further testing. In the third aim, we will test if the RNAi approaches can improve the phenotypes characterized in the first aim. The phenotypes we will evaluate range from changes in gene expression caused by the mutant ataxin-7, neuropathology in the hindbrain and the retina, behavior changes (ataxia), and retinal function. Importantly, we have made progress in delivery to these tissues, so the critical question can be

Dr. Beverly Davidson

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addressed without the need for obtaining the technical expertise needed to get the material to the disease target. Overall, these studies are an important step in moving these novel therapies into humans. The outcome of this work will be used to support a larger grant application to the NIH for monies to develop the lead RNAi sequences for human testing.

Arnulf Koeppen, MD

Albany Research Institute at VA Medical Center, Albany, NY

The Pathogenesis of Hereditary Ataxia

Anatomy and pathology are basic disciplines of medicine. The founder of the National Ataxia Foundation (NAF), Dr. John W. Schut, who was himself a victim of dominant ataxia, stressed over 50 years ago that the science of pathology was important for our understanding of hereditary ataxia.

Dr. Arnulf Koeppen

He followed the same reasoning of the famous physicians of the late 19th and early 20th century who studied hereditary ataxia: Nikolaus Friedreich, Piere Marie, and Gordon Holmes. Pathology implies the harvesting of tissues by autopsy of patients who have succumbed to a disease so his or her survivors may gain insight into their own ailments, develop a rational therapy, and prevent the disorder from affecting children and grandchildren. The principal investigator, who is a neurologist and neuropathologist, has organized tissue donations on behalf of NAF for 18 years and gained important insight into the mechanisms by which spinocerebellar ataxia (SCA), sporadic ataxia, and Friedreich's ataxia (FRDA) damage the nervous system.

In FRDA, the disease also gravely affects the heart and the insulin-producing cells of the pancreas. Therefore, physicians must be familiar with the cardiomyopathy of FRDA and diabetes mellitus. Many patients with sporadic ataxia actually have multiple system atrophy (MSA) that often includes autonomic dysfunction such as blood pressure instability, erectile dysfunction, and urinary incontinence.

The **specific aim** of this proposal is to continue the effort to make the correct diagnosis in patients with ataxia, communicate results to the next-of-kin and the patient's physician, and above all, make tissue samples available to other ataxia researchers. Examination of human tissues will confirm the important insights that ataxia researchers have made in transgenic mice, other animal models, and tissue cultures. The investigator's archival collection of frozen, fixed, and embedded tissues includes representative samples of SCA-1, SCA-2, SCA-3, SCA-6, SCA-7, and SCA-17; dominant ataxias without known mutations; MSA; and FRDA.

The investigator seeks financial support from NAF to continue this program. Access to autopsy services has become more difficult in recent years due to the involved cost, at $ 1,000 to $2,000 per examination. The investigator's long-term membership in neurological and neuropathological societies in the United States and Canada, however, allows him to reach out to professional colleagues and request their free collaboration. The scientific rewards of the program have been large, but the outstanding benefit of this program is the sense of closure that the detailed knowledge of the fatal disease conveys to the bereaved families. ▸▸

Susan Perlman, MD
University of California Los Angeles

Web-based National Ataxia Database

The National Ataxia Registry (PI Dr. S. Subramony), the National Ataxia Database (PI Dr. S. Perlman), and the Ataxia Tissue Donation Program (PI Dr. A. Koeppen) form the infrastructure for clinical research in the ataxic disorders. They enable ataxia researchers to notify ataxia patients of upcoming research projects, to store and analyze data from those projects, and to examine tissues from ataxia patients to find out how ataxia develops and how the body responds to it.

Four prior National Ataxia Foundation grants (2001, 2004, 2005 and 2007) were used to develop the web-based National Ataxia Database. It is currently housed on the UCLA computer servers, and over the years since its development has provided natural history database support to the UCLA Ataxia Clinic, as well as to the Ataxia Clinic at Johns Hopkins University. Other "ataxologists" in California, Arizona, Nevada, and Colorado have expressed interest in using it as well. It has begun to provide a platform to support and join specialists in clinical care and clinical research of ataxia. It will ultimately assist all members of the Ataxia Clinical Research Consortium in future collaborative endeavors in clinical research and in setting standards for clinical care.

Dr. Susan Perlman

The templates for the Rare Disease Network-supported CRC-SCA natural history study (PI T. Ashizawa) are now part of the National Ataxia Database. With the current gap in funding of that project, we are planning to import the existing coded data as a back-up plan, to enable continued enrollment and follow-up of subjects in this important study of SCA 1, 2, 3, and 6.

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

The National Ataxia Database will provide stability for these collaborative clinical endeavors and will also provide a bank of clinical data on ataxia patients that can be made available for future studies.

Any ataxia patient whose clinical data is entered into the National Ataxia Database will be asked to sign a consent form authorizing this use of their clinical data for current and future research. All data entered into the database will be coded so no individual patient can be identified.

Joseph P. Sarsero, Ph.D.
Murdoch Childrens Research Institute, Victoria, Australia

Non-viral Gene Therapy for the Correction of Friedreich Ataxia iPS Cells

Friedreich ataxia (FRDA) is an autosomal recessive disorder characterized by neurodegeneration and cardiomyopathy. The presence of a GAA trinucleotide repeat expansion in the first intron of the FXN gene results in the inhibition of gene expression, reduced levels of full length FXN transcript and an insufficiency of the mitochondrial protein, frataxin. Stem cell therapy has the potential to repair or replace damaged

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tissue and restore organ function in individuals with FRDA. Gene correction of patient-specific induced pluripotent stem (iPS) cells followed by their differentiation could provide a useful source of immunocompatible cells for transplantation therapy of FRDA. An essential prerequisite for the clinical application of human iPS cell therapeutics will be assurance that iPS cells and derivatives do not contain genetic abnormalities introduced during their establishment or modification. The process of gene correction itself should also not contribute unnecessary operational DNA sequences into the genome or modify extrinsic gene expression patterns. In this project we propose a means to correct the GAA trinucleotide repeat expansion inherent in FRDA iPS cells by bacterial artificial chromosome (BAC)-based non-viral gene therapy in a manner that does not introduce any operational sequences and maintains the endogenous regulation and expression patterns of the FXN gene. The proposed methodology has the potential to correct the defect inherent in FRDA iPS cells and addresses major safety concerns for the clinical use of iPS cells in transplantation medicine.

Dr. Joseph P. Sarsero

S.H. Subramony, MD
University of Florida, Gainesville

New Initiatives for Clinical Research on Ataxia

This proposal is requesting continuation of funding for "New Initiatives for Clinical Research on Ataxia," a project funded by NAF during the last two years. The intention of the funding was to promote clinical research in the field of ataxia primarily by establishing a patient registry on behalf of the National Ataxia Foundation. In addition, it was hoped that the grant would revive the clinical research network in the USA by establishing an Ataxia Clinical Research Coordinating Center (ACRCC) at the University of Florida. The PI worked closely with a volunteer group (estimated contribution close to $50,000) from the HP-EDS company to generate the software needed to establish a web based ataxia registry (*www.nationalataxiaregistry.org*).

Dr. S.H. Subramony

The National Ataxia Registry (NAR) is still actively recruiting subjects with over 1,000 subjects in contact and over 320 already confirmed and activated since it became functional this spring, an activity that is mostly done under the direction of our coordinator, Becca Beaulieu. Becca also has maintained all the regulatory documents needed for this effort. In the last few months, we have been involved in revising the registry process so that the cumbersome process of phone consent can be avoided. This effort ⏩

is still under progress with the help of our volunteer group from EDS since this will involve changes in the software. Once this is achieved, we expect a speedier increase in the number of participants.

The funds requested will continue to support primarily the coordinator to further increase the number of registrants, work with the software consultants to revise the web site, maintain accurate logs of the subjects in the registry and field requests from research groups that need particular types of subjects for research. In addition, the coordinator and the PI will maintain close contact with NAF to further this effort. Lastly, the PI has helped significantly in the conduct of the NIH funded natural history study of SCA's. The continued collaboration of NAF and clinical investigators is essential to maximize our chances of getting additional competitive funding and the registry will continue to be a significant piece of "preliminary data" in applications for such grants.

Filippo Tempia, MD, PhD
University of Turin, Italy

Pilot Study of the First Knock-in Animal Model of SCA28, Harboring the M666R Mutation

The spino-cerebellar ataxia type 28 (SCA28) is due to mutations of the gene *AFG3L2*, which encodes for a protein localized in mitochondria, the energy factory of the cell. SCA28 is inherited as a dominant disease, which means that patients have one mutated copy of the *AFG3L2* and a normal one. At present, the knowledge of SCA28 mechanisms is based on experiment either in yeast or in mice lacking one of the two copies of the gene *AFG3L2*. One major difference between the existing mouse model and the human disease is that such mouse model completely lacks one copy of the gene, whereas humans affected by SCA28 have one normal copy and one mutant copy. Recently, we have generated the first SCA28 knock-in mouse, in which one SCA28 gene is normal and the other has the mutation of the most severe case of SCA28. Aim of this pilot project is to provide the first description and validation of such a SCA28-knock-in mouse. The final goal of this and a larger subsequent study, is to unravel the pathogenesis of SCA28 and to identify therapeutic targetable pathways. The experiments are aimed at uncovering, in SCA28-knock-in mice, the neurologic symptoms related to SCA28 and the structural alterations of the cerebellum and other brain regions. We expect that the results of this pilot study will provide a basis for a larger project, aimed at outlining the network of dysfunctions causing SCA28, and providing clues for therapeutic targets.

