Generations

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The National Ataxia Foundation 2006 Annual Membership Meeting

"Beacon of Light"

Boston, Massachusetts — March 17-19, 2006

The 2006 Annual Membership Meeting was hosted by our New England Ataxia Support Group and held in Quincy, MA. Thank you all for your efforts in making this meeting a success. Approximately 475 people attended the 49th conference from around the world.

Thursday, March 16, was the early adult arrival and teen group outing to the Boston Museum of Science. It was great fun by all that attended and experienced the featured Star Wars exhibit and Omni Theatre.

Friday started the general session program with many new and familiar medical professionals and researchers from across the United States. Dr. Jeremy Schmahmann (Massachusetts General Hospital) presented on a new and exciting direction for treatment of the cerebellum, Dr. Elizabeth O'Hearn (John Hopkins University School of Medicine) gave us an update on her SCA 12 research, Dr Alexander Runko (National Institute of Health) presented on his FA Research work that was partially funded by the National Ataxia Foundation and Dr. Joanna Jen (UCLA) informed us about Episodic ataxia syndromes. Friday afternoon gave attendees the opportunity to meet others by type of ataxia in smaller groups to get personal questions answered from medical professionals and share experiences with others through the Birds of a Feather Session. Moving Birds of a Feather to Friday was part of the new schedule that was implemented this year in response to past years surveys and was well received by the members.

Friday evening the local group hosted a St. Patrick's Day hors d' oeuvre and cake reception. At the reception there was a free raffle where several handmade scarves, patriotic beanie babies, lighthouse notebooks and NAF shoulder bags were awarded to the raffle winners. Thank you to those who generously donated the items for this evening's raffle. We would like to extend a special thank you to the Senior Class Barbershop Quartet for their pleasurable entertainment at this event.

Saturday began with more general session speakers starting with Dr. Stephan Pulst (Cedars-Sinai Medical Center), reviewing research being done around the world for a better understanding of ataxia. Dr. Arnulf Koeppen (VA Medical Center in Albany, NY) then explained the occurrence of ataxia

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through neuroanatomy and neuropathology followed by Dr Laura Ranum (University of Minnesota) who presented us with her discovery of SCA 5 in President Lincoln's family along with outlining the research process. Dr. John Day (University of Minnesota) and Larry Schut (CentraCare Clinic in St. Cloud, MN) followed Dr. Ranum's presentation and discussed their work with the clinical features of SCA 5. Saturday afternoon breakout and workshop sessions provided several resourceful topics such as Coping, Caregiver Coping, OT PT, Speech and Swallowing, Computer Adaptations for People with Physical Disabilities, Home for a lifetime; Universal Design and In Home Renovation, Tricks of the Trade, Planning for the Financial Future for Persons with Disabilities, Intimate Relations, Nutrition, Pilates, Genetics & Ataxia, Fundraising, and Communicating with your doctor. These topics were presented by individuals with either personal or professional experience. Thank you to all the presenters for the practical applications that were presented.

Saturday's St. Patrick's Day themed banquet was a most enjoyable experience for all that attended. Maureen Lally and family handmade the beautiful centerpieces and Veronica Pepe made and packaged the NAF chocolates at each table. Kevin Cardoso was the DJ which provided endless enjoyment to this event and the many that danced the night away. DeNiece Roach, NAF President, presented four plaques to Arnie Gruetzmacher, Earl McLaughlin, Harold Crawford and Deniece Drake-Asselin for their dedicated service on the NAF Board of Directors. The raffle was great fun and raised more then $3,000. Congratulations to the winners of the raffle. Thank you to the Quincy Marriott for their raffle prize donation of $150 valid at any Marriott hotel, Char Danielson, who handmade the beautiful afghan, and Marion Pouliot who handmade the quilt. Thank you to everyone that donated items for the silent auction and to those that participated in this event which raised approximately $4,500.

On Sunday Dr. Friedman (Brown University) started out the day's general sessions with his presentation on SCA 3, followed by Dr. Susan Perlman's (David Geffen School of Medicine at UCLA) review of Sporadic Ataxia. Lisa Demers (Boston University School of Medicine) informed us about genetic testing followed by Dr. Henry Gerwirtz (Harvard

The Boston Marriott Quincy

Medical School) who discussed the genetic mechanisms active in blood flow in FA. Dr. Chris Gomez (University of Chicago) presented work he has been doing with SCA 6 and Dr. Michael Wilensky (Greater New Orleans Area private practice) gave us practical advice during his presentation "Surviving the Storm Associated with Ataxia Syndromes." Dr. John Day gave the closing presentation of the conference with his top 10 review of what we have learned throughout the weekend.

Each day's general session was followed by a question and answer session facilitated by Dr. John Day and attended by the presenters of each day.