Dr. Filippo Tempia

Young Investigator for the SCAs Awards

Janghoo Lim, PhD
Yale University, New Haven, CT

Molecular Pathogenesis Studies of Spinocerebellar Ataxia Type 1

The human inherited cerebellar ataxias are a genetically heterogeneous but clinically similar group of disorders that share many neurological and pathological features, such as loss of balance and coordination, as well as cerebellar Purkinje cell degeneration. We have utilized spinocere-

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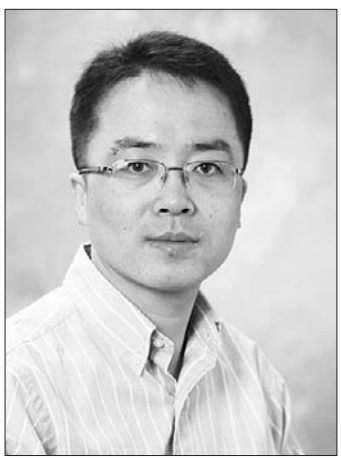
Dr. Janghoo Lim

bellar ataxia type 1 (SCA1) as a prototype of dominantly inherited cerebellar ataxias. By investigating the fundamental mechanisms of SCA1 pathogenesis, we hope to gain insight into the common key features of this and several other neurodegenerative diseases. SCA1 is caused by a polyglutamine expansion in the protein Ataxin1. Building on our studies of SCA1 and Ataxin1, we have recently found that Wnt signaling might be affected in SCA1. In this proposal, we will test the hypothesis that SCA1 affects Wnt signaling and that this may cause or modulate the disease pathogenesis. We believe that this study will lead us to better understand the pathogenic mechanisms of SCA1 and several other inherited ataxias, which we hope will open the possibility of future therapies.

Francesca Maltecca, PhD
San Raffaele Scientific Institute, Milan Italy

Spinocerebellar Ataxia Type 28, from Molecular Hypothesis to Preclinical Treatment

Spinocerebellar ataxia type 28 (SCA28) is a novel form of juvenile-onset, slowly progressive, autosomal dominant 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 is crucial for energy production and cellular function. We developed and characterized a mouse model of SCA28 that recapitulates very well the features of patients. In fact, it shows progressive ataxia due to degeneration and loss of Purkinje cells (PCs), the typical pathological hallmark of SCAs. We found that SCA28 PCs degenerate by cell shrinkage, cytoplasm darkening and atrophy (dark degeneration). These pathological findings have been documented also in SCA5 and SCA7 and are due to different causes. Peculiarly, in the SCA28 mouse this type of degeneration originates for the first time from mitochondrial dysfunction. Our studies focus on disclosing the molecular basis of SCA28, defining a functional link between mitochondria dysfunction and PC degeneration. Moreover, we have encouraging outcomes from a pharmacological approach on SCA28 mice, which represents a first step towards a therapy of this disease and other SCAs. ▸▸


Dr. Francesca Maltecca

Edgardo Rodriguez, PhD
University of Iowa, Iowa City, IA

Development of a Mouse Model for SCA6

Spinocerebellar Ataxia type 6 (SCA6) is a dominantly inherited form of ataxia for which there is no effective treatment. SCA6 belongs to a family of neurological diseases known as the CAG triplet repeat disorders. Because the clinical severity of these neurodegenerative diseases, including SCA6, is linked to the presence of a "toxic" protein, turning off production of the disease protein is a promising route to therapy. We have pioneered the use of RNA interference (RNAi) as a means to block the expression of toxic disease genes in the brain. Our goal is to carry out the preclinical studies needed to bring RNAi therapy to the clinic for patients with SCA6 and other forms of dominantly inherited ataxia (i.e. SCA1, SCA3, SCA7, etc).

Dr. Edgardo Rodriguez

To accomplish this goal, we propose to generate a new mouse model of SCA6. Our approach is based on the use of well-established genetic engineering techniques. Moreover, the successful completion of these studies should result in the production of a model that accurately mimics important aspects of the human disease. This would allow us to pursue federal funding to continue studies towards the understanding of the pathogenic mechanisms that underlie SCA6 and the preclinical development of new therapeutic strategies.

Thorsten Schmidt, PhD
University of Tuebingen, Germany

Isoforms and Polymorphisms of Ataxin-3 as Modifiers 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. SCA3 patients, however, have more than 62 of these CAG repeats. Everybody has two copies of the

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National Ataxia Registry

The web-based National Ataxia Registry (NAR) is an essential component for rare disease research because it fosters connections between patients and researchers for participation opportunities in drug trials and other research.

Even if you are registered on another patient registry, you are encouraged to sign up on this ataxia patient registry for individuals in the United States with any type of ataxia or who are at risk for ataxia.

Go to *www.nationalataxiaregistry.org* to register. If you have questions or encounter problems, please contact the Research Coordinator by e-mail at *nationalataxiaregistry@neurology.ufl.edu*, or leave a voicemail message with your name and phone number at (352) 273-9194.

Thank you for your willingness to sign up on the National Ataxia Registry.

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ataxin-3 gene, one inherited by the mother, one inherited by the father. In most cases, 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 of age. In order to improve the prediction when first symptoms may occur, we analyzed in more than 500 European SCA3 patients 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.

Dr. Thorsten Schmidt

Within this project, we want to find out why the patients with this specific haplotype develop first symptoms five years later. What is so different in these 2% of patients? Why do they get first symptoms much later? Is it the copy with the normal CAG repeat which modifies the disease? Or are these additional variations we analyzed in the expanded allele responsible? We will try to replicate the situation present in these patients in our lab in order to answer these questions. 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 strategies for a possible future therapeutic intervention.

Sokol V. Todi, PhD

Wayne State University School of Medicine, Detroit, MI

Mechanisms of Neuroprotection in Spinocerebellar Ataxia Type 3

Spinocerebellar Ataxia Type 3 (also known as Machado-Joseph Disease; SCA3/MJD) is perhaps the most common dominantly inherited ataxia. 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.

Dr. Sokol V. Todi

Normal ataxin-3 appears to be involved in cellular mechanisms that discard abnormal proteins. However, it is unknown what goes wrong with ataxin-3 functions when it is mutated in SCA3/MJD. Here, we propose to investigate how ataxin-3 functions relate to SCA3/MJD by using genetics, behavior, morphological differences, and physiological assays in a fruit fly model of SCA3/MJD, which causes progressive neurodegeneration and early death in adult flies. We also seek to discover proteins whose ⏩

function may slow down or stop neurodegeneration in SCA3/MJD.

Our research aims to answer key questions on SCA3/MJD: 1) How are the normal functions of ataxin-3 tied to SCA3/MJD? Can this information be used for therapeutic strategies? And 2) What other, previously unexplored factors impact SCA3/MJD pathogenesis? We hope to both expand our understanding of SCA3/MJD pathogenesis, as well as identify new therapeutic targets for this debilitating disease.

Research Fellowship Awards

Fadi A. Issa, PhD

University of California, Los Angeles

The Effects of SCA-13 Mutations on the Development and Electrical Activity of the Purkinje Neurons

Spinocerebellar ataxia type 13 (SCA13) is an autosomal dominant genetic disease caused by mutations in the KCNC3 gene. This gene encodes the Kv3.3 voltage-gated potassium channel, which plays an essential role in facilitating proper electrical activity in cerebellar Purkinje neurons. There are two identified SCA13 mutations and depending on the mutation, SCA is characterized by ataxia and cerebellar neurodegeneration during aging or persistent motor deficits and cerebellar mal-development starting early in life. In my research I am testing the hypothesis that SCA13 mutations have adverse effects on the electrical activity of developing Purkinje neurons that lead to their abnormal development. Changes in neuronal function have been reported in several neurodegenerative diseases, including those caused by toxic, misfolded proteins, but whether changes in neuronal electrical activity are involved in pathogenesis is unknown. SCA13 provides a novel opportunity to investigate the relationship between neuronal activity, development and motor control in the absence of other complicating factors such as misfolded proteins. I am using zebrafish to investigate these questions because zebrafish provides numerous technical advantages making it an attractive system to address my research interests. One important advantage is that neuronal function can be assessed using genetically-encoded calcium indicators to monitor changes in electrical activity that are due to the SCA13 mutations, and we can follow the development of the cerebellum in living animals.

Sukanya Karan, PhD

University of Utah, Salt Lake City, UT

Identification of the Mutation Causing Progressive Purkinje Cell Degeneration in the Shaker Rat

Dysfunction of cerebellum and its associated systems lead to a group of neurological disorders that include different types of ataxias. Ataxias can be hereditary or acquired. Hereditary ataxias are group a genetic disorders characterized by slow progressive incoordination of gait and movements. Hereditary ataxias can be inherited in an autosomal dominant or recessive manner or it can be X-linked. Mutations in many genes have been identified for autosomal dominant and recessive forms of hereditary ataxias. However, X-linked ataxias are not yet well understood. Therapeutic strategies such as cell transplantation and gene replacement are beginning to emerge. However, lack of knowledge of the underlying mechanisms and insights into the pathogenesis are barriers for such strategies, Therefore identification of new genes and gene defects underlying these diseases are useful for understanding the mechanisms at molecular, cellular and protein levels and are the fundamental steps towards developing appropriate treatments for these diseases.

The shaker rat is a naturally occurring model

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NAF Funded Ataxia Research
Continued from page 15

for Purkinje cell degeneration, exhibiting the ataxic phenotype. However, the gene responsible for this phenotype is not yet identified in this model. Identification of the causal gene in this shaker rat will pave way for understanding the mechanism in the context of disease etiology. This will then lead to the development of therapeutic treatment. My research proposal aims at (1) identifying the target gene responsible for the ataxic phenotype in the shaker rats and eventually (2) to detect mutations(s) in this disease gene. ❖

From My Perspective

By Elise Gorzela

Being the teenage child of someone who suffers from an incurable disease is a lot simpler than you would think. It's not like the movies "My Sister's Keeper" or "Listen to Your Heart." Ataxia is never really like that – it's a constant. Something, unfortunately, that is always there and always will be. I've never known the reality of my mother not having ataxia. I don't even remember being told why my mother walked funny. It's just always been.

In elementary school no one asked me about my mother. And my mom didn't need to be rushed to the hospital or have lots of tests done so [ataxia] was rarely on my mind. There was one incident in an afterschool class where I was with my brother, his friend, and some new kid we had just met. I don't remember how the conversation had even gotten to this point, but the new kid looked at me angrily and said the three words that horrified me, "Your mom's retarded!" He probably had just said it out of anger and hadn't realized the enormity of what he just said, but it resulted in me pushing him onto the ground and me being banned from activities for the rest of the afternoon.

Misunderstanding is really the only hard part us youth get from knowing someone who walks like a drunken sailor. We learn though to just look people back in the eye when they stare at us for holding someone's hand because they can't get down a six inch curb or to not care that someone thinks we are the children of some alcoholic and thinks they should feel badly for us. We've seen what our parents might become and their future. We try not to think about it and for some of us we will have to think of it sooner than others. For most of us this is how our life is and we've learned to deal with it. We are not there to be embarrassed of them or feel ashamed.

We are there to stand for them. That's how simple it is. ❖

Let's Get Small

Janelia researchers are working their way up from simple to more complex organisms to measure brain activity

by Helen Fields

To Tim Harris, understanding the brain is like understanding a building – a really big building – from the vantage point of the sidewalk. "The brain is the Empire State Building, and it's opaque. You're standing there looking at the outside and wondering: is the hot water faucet on the third sink of the 65th-floor restroom on the left or the right?"

This is the situation neuroscientists find themselves in, Harris says. They can see your head, they can see you sensing your environment and doing things, but they have only the murkiest sense of your brain's inner workings. Harris, a physicist at HHMI's Janelia Farm Research Campus in Ashburn, Virginia, develops tools neuroscientists can use to measure the brain's activity, to give them a quantitative view inside the elaborate structure of the brain.

Harris spent the early part of his career at Bell Labs, where he developed optical methods for studying semiconductors. Later, at Helicos Biosciences and elsewhere, he became interested in biological measurements that generate huge amounts of data. He sees neuroscience as one big measurement problem. All science depends on good measurements. But the unbelievably complex brain makes measuring particularly challenging. The human brain has more than 80 billion neurons, and each neuron can have 10,000 connections to other neurons. There's no way to measure the whole thing at once.

Taking it apart, however, isn't the answer. The brain is a live, working system; cut out a piece and you're left with a blob of goo. Then there's the problem of the unyielding skull. Cutting a hole in it opens a window to the electrical signals that carry information but offers only a limited view: "If I punch a hole in a wall and look through the hole, I can see many things. I'm not sure what fraction of them are engaged in my problem and what fraction are not relevant to my problem," Harris says.

To study the brain, he adds, "the question is, where did the electricity go and when did it go? The essence of all neuroscience is summed up in that one thing." Since it's impossible to work out the entire human brain at once, Harris and the other instrument experts at Janelia help neuroscientists figure out what they can measure and how to do it. They're getting at the brain by studying simpler animals, like nematodes and fruit flies, with tools that can measure electricity either directly, with an electrode, or indirectly, with proteins that light up when an electrical pulse goes by.

Start Simple

One way to understand a behemoth like the Empire State Building, Harris says, is to first figure out the workings of a one-room, mud-brick hut. In neuroscience, that's the nematode *Caenorhabditis elegans*. The tiny, see-through worm has 302 neurons – much easier to study than a human brain. Rex Kerr, a fellow at Janelia Farm, is trying to understand how worms do what they do. And one of the tools he's using to measure the worm's brain was developed at Janelia by group leader Loren Looger's team: GCaMP3, a protein that lights up in the presence of calcium and is now used in labs throughout the world.

Continued on page 18

Let's Get Small
Continued from page 17

Neurons make their electrical impulses by moving ions around. One of the main ions is calcium. GCaMP3 is a kind of protein known as a genetically encoded calcium indicator, or GECI. The cell is engineered to express GCaMP, so when a blue light is shined on it, the GCaMP lights up – giving off green light – when it detects calcium. These proteins let neuroscientists see electricity in the brain, with the help of a microscope.

"The challenge here is that we have neurons in three-dimensional space," Kerr says. A worm's brain is tiny and clear, but it's still 3-D, with cells stacked on top of each other and intertwined. With instrument design experts at Janelia, Kerr developed a microscope that can image the whole brain. A laser sweeps through the brain over and over, lighting it in sheets from the side. As the laser beam touches each level, it hits the GCaMP3 proteins and they fluoresce, sending light to the waiting microscope to record which neurons are active.

Kerr can measure neuron activity in live worms while they are sensing the environment. An individual worm is placed under the microscope lens and herded into a wedge-shaped chute like a sheep waiting for a vaccination. A researcher uses a setup of syringes to squirt chemicals past it – and then watches to see how neurons that have been engineered to make GCaMP3 react to, for example, a scent that the nematode associates with food.

For now, the worm has to be stuck in a chute to line up its brain just so with the laser and microscope lens. But Kerr's dream is to be able to take a dish of free-swimming worms, "and tell the scope, 'Follow that worm! Tell me what it's thinking wherever it goes.' Or tell me what that small subset of neurons is doing wherever it goes." He's working on a system to do this – it involves putting the dish on a platform that tracks the worm's movement and moves the plate so the worm's head stays centered under the lens. He already has a system that can track worms as they squirm around under a microscope

Kerr thinks it might be possible to learn how a worm does what it does in the next decade or so. And those lessons could be applied to understanding more complicated animals.

Moving on Up

It's still just a worm, but Tim Harris says that's a good start. "Learning how to build a one-story, mud building is a pretty good idea," he says. "Then people think, 'OK, so, mud is never going to get us to the Empire State Building. We've got to learn how to build using bricks and do plumbing and all that jazz.' So that's now another measurement problem that's even harder."

A fruit fly brain is a lot easier to study and less complex than a human brain, but more complicated than a worm brain. When dealing with a lot more neurons, you want more measurements. It's possible to buy a probe from a supply company with many tiny wires on the end. Ease it into the brain and the tip of each wire records the electrical impulses around it. The probe can record data for many neurons at once, Harris says. "But, you're still poking a stick into a brain. You've probably caused some damage. We'd rather have a magic microscope that could see through the brain and measure the electricity, but we don't know how to make that."

Instead, he's making better probes. Along with fruit fly researcher Vivek Jayaraman, Harris and Mladen Barbic in his group have developed smaller, skinnier probes for fly brains. Because they're 10 times narrower than commercial probes, they destroy less tissue on the way in, and the tips of the wires are tiny, suited to flies' small neurons.

Like Kerr, Jayaraman wants to measure neuron activity in flies living in a sort of virtual reality arena. An individual fruit fly is glued by its head to a bracket and then allowed to fly or to walk on a ball, like a treadmill. Meanwhile, the researchers display moving patterns on a ⏩

U-shaped bank of light-emitting diodes designed by Janelia group leader Michael Reiser. The fly sees and reacts to those patterns, trying to walk or fly toward a fixed line or fly straight when it seems the world is moving to the left.

Crucially, the top of the fly's head is open and bathed in saline under a microscope; a researcher removes a smidgen of the fly's cuticle, and nudges a probe into the working brain. Harris's improved probes should help Jayaraman get better measurements from neurons and understand more about how the brain makes decisions.

Illuminating Windows

The next step on the way up to the Empire State Building, Harris says, is the mouse. "The mouse brain is even bigger, with even more neurons. So you have to study smaller parts of it to understand what's going on."

Karel Svoboda, a group leader at Janelia Farm, studies mouse brains. His team builds a tiny glass window into each animal's head. This doesn't seem to bother the mice, and the researchers can follow one mouse for months as its brain changes to accommodate its new knowledge.

He uses GCaMP3 and other tools to measure electrical activity in mouse brains. But he says the tools available to do neuroscience today still aren't good enough. "In brain research, we make up a lot of stories based on incomplete information," Svoboda says. "We're still looking at large populations of neurons, but we have only probed a small part of the brain. In many ways we're still very much limited by measurements."

As part of the GECI project at Janelia, Svoboda, Jayaraman, and Kerr are working with protein engineer Looger to develop improved versions of GCaMP3. The new proteins should be better at binding calcium, so they will respond when there's less calcium. They hope newer versions will also light up sooner after calcium rushes into the cell. And while the current version can impair cells when it builds up, the next proteins may do less damage.

"The major discoveries of neuroscience in the modern era correlate directly with advances in measurement technology," Svoboda says. Around the turn of the 20th century, Spanish physiologist Santiago Ramón y Cajal perfected a technique for looking at slices of brains and determined that brains were made of cells. Neuroscientists figured out some basics about how the visual cortex works because they invented a technique for recording electrical signals from cells.

This work continues at Janelia Farm, as its neuroscientists keep working to understand the brain. Harris thinks neuroscientists won't understand the human brain for a thousand years, at least; but with new tools, they can keep chipping away at the problem – and make a little bit more sense of what goes on inside our heads.

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BOOKS

— ATAXIA RESOURCES —

Evaluation and Management of Ataxic Disorders for Physicians

by Susan Perlman, M.D.

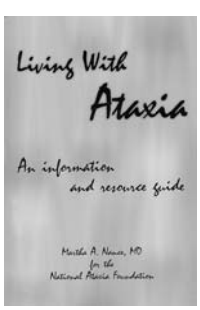
This resource is intended to inform and guide physicians who may be caring for patients with ataxic symptoms or who have been diagnosed with ataxia. It will provide health care practitioners with a vocabulary to aid in the understanding of what is and is not ataxia, diagnostic protocols for use in defining the types and causes of ataxia and resources for use in counseling and managing the ataxic patient. Consider buying one for your neurologist and other health care providers. Published in 2007. $5

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 —

Summer Born: A Life with Cerebellar Ataxia

By Cheryl Wedesweiler

Although the characters are fictional, the story is based on the author's real life experiences with having cerebellar ataxia. $15.95

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

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The National Ataxia Foundation 2012 Annual Membership Meeting Review

"Roundin' Up a Cure to Give Ataxia the Boot"

San Antonio, TX – March 16-21, 2012

The 2012 Annual Membership Meeting (AMM) was hosted by NAF's Central Texas, Houston, and North Texas Ataxia Support Groups. 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 500 attendees, 22 speakers, and 14 exhibitors were in attendance for the three-day event. Attendees came from 36 U.S. states and from international countries including Belgium, Canada, and the United Kingdom.

Thursday, March 15 was the major arrival day for most attendees and the day kicked off with registration and exhibitors. We would like to thank all the sponsors that contributed to the 2012 AMM welcome bags, Alamo cookies, and bottled water that each of our attendees received upon arrival. Thursday evening attendees were able to view the posters presented at the NAF Ataxia Investigators Meeting (AIM) and visit with the AIM poster presenters.

Friday morning started out with the general session program. NAF Board Vice-President Camille Daglio and representatives of the Texas support groups gave welcome announcements which were followed by an update from the NAF office by Michael Parent, NAF executive director. Other presentations on Friday morning gave attendees information about physical therapy, assistive technology, and medications.

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 the groups.

On Friday and Saturday attendees were able to observe and try the Nintendo Wii game system and get a NAF temporary tattoo in the Activity Room. Thank you to Heather Evans for facilitating the Activity Room again this year.

Friday evening was the Southwest Welcome Reception. The festive décor, cowboy attire, delicious food, and great company were enjoyed by all. Thank you Linda Crawley for providing the festive centerpieces for this evening. During the reception a presentation was shown about fundraisers held in 2011 that benefitted NAF. Thank you to all the supporters and organizers of these events!

Saturday continued with the general session program with both new and familiar medical professionals and researchers presenting. Dr. Henry Paulson kicked off the sessions with a recap of the Ataxia Investigators Meeting. Throughout the day attendees heard about genetics, stem cell research, occupational therapy strategies and much more.

Saturday evening's St. Patrick's Day Banquet was a fun-filled and green experience for all in attendance. Thank you to Linda Crawley for bringing the wonderful centerpieces for this event. Throughout the conference attendees had a chance to purchase yellow tribute roses that were distributed at the banquet as a way to honor those that were named on each rose. NAF recognized Denise Drake and Earl McLaughlin for their years for service on the NAF Board of ⏩

Directors. The Leader Family and Lealan LaRoche each received a, "I am the Strength Behind Ataxia" award for their support of the Foundation. The 50/50 raffle raised $2,500 and the silent auction raised more than $3,900. Thank you to everyone who participated and donated items for these events. Thank you to DJ Masquerade who provided such wonderful dancing music!

The Sunday morning general session program included informative presentations on financial planning, barriers to treatment, and a review of current ataxia research. Dr. Susan Perlman gave the closing presentation of the conference with a summary of the various topics and presentations from the weekend.

Each day's general session was followed by a question-and-answer session which included the presenters of each day. Please watch future issues of *Generations* for publication of these presentations. You can view the presentation slides on NAF's website, *www.ataxia.org*. Audio presentations synced with PowerPoint presentations can be purchased through Digital Conference Providers at *www.dcprovidersonline.com/naf/*.

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 annual meeting.

This conference would not have been possible without the time, contributions, and efforts given by so many. We appreciate your participation in making this conference so successful. Thank you so 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 invaluable and worth more than any words can say. It was a pleasure working with Linda Crawley, David Henry Sr., David Henry Jr., and Jimmy Meyers. We would like to thank Lora Morn for again volunteering as our on-site nurse at the conference. We would also like to thank David Garcia for taking such memorable pictures of this year's event.

We would also like to thank this year's sponsors Athena Diagnostics, the Bill & Melinda Gates Foundation, FA Project, Gabe & Izzy Foundation, MetLife Center for Special Needs Planning, and Santhera Pharmaceuticals. Thank you to the Central Texas Support Group, the San Antonio Convention and Visitors Bureau, Sequent Energy Management, South Mississippi Power Association, Southcross Energy, and Walgreens for the welcome bags, name badges, bottled water, and Alamo cookies for this year's conference. Thank you to the San Antonio Grand Hyatt and Hilton Palacio del Rio Hotels for their service and hospitality throughout this event. ❖

2012 AMM Experience

My name is Omega Amanda Grier and at 24 years old I was diagnosed with Friedreich's ataxia. After that insight, I made the decision to place focus on my education and earned my Bachelor's degree in Interdisciplinary Social Scences/ Psychology from the University of West Florida.

In August 2011, at the age of 30, I gave birth to my precious daughter Emmalee Elizabeth and my life has never felt more meaningful. I am a very proud stay-at-home mother and devoted to spending my days watching her grow up.

These yearly conferences have been so extremely important to me and this year I'm excited to say will be my fifth. I cannot begin to explain how much comfort I receive from attending these conventions with others like myself who share the difficulties of living with this condition. Knowing that you are not alone truly makes such a difference; the connections made with the wonderful people I've met have touched my life in many positive ways.

THE NATIONAL AT

55th Annual Men

"Roundin' Up a Cure to

San Antonio, Texas

Attendees enjoy the Saturday evening banquet.

Board member Denise Drake (left) and support group leader Tanya Tunstull.

The Leader family accepts an "I am the Strength Behind Ataxia" award for their support of NAF.

Attendees enjoy the Saturday evening banquet.

Attendees enjoy the Welcome Reception.

Attendees enjoy dancing at the Saturday evening banquet.

Support Group Leaders Charlotte DePew (top) and Mary Fuchs enjoy the Saturday evening Banquet.

AXIA FOUNDATION

nbership Meeting

Give Ataxia the Boot"

– March 16-18, 2012

Attendees enjoy the Saturday evening banquet.

Meeting attendees Chantal Mahler, Fred Blasberg, and Tina Blasberg enjoy the Saturday evening banquet.

Earl McLaughlin and family.

Attendees enjoy the Saturday evening banquet.

Attendees enjoy the Saturday evening banquet

Attendees enjoy the Saturday evening banquet.

Lealan LaRoche accepts an "I am the Strength Behind Ataxia" award from NAF President Char Danielson and NAF Executive Director Mike Parent.

NAF Vice President and AMM Co-Chair Camille Daglio

Speakers from the Saturday afternoon presentations pose for a photo (left to right): Patricia Maciel, PhD; Bridgett Piernik-Yoder, PhD, OTR; Laura Gregory, MA, CCC-SLP; and John H. Ferguson, MD).

Dr. Gulin Oz presents on the topic "What can MRI do for ataxias?"

Speakers from the Saturday morning presentations pose for a photo (left to right): Matthew Bower, MS, CGC; Gulin Oz, PhD; R. Mark Payne, MD; and Puneet Opal, MD, PhD).

NAF would like to thank David Garcia for capturing photos at the AMM (pictured above with wife Rita Garcia).

Ataxia Investigators gather at the Ataxia Investigators Meeting (AIM).

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

National Ataxia Foundation

55th Annual Membership Meeting - Recordings

March 16-18, 2012

Grand Hyatt San Antonio Hotel - San Antonio, TX

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****SPECIAL*** *Visit* ***www.dcprovidersonline.com/naf/*** *for*
A ***Free Session View*** *from the 54th Annual Membership Meeting*

General Sessions at the Annual Membership Meeting Inspire, Inform, and Educate

The Annual Membership Meeting of the National Ataxia Foundation took place March 16-18 and provided attendees an opportunity to hear from the foremost researchers and clinicians in the field of ataxia.

Twenty individual presentations covered practical and medical interventions to assist in living with ataxia as well as various reports on issues that have a significant impact on ataxia research.

After NAF's Executive Director Michael Parent gave an update on NAF's activities, both past and present, the educational sessions began. The session titles and brief take-away points from each presentation are provided below.

PRACTICAL ASPECTS

Affirming yourself for life's challenges

- Your mindset matters when you are dealing with a difficult disease
- Give yourself grace when you occasionally blow it

Cerebellar non-motor functions: What it means for you

- In the same way that the cerebellum regulates the rate, force, rhythm, and accuracy of movements, so does it regulate the speed, capacity, consistency, and appropriateness of mental or cognitive processes.
- Suggestions for what you can do about non-motor problems that you may experience are shown on page 42.

Financial Planning

- When should you begin planning – NOW
- Learn the difference between Entitlement Programs and Needs Based Programs
- Learn the difference between Medicare and Medicaid
- Understand that benefits change and it is important to keep up with the laws

Genetics and Family Planning

Options for family planning for people who have ataxia or are at risk:

- Having children without any genetic testing
- Adoption / Foster parenting
- Pregnancy with prenatal diagnosis
- In vitro pregnancy with donor egg/donor sperm
- In vitro pregnancy with genetic testing (pre-implantation genetic diagnosis)

Home modification and assistive technology

- Home adaptation needs to be individualized because each person with a disability is unique – there is no one-size-fits-all
- The PowerPoint slides for this presentation are well worth reviewing on NAF's website

Occupational Therapy Strategies

- Intensive therapy has potential to improve motor function in some with ataxia
- Focus of occupational therapy is dependent on the goals of the client

Speech and Swallowing

Swallowing: Compensatory strategies

- Sit upright at 90° with good postural support
- Stay upright for 30 minutes after meals
- Take small bites and sips
- Reduce distractions, including talking
- Eat several small meals if fatigue is a factor
- Avoid problematic consistencies

Speech: Compensatory strategies

- Speak face to face without distractions
- Educate unfamiliar listeners
- Break sentences into shorter phrases when you are not understood
- Introduce the topic using a single word
- Take your time

▸▸

MEDICAL ASPECTS

Medication and therapies for ataxia:

- There are treatable ataxias and there are treatable symptoms of ataxia
- Download the PowerPoint presentation from the website for an extensive list of medications that treat the symptoms of ataxia

Move and Improve – coordinative training helps ataxia

- Research shows that physiotherapy is able to improve ataxia and the effects persist over long term, especially if therapy and training continues

The Heart in Friedreich's ataxia

- All patients with Friedreich's ataxia should be seen by a cardiologist every year. The most common cause of death for a person with FRDA is heart failure.

RESEARCH

Spinocerebellar ataxia – working towards a treatment

- Low VEGF could be the cause of atrophy in the SCA1 cerebellum. Using an intracerebroventricular route of drug administration could prove to be an effective therapy.

Stem cell research for ataxia

- Stem cells have the potential to replace cell tissue that has been damaged or destroyed by severe illnesses, however it is still too early in the science to think about therapeutic application
- Understanding how stem cells develop into healthy and diseased cells will assist in the search for cures.

Therapeutic strategies for MJD/SCA3

- Slides illustrating mouse and worm models of SCA3/MJD are available on the website
- Difficulties in human clinical trials
  - Large patient samples not available in rare diseases
  - Differences between patients in terms of clinical presentation
  - The need for clinical severity scales
  - The need for good knowledge of the natural history of the disease
  - The need for biomarkers

What can MRI do for ataxias

- Currently: Can be used in clinical care as a diagnostic aid to detect cerebellar atrophy
- In the future: Can help with understanding disease processes, differential diagnosis and monitoring drug effects in clinical trials

REPORTS

Ataxia Investigators Meeting Review

- Senior and junior ataxia investigators met for three days in an interactive environment where the brain capacity of the collective group and their desire to find answers to the questions raised in ataxia was phenomenal.

Barriers to treatment

- Developing a treatment is hard and expectations for treatments can be unrealistic
- What is needed to develop effective treatments
  - Knowledge of the disease pathophysiology
  - A way to measure the disease
  - An understanding of the natural history of the disease
  - Research infrastructure

NAF Update

- NAF celebrates 55 years of service to the ataxia community
- First ataxia research award was given in 1978 to Dr. Robert Currier
- In 2011, 19 research grant applications were awarded funding
- The future: NAF will continue to be a world leader in providing current and accurate information about ataxia

Office of Rare Disease Research

- 18-25 million people in the U.S. are affected

Continued on page 30

General Sessions at the AMM…
Continued from page 29

by a rare disease
- There are approximately 7,000 genetic and acquired rare diseases
- A disease is considered rare if it affects less than 200,000 people in the U.S.

Patient Registry Update
- The usefulness of the Patient Registry is to promote research and allow for quicker patient recruitment for studies and trials
- Visit the NAR website *www.NationalAtaxiaRegistry.org* to enroll
- Web-based consent coming soon to speed up registration process

Research review
- NAF funded five types of grants: Research, Young Investigator, Post-Doc Fellowship awards, Young Investigator for the SCAs and Pioneer SCA Translational awards
- Research Infrastructure awards for the Tissue Donation Program, the National Ataxia Registry and the Ataxia Database
- Thank you to patients, families and friends who make research happen

Review of what we have learned at this meeting
- All the presentations were summed up by Dr. Susan Perlman when she gave the take-home message of each presenter.

Question-and-answer sessions followed each set of presentations giving meeting attendees the opportunity to write out questions that were brought forward to the panel of experts. The quality of questions asked demonstrated the high level of lay understanding of the ataxias that has been achieved over the years.

PowerPoint presentations are available to download on NAF's website, but an even more valuable resource is the DCP Conference Media audio synchronized presentation material which can be ordered on page 27. ❖

PATIENTS WITH

SCA1, SCA2, SCA3, SCA6 and MSA-C
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 ~1.5 hour 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 @ (612) 625-2350 or email hutte019@umn.edu.

The NAF Board of Directors along with the
Northeast Regional Support Groups would like to invite you to attend the

National Ataxia Foundation
56th Annual Membership Meeting
March 15-17, 2013

Join us in Detroit for the Annual Membership Meeting!

The Detroit Marriott at the Renaissance Center is pleased to provide the facilities for the 2013 National Ataxia Foundation Annual Membership Meeting. The Detroit Marriott is situated on the downtown River Walk, overlooking the Detroit River and Canada, with easy access to shopping, restaurants, entertainment, and the People Mover.

— RESERVATION INFORMATION WILL BE ANNOUNCED SOON —

About Detroit: Only a 90-minute flight from 60 percent of the nation's population, Detroit is an international destination located only one mile from Windsor, Ontario, Canada. Detroit has world-class cultural attractions, entertainment, and dining. In fact, the city was recently named by *AmericanStyle* readers as one of the top 25 arts destinations in the nation.

For more information on Detroit visit *www.visitdetroit.com*. For the latest information on reservations, conference registration, schedules, and area information, keep checking the National Ataxia Foundation website, *www.ataxia.org*.

From the Desk of the Executive Director

David Thomas once said on the subject of volunteerism, "Unselfish and noble actions are the most radiant pages in the biography of souls."

National Volunteer Week began in 1974 when President Richard Nixon signed an executive order declaring the week as an annual recognition to honor volunteers. Every United States president since that time has signed a proclamation recognizing National Volunteer Week.

Michael Parent

In honor of National Volunteer Week (April 15–21), I would like to take this opportunity to sincerely thank all of our volunteers who have given so much of their time, talent and energy throughout the year to help strengthen the ataxia community. Your commitment continues to clearly demonstrate how your collective power has continued to foster positive growth and change.

Thank you to the volunteers who have taken it upon themselves to conduct fundraisers to help support the important work of the National Ataxia Foundation. Thank you to all our volunteers who give so much of their time to staff information booths at Abilities Expos, medical conferences, and at other venues.

We are truly grateful to the volunteers who participate in clinical trials and register on the National Ataxia Registry to help further important research. To NAF support group leaders, chapter presidents, and ambassadors who volunteer throughout the year: thank you for your commitment in helping your local ataxia community in providing a setting for ataxia families to learn, share, and network with one another.

Our wonderful volunteers come from all walks of life and of all ages. Each has chosen to make a difference. It is through their efforts that others are inspired and encouraged to seek out ways to engage and create dialog within their own communities in helping to build greater ataxia awareness.

It is about demonstrating to the nation through events such as the NAF Walk n' Rolls that by working together we can overcome challenges and accomplish our goals in bringing a brighter future to ataxia families.

NAF recognizes the power of volunteerism and the individual transformation which occurs within each of us as we reach for a goal to help others who are affected by ataxia. In honor of National Volunteer Week, I would like to thank all of our amazing volunteers in creating change in our communities and for your dedication to improve the lives of persons affected by ataxia. Your actions have a profound impact in generating greater awareness of ataxia and offering hope through research. Thank you.

Attention Chapter and Group Leaders

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

Chapter and Support Group News from Around the Country

Greater Atlanta Support Group Update

By Dave Zilles

The Greater Atlanta Ataxia Support Group held their annual holiday event in December. At the event we shared food and time together as well as traded gifts using a time-old game where everyone brings a small, inexpensive gift and we draw numbers and pick and steal. It was great fun.

In February we held our support group meeting and had Kathi Geisler from Florida present the Dashaway Walker. We also discussed our plans for 2012, which include a picnic in June and our second annual Walk n' Roll in September. The support group also participated in the NAF booth at the Atlanta Abilities Expo. We had a great turnout and were able to connect with a few new Ataxians. The Expo is coming back again in February 2013.

New England Ataxia Support Group Update

By Donna Gorzela

Our fall meeting at Massachusetts General Hospital (MGH) in Boston was fairly small. The time was spent in roundtable discussions which included discussions about one of the participant's service dog, Luca. We also shared several websites, including one site about driving safety programs (a concern that arose out of our discussions about whether or not a disabled person should give up their license). We also discussed van conversions, wheelchair ramps, home modification loans, and shared more websites. We also watched YouTube videos of a Parkinson's group line dancing.

Our next big meeting at MGH will be

Continued on page 34

The Greater Atlanta Support Group at their December holiday event.

Chapter and Support Group News
Continued from page 33

sometime in May. Dr. Schmahmann will be speaking at that meeting in our ever-popular "Ask the Doctor" session.

Because our MGH meetings are so few and far between we also have informal get-togethers for coffee or lunch in different locations convenient to group members. At this time, we have two such groups going. One group meets in the North Shore Mall food court in Peabody, MA. Our next scheduled meetings there are April 21 and May 19. Another group meets in the Cape Cod area of Massachusetts.

Tri-State Ataxia Support Group Update

By Kathy Gingerelli

The first two meetings of the Tri-State Ataxia Support Group this year were held at the Beth Israel Medical Center, Phillips Ambulatory Care Center.

The January meeting was our annual "potluck" dinner starting with welcoming returning members and making introductions to new attendees. After a quick speech going over the basis of our meetings (including the fact that this is our fifth year of our meetings) we got down to the important part of the evening – the food! Thanks to all who contributed to the night.

Our March meeting started with the usual greeting and introductions. The focus of the evening was placed on our very own Dr. Ann Hunt, who gave a very thorough and enlightening talk to a packed room. Her talk was all about going back to "basics" and explaining about the workings of the cerebellum. Dr. Hunt answered numerous questions throughout her talk and reminded us that exercise is a very important course to follow for everyone. A lot of members were introduced to Charley Steward, a journalism graduate student from Columbia University who is putting together information for an article on ataxia. She set up many interviews and will keep us updated as she goes along.

We concluded our meeting by 8:30 p.m. and gave well wishes to everyone attending the NAF Annual Membership Meeting in San Antonio, TX. We will be expecting updates at our next meeting on May 10 at 6:30 p.m.

For more information on the Tri-State Ataxia Support Group meetings, please contact Denise Mitchell at *markmeghan2@gmail.com* or Kathy Gingerelli at *kgingerelli@msn.com*. ▸▸

The Tri-City Ataxia Support Group is all smiles at their January meeting.

Greater Denver Ataxia Support Group Update

By Charlotte DePew

At our January 21 meeting we had 28 individuals in attendance. After the traditional potluck lunch and socializing, we had announcements and a speaker.

Our speaker's topic was Emotional Freedom Technique (EFT) which was very appreciated and well received by the group. The speaker demonstrated an abbreviated yet very effective procedure with a brave volunteer from our membership. This method can be self-administered at any time in managing stress, fear, grieving, frustration, and/or most emotional situations to achieve peace of mind. The procedure is simple: tapping your middle three fingertips in a specific sequence on facial areas and the sternum (breast bone) while repeating a message to let the feeling go or to release it. The process concludes with a similar message while grasping your wrist with the opposite hand. More information on EFT can be found on the Internet.

Announcements and upcoming events:

(1) Dr. Abby Collins will speak at our April 21 meeting and give us an update from the San Antonio AMM;

(2) Dr. Clouse will speak at the July 21 meeting to discuss "Walking with Ataxia" and will make reservations for private sessions while in the area; and

(3) Planning has started for our 2012 Run, Walk n' Roll on Sunday, September 9, in Denver's City Park.

West Central Florida Ataxia Support Group Update

By Linda Farrow

Our January 7 meeting began after we greeted each other and new attendees were introduced. Our presenter, Julia, was from the Disability Achievement Center of Pasco and Pinellas Counties. She informed us that she was completely deaf and we would need to make sure we faced her when we spoke so she could read our lips. The organization is staffed by people with disabilities to help people with disabilities cope with independent living. As a center for independent living their goal is to assist people to gain or maintain independence at home, at work, and in all aspects of community life.

We were impressed with her presentation and learned a lot. They have five core services and are geared to helping in a variety of ways which include answering your questions, gaining skills to live more independently, sharing knowledge with others in similar circumstances, learning your rights and how to navigate systems, and to support the rights of others. They would also help in the use of medical equipment, either by aiding in the repair or helping recycle such equipment, or teaching a person how to use it.

We were also reminded of the cruise we have planned for Nov. 15-19, sailing from Tampa, FL. This cruise has been designed by our support group leader, Cindy Steever-Zeigler, for people with ataxia as a way for us to share our living experiences with others and have fun at the same time. It's a five-day, four-night cruise to the Western Caribbean. There is room for others so if you are interested, please feel free to contact Cindy Steever-Zeigler at *csteever@msn.com*. ❖

CFC Number

The mission of the Combined Federal Campaign (CFC) is to promote and support philanthropy by providing federal government 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.

Hope for Ataxians

Anonymous author

It's all about the journey not the destination.

When I was diagnosed with ataxia six years ago after three days of exhaustive tests, my neurologist said "I am sorry there is nothing we can do for you" and left the room without saying another word. It was almost like the pronouncement of a death sentence.

Not only was this insensitive but it was also inaccurate. Although currently there is no cure for ataxia, there is always hope that one is just around the corner or a year from now or in 10 or 20 years.

This timing may be too late for many of us but there are lots of things that ataxians can do in the meantime to make their life meaningful and hopeful.

For starters they can take satisfaction in meeting their daily challenges. It is always a new battle because the condition is always on the move, always changing, unfortunately always deteriorating.

Today I learned to lean up against the kitchen counter so I could do the dishes. Today I was successful getting out of the car and getting my walker by leaning against the outside of the car all the time. These are little things, nothing earthshaking, but it gives me hope that I can meet challenges and it gives me satisfaction when I have success.

For ataxians their many challenges are also opportunities. One success leads to the confidence of another success in the future.

But what about failure?

I fell recently. I was lucky, no broken bones, only bruises. I analyzed what happened. What could I have done differently to avoid the fall? Then I practice the improved procedure and hope I found a fix.

And what about the myriad of opportunities available for those with disabilities?

- Special cruises
- Special trips to foreign countries
- ADA buses
- Special nature trips
- Volunteering of all kinds (I teach GED math)
- Ataxians may qualify for financial benefits
- Physical therapy
- Ataxia support groups
- Scooters
- Swimming pools
- A good physical therapist
- And more

My ataxia support group is especially helpful. We share our successes and give each other hope. As I look around the group everybody is struggling, but smiling. We try not to make it a pity party. Sometimes we laugh. Like when I told about how I picked up a grape, put it in my mouth to eat it, and bit my finger because I could not coordinate withdrawal of my finger with the closing of my jaw.

It's all about the journey not the destination. ❖

Tissue Donation

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

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113 Holland Ave., Albany, NY 12208
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NAF Directory of Chapters, Support Groups and Ambassadors

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

If you or a loved one has been newly diagnosed with ataxia, please contact the NAF leader nearest you. If there is not a group in your area, we encourage you to visit our online social networks. You may also consider starting a support group in your area or becoming an NAF ambassador. If you are interested in these volunteer positions please contact Lori Shogren of the NAF staff at *lori@ataxia.org* 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.

Social Networks

NAF BULLETIN BOARD
Moderator – Atilla
ww.ataxia.org/forum/toast.asp

NAF CHAT ROOM
Moderator – Della (blondie.echat@gmail.com)
www.ataxia.org/connect/chat-rooms.aspx

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

NAF FACEBOOK CAUSES
www.causes.com/causes/368602?m=71bb3202&recruiter_id=52877151

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

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NAF Directory
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NAF Directory
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Cerebellar Non-Motor Functions: What It Means for You

Jeremy Schmahmann, MD, at Harvard Medical School has described a syndrome called the Cerebellar Cognitive Affective Syndrome. In his presentation at the Annual Membership Meeting in San Antonio he described this syndrome and shared what it means for those with ataxia. His PowerPoint presentation can be downloaded on the NAF website or an audio synchronized with the presentation material can be purchased using the order form on page 27.

The Cerebellar Cognitive Affective Syndrome

- Executive Function – Planning, set-shifting, verbal fluency, abstract reasoning, working memory
- Spatial Cognition – Visual spatial organization and memory
- Language Deficits – Agrammatism and aprosodia
- Personality Change – Blunting of affect, disinhibited and inappropriate behavior

What does this mean for you (the patient with ataxia, and family members)?

1. Understand the science
   - Cerebellum acts automatically, without us knowing about it
   - It adjusts behavior optimally, in a manner suitable to context
   - This applies to motor control (gait, balance, speech, eye movements); cognition (all forms of intellectual function); and emotional life
   - When the cerebellum is not working properly, what came naturally before, no longer does

2. Understand the problems this causes
   - The cerebellar cognitive affective syndrome includes problems with
     - executive function
     - visual spatial cognition
     - language difficulties
     - emotional dyscontrol

3. Non-motor problems that a person with ataxia may experience
   - Problems with multitasking
   - Less mental agility with planning, forming strategies, and organizing oneself
   - Mental flexibility may be affected
   - Working memory is not as sharp
   - Short term recall can be troublesome
   - Mental arithmetic, and complex concepts are challenging
   - Big picture thinking, creativity, spatial skills may be impaired
   - Depression, apathy, irritability, aggression sometimes noted
   - Emotional expression may be excessive or inappropriate

4. What you can do about it
   - Bring actions to conscious awareness: motor, cognitive, and emotional
   - Avoid multitasking
   - Simplify actions into manageable steps
   - Use aids for recall if necessary
   - Take notes, keep a diary, maintain consistency
   - Stay mentally and physically active
   - Engage in cognitively challenging and new tasks
   - Be kind to yourself
   - Get help – counseling, medications, new approaches

5. Be empowered by knowledge

   It is not "in your head," it is in your brain ❖

Calendar of Events

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

SUPPORT GROUP MEETINGS

— Saturday, April 21, 2012 —

Central NY Ataxia 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*. *www.ataxia.org/chapters/CentralNewYork/default.aspx*

Denver Area Ataxia Support Group Meeting

Time: 1 – 4 p.m.

Location: The Swedish Medical Center, 501 E. Hampden Ave., Englewood, CO 80113.

Details: We meet in Meeting room Spruce A & B. For more information contact Charlotte DePew at (720) 783-3190 or *cldepew77@comcast.net*. *www.ataxia.org/chapters/Denver/default.aspx*

Greater Cincinnati Area Ataxia Support Group Meeting

Time: 1 – 3 p.m.

Location: Groesbeck Public Library, 2994 W. Galbraith Rd., Cincinnati, OH.

Details: For more information contact Jennifer Mueller at (513) 834-7002 or *jenmu@yahoo.com*. *www.ataxia.org/chapters/JenniferM/default.aspx*

Orange County Ataxia Support Group Meeting

Time: 4 – 5 p.m.

Location: Orange Coast Memorial Medical Center, Breast Center Building, Classroom 1A (building nearest to Talbert Ave. & Foster St.), 9900 Talbert Avenue, Fountain Valley, CA 92708.

Details: For more information contact Daniel Navar at (323) 788-7751 or *danieln27@gmail.com*. *www.ataxia.org/chapters/OrangeCounty/default.aspx*

Twin Cities Ataxia Support Group Meeting

Time: 10 a.m.

Location: Langton Place located on the south side of the road on County Road D roughly four tenths of a mile east of I-35W in Roseville at 1910 W. Cty. Rd. D, Roseville, MN 55112.

Details: The Twin Cities Ataxia Support Group meets once a month. Family and friends of an afflicted individual are always welcome! We meet on the third Saturday of every month. Please join us and make new connections! For more information contact Lenore Healey Schultz at (612) 724-3784 or *cshultz.lenore@yahoo.com*. *www.ataxia.org/chapters/TwinCities/default.aspx*

— Saturday, April 28, 2012 —

Alabama Ataxia Support Group Meeting

Time: 10 a.m. – 2 p.m.

Location: Covenant Presbyterian Church, Homewood, AL.

Details: This meeting will include a luncheon. For more information contact Becky Donnelly at (205) 987-2883 or *donnelly6132b@aol.com*. *www.ataxia.org/chapters/Birmingham/default.aspx*

— Saturday, May 5, 2012 —

Central Texas Ataxia Support Group Meeting

Time: 11 a.m. – 1:30 p.m.

Location: Dell Children's Medical Center of Central TX, 4900 Mueller Blvd., Austin, TX 78723. We will meet in Central Conference Room 4E.031 A&B (located between 4N and 4C) on the 4th floor.

Details: We meet on the first Saturday of every other month. The medical center's main number is (512) 324-0000. For more information contact Linda Crawley at (512) 635-9478 or *calebsnana2@msn.com*. *www.ataxia.org/chapters/Linda/default.aspx*

West Central FL Ataxia Support Group Meeting

Time: Noon – 3 p.m.

Location: USF Morsani Center, 13330 USF Laurel Dr., Tampa, FL.

Details: For more information contact Cindy Steever-Ziegler at (239) 878-3092 or *csteever@msn.com*. *www.ataxia.org/chapters/TampaBay/default.aspx*

— Wednesday, May 9, 2012 —

Willamette Valley Ataxia Support Group Meeting

Time: 11:30 a.m. – 1 p.m.

Location: Albany General Hospital, 1046 6th Ave. SW, Albany, OR 97321.

Details: We meet on the second Wednesday of every month. For more information contact Ivy Stilwell at (541) 812-4162 or *istilwell@samhealth.org*. *www.ataxia.org/chapters/Willamette/default.aspx*

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Calendar of Events
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— Thursday, May 10, 2012 —

Tri-State Ataxia Support Group Meeting

Time: 6 – 8 p.m.

Location: Beth Israel, Phillips Ambulatory Care Center (PACC), 2nd floor, 10 Union Square, New York, NY.

Details: For more information contact Denise Mitchell at (212) 844-8711 or *markmeghan2@gmail.com*. *www.ataxia.org/chapters/Tri-State/default.aspx*

— Saturday, May 12, 2012 —

Arizona Ataxia Support Group Meeting

Time: 1:30 – 3:30 p.m.

Location: The Disability Empowerment Center, (DEC), Arizona Bridge to Independent Living (ABIL), 5025 E. Washington St., Ste. 200, Phoenix, AZ 85034.

Details: For more information contact Rita Garcia at (480) 726-3579 or *rtg22@cox.net* or Mary Fuchs at (480) 883-7633 or *Mary11115@msn.com*. *www.ataxia.org/chapters/Phoenix/default.aspx*

Los Angeles Area Ataxia Support Group Meeting

Time: 2 – 4 p.m.

Location: TBA

Details: For more information contact Sherry McLaughlin at (626) 791-1558 or *ccherilynmc@yahoo.com*.

North Texas Ataxia Support Group Meeting

Time: 10 a.m. – noon

Location: The Las Colinas Cancer Center Located at 7415 Las Colinas Blvd., Irving, TX 75039.

Details: The group meets the second Saturday of every month. The parking is free and the building is handicap accessible. We meet in the front lobby of the Las Colinas Cancer Center, it is a one story building behind the Regions Bank. There is a map on their website: *www.LasColinasCancerCenter.com*. Most of the meeting time is for sharing and asking questions about the difficulties and successes we have in our everyday life with ataxia. From time to time we do have an outside speaker address some of our concerns from the caregivers, patients and families. For additional information please contact David Henry Jr. at *cheve11e@sbcglobal.net*. Please check the group's web page for updates. *www.ataxia.org/chapters/NorthTexas/default.aspx*

— Saturday, May 19, 2012 —

Greater Atlanta Ataxia Support Group Meeting

Time: 1 – 3 p.m.

Location: Emory Center for Rehabilitation Medicine, 1441 Clifton Rd., Room 101, Atlanta, GA 30322.

Details: For more information contact Dave Zilles at (770) 399-6710 or *dzilles@earthlink.net*. *www.ataxia.org/chapters/Atlanta/default.aspx*

Twin Cities Ataxia Support Group Meeting

Time: 10 a.m.

Location: Langton Place located on the south side of the road on County Road D roughly four-tenths of a mile east of I-35W in Roseville at 1910 W. Cty. Rd. D., Roseville, MN 55112.

Details: The Twin Cities Ataxia Support Group meets once a month. Family and friends of an afflicted individual are always welcome! We meet on the third Saturday of every month. Please join us and make new connections! For more information contact Lenore Healey Schultz at (612) 724-3784 or *cshultz.lenore@yahoo.com*. *www.ataxia.org/chapters/TwinCities/default.aspx*

Sunday, May 20, 2012

Chicago Area Ataxia Support Group Meeting

Time: 1 p.m.

Location: The Good Samaritan Hospital - White Oak Room, 3815 Highland Ave, Downers Grove, IL.

Details: For more information contact Richard Carr at (847) 253-2920 or *caasg@aol.com*. *www.ataxia.org/chapters/Chicago/default.aspx*

— Saturday, May 26, 2012 —

Detroit Area Ataxia Support Group Meeting

Time: 1 – 4 p.m.

Location: Harper Hospital (Wertz Classroom 1237) Near the main entrance off of John R (3990 John R).

Details: For more information contact Tanya Tunstull at (313) 397-7858 or *tinyt48221@yahoo.com*. *www.ataxia.org/chapters/Detroit/default.aspx*

— Saturday, June 9, 2012 —

Kansas City Area Ataxia Support Group Meeting

Time: 2 – 4 p.m.

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

Details: We meet the second Saturday every other month. For more information contact Lois Goodman at (816) 257-2428 or Jim Clark at (816) 468-7260 or *clarkstone9348@sbcglobal.net*. ▸▸

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

North Texas Ataxia Support Group Meeting

Time: 10 a.m. – noon

Location: The Las Colinas Cancer Center Located at 7415 Las Colinas Blvd., Irving, TX 75039. The parking is free and the building is handicap accessible.

Details: The group meets the second Saturday of every month. For additional information please contact David Henry Jr. at *cheve11e@sbcglobal.net*. Please check the group's web page for updates. and see the May 12 listing on page 44 for more information. *www.ataxia.org/chapters/NorthTexas/default.aspx*

South FL Ataxia Support Group Meeting

Time: Noon – 3 p.m.

Location: TBA

Details: For more information contact Cindy Steever-Ziegler at (239) 878-3092 or *csteever@ msn.com*. *www.ataxia.org/chapters/TampaBay/default.aspx*

— Wednesday, June 13, 2012 —

Willamette Valley Ataxia Support Group Meeting

Time: 11:30 a.m. – 1 p.m.

Location: Albany General Hospital, 1046 6th Ave. SW, Albany, OR 97321.

Details: We meet on the second Wednesday of every month. For more information contact Ivy Stilwell at (541) 812-4162 or *istilwell@samhealth.org*. *www.ataxia.org/chapters/Willamette/default.aspx*

— Saturday, June 16, 2012 —

Central New York Ataxia Support Group Meeting

Time: 1 – 3 p.m.

Location: North Syracuse Community Center, 700 South Bay Rd., North Syracuse, NY 13212.

Details: Contact Judy Tarrants at *jtarrants@aol.com* or (315) 683-9486. *www.ataxia.org/chapters/CentralNewYork.default.aspx*

Greater Cincinnati Area Ataxia Support Group Meeting

Time: 1 – 3 p.m.

Location: Groesbeck Public Library, 2994 W. Galbraith Rd., Cincinnati, OH.

Details: For more information contact Jennifer Mueller at (513) 834-7002 or *jenmu@yahoo.com*. *www.ataxia.org/chapters/JenniferM/default.aspx*

Orange County Ataxia Support Group Meeting

Time: 4 – 5 p.m.

Location: Orange Coast Memorial Medical Center, Breast Center Building, Classroom 1A (building nearest to T.albert Ave & Foster St.), 9900 Talbert Ave., Fountain Valley, CA 92708.

Details: For more information contact Daniel Navar at (323) 788-7751 or *danieln27@gmail.com*. *www.ataxia.org/chapters/OrangeCounty/default.aspx*

Twin Cities Ataxia Support Group Meeting

Time: 10 a.m.

Location: Langton Place located on the south side of the road on County Road D roughly four-tenths of a mile east of I-35W in Roseville at 1910 W. Cty. Rd. D., Roseville, MN 55112.

Details: The Twin Cities Ataxia Support Group meets once a month. Family and friends of an afflicted individual are always welcome! We meet on the third Saturday of every month. Please join us and make new connections! For more information contact Lenore Healey Schultz at (612) 724-3784 or *cshultz.lenore@yahoo.com*. *www.ataxia.org/chapters/TwinCities/default.aspx*

INFORMATIONAL AND AWARENESS EVENTS

Friday, April 27, 2012

3rd Annual Chuck and Duck Dodgeball Tournament

Time: 4 – 8 p.m.

Location: Charlton Heights Elementary School in Ballston Lake, NY.

Details: All proceeds benefit NAF. For more information contact Andrew Haluska at *ahaluska@ bhbl.org*.

Sunday, April 29, 2012

Strike Out Ataxia Celebrity Bowling Tournament

Time: 4 – 7 p.m.

Location: Pin Chasers in Tampa, FL.

Details: Proceeds benefit NAF. Tickets include unlimited bowling, shoes, food, and drinks. *http://strikeoutataxia. eventbrite.com/*

— Thursday, May 31, 2012 —

Spacefest IV Moonwalker Invitational Charity Golf Tournament

Location: JW Marriott Starr Pass resort in Tucson, AZ.

Details: All proceeds benefit NAF. Many famous astronauts and moonwalkers will be in attendance. Be part of this historic event. Come play golf with some true pioneers and American heroes of the current age. *http://www.spacefest.info/IV.html* ❖

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 October 2011 through February 2012. 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.

Gordon & Marilyn Macklin Foundation
The Gabe & Izzy Foundation
Tim Adkins
Ray Agostini
Paul Aiello
Jennifer Alexander
Crystal Allsopp
Robert Alto
Anthony Alto, Sr.
Richard Alto, Sr.
Russell Anderson
Charles Ayres
David Ayres
Sharon Baggett
James Baldwin Family
James Bambery
Jay Bambery
Brandon Barker
Lee Barnes
Mary Barros
Maureen Bartlett-Carter
LeAnn Bartok
Barton Beck
Betty Beck
Clair Beck
Nancy Bellamy
Jerry Bender
Theodore Benson
Anna Billings
Fred Blasberg
Tina Blasberg
Joseph Botelho, Sr.
John Boudreaux
Kathy Boudreaux
Ed Boyles
Jacob Brakebill
Muriel Breland
Larry Britt
Angela Brown
David Brown
Emma Brumbach
Martin Burke
Bob Burman
Edward Burman
Jim Burman
Christian Campos
James Carr
Richard Carr
Kristine Caruso
Susan Chaffin
Eileen Channing
The Chernoff Family
Quock Chin
Richard Chin
Norbert Chubinski
JoAnn Ciecierski
Eugene Clark
Krista Clarke
Patricia Clementz
Iris Cline
The Coffey Family
Janice Cohen
Lou Coletti
Garry Cooley
Jack Cooley
Les Cooley
Lola Cooley
Roger Cooley
Rob Cotton
Nolan Cotton, Jr.
Russ Crystal
Russell Crystal
Edward Cunha
J.D. Amason
Charles Davis
Kennon Davis
Page Davis
Raffaela Deluca
Jacqueline DeVito
Paul Dolan
Fred Donnelly
Rebecca Donnelly
Denise Drake
Denise Dudley
Margaret Duggan
Andrew Egeressy
The Eustache Family
Forest Evashevski
Ruth Evashevski
Joseph Falcon
Katherine Falcon
Trinity Falk
Charlie Fisher
Dorothy Fisher
Carolyn Flynn
Kenneth Flynn
Laureen Flynn
Gabrielle Ford
Doris Forman
Willard Forman
Ann Foster
Albert Frei, Sr.
Rosemary Frick
William Fry
Jack Gallant
Gregson Gann
Bob Ganss
Jeffrey Gibson
Maria Gilbert
Ken Gilbraith
Kenneth Gilbraith
Donna Giles
Richard Goldman
Tanya Goldman
Peggy Golminas
Steve Golomski
Ann Goodspeed
Matthew Gras
Jacqueline Gray
Evelyn Green
Dick Gregory
Larsen Gregory
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Bryon Hackett
Wilbur Hackett
Betty Hall
Evelyn Hankins
James Hankins
Jim Hankins
Jimmy Hankins
Jeffrey Helman
Michael Helman
Phyllis Herriff
Alice Hicks
Ruth Hinsdale
Dewayne Hite
Phyllis Hoekstra-Meima
Arthur Hollis
Sidney Howell
Jordan Hubbard
Sydney Hubbard
Krista Humes
Howard Hunnius
Dorothy Jaber
Jane Jaffe
Larry Jaffe
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