This was an excellent meeting! Thank you again to the outstanding job done by the New England Ataxia Support Group! ❖

2006 NAF Awarded Grants

Your research contributions are used to fund important studies that result in a better understanding of the ataxias. Some scientists are looking for additional genes, while others study identified mutated genes to understand the process by which they cause ataxia. With this understanding they can move on to develop a treatment. The following are summaries of work that you supported for 2006. We look forward to publishing the results when they become available at a later date.

Ilya Bezprozvanny, PhD

University of Texas
Southwestern Medical Center in Dallas

Deranged calcium signaling in SCA 3 neurons

Summary: Spinocerebellar ataxia type 3 (SCA3) a fatal neurodegenerative disorder

SCA3 is caused by mutation in protein ataxin-3. We discovered that mutated ataxin-3 binds to and activates the type 1 inositol (1, 4, 5) trisphosphate receptor (InsP3Rl) neuronal intracellular calcium (Ca^{2+}) release channel. In this grant I propose experiments with SCA3 mouse model aimed to determine the importance of InsP3R 1 association with mutanted ataxin-3 for SCA3 pathology.

Michael D. Herbert, PhD

The University of Mississippi
Medical Center

PolyQ proteins and pre-mRNA splicing

Summary: Studies of nuclear organization and function have revealed that the nucleus contains a myriad of dynamic, highly organized domains, territories and bodies. Various diseases are characterized by the disruption of these structures or alteration in their protein composition.

For example, most patients with the neurodegenerative disorder Spinal Muscular Atrophy have a mutation that prevents a crucial protein from localizing to a specific nuclear domain called the Cajal body (CB). In the group of polyglutamine (polyQ) neurodegenerative diseases, the mutant proteins form distinctive nuclear inclusions that may affect the function of the CB.

Current evidence implicates the CB as the site for the maturation of factors necessary for proper RNA processing. The mutant proteins that cause spinocerebellar ataxia 1 or Huntington's disease do not form nuclear inclusions which dramatically alter CB localization. In contrast, mutant ataxin-3 (which causes Machado-Joseph disease) forms inclusions that tether CBs.

We therefore hypothesize that diseases which disrupt the functional organization of the nucleus adversely affect the maturation of factors required for RNA processing. The experiments proposed in this application should greatly clarify our understanding into how polyQ diseases affect the functional organization of the nucleus.

These studies will also provide a rationale for exploring if patient samples have reduced pre-mRNA splicing. With such knowledge, we will be able to ascertain if alterations in RNA processing account for neuronal demise in both polyQ disorders as well as other neurodegenerative diseases such as Spinal Muscular Atrophy. Consequently, therapies designed to increase splicing may be beneficial to patients that suffer from these insidious diseases. ▸▸

Pawel Kermer, MD

University of Goettingen

Function of the multifunctional protein BAG1 in SCA-3 pathology

Summary: Worldwide, SCA affects some 0.9-3/100,000 individuals, of which SCA-3 is the most common dominantly inherited ataxia. Treatment of the disease is still symptomatic.

Today, neuronal degeneration in the basal ganglia, the brain stem and the cerebellum leading to physical/mental disability and death within years can not be prevented or stopped. Thus, we are in great need for therapeutic strategies aiming at blocking continuous pathology in SCA.

In the present proposal, we suggest experiments involving the neuroprotective protein BAG1, which has been characterized as multifunctional protein linking cell cycle, cell death and stress responses. With its neuroprotective activity being linked to increased levels and foldase activity of Hsp70, BAG1 is a highly interesting gene to study in the context of SCA-3 pathology.

Identification of BAG1 as neuroprotectant in SCA as well as identifying the potential underlying mechanisms could have clinical implications, since the three-dimensional structure of the BAG1/Hsp70-ATPase domain complex has been solved, and critical contact sites have been mapped for BAG1 binding and co-chaperone activity.

Thus, it is conceivable that small-molecule drugs could be identified or synthesized for neuroprotection that occupy the BAG1-binding site on the ATPase domain of Hsp70/Hsc70, acting as BAG1 mimics, and thereby enhancing Hsp70/Hsc70 function.

Arnulf H. Koeppen, MD

VA Medical Center

The pathogenesis of hereditary ataxia

Summary: Cerebellar ataxia is the aggregate result of disturbed connections between the cerebellum, the brain stem, and the spinal cord. One group of fiber connections constitutes the "cerebellar module." The participating nerve fibers form a precise triangle between the lower brain stem where the important inferior olive is located, and the Purkinje cells of the cerebellar cortex.

In turn, Purkinje cells send their impulses to a gray matter structure in the depth of the cerebellum, the dentate nucleus. This nucleus is the main way station for information that exits the cerebellum and streams towards the forebrain. However, the dentate nucleus must also report back to the inferior olivary nucleus. The triangular module is continuously active during movement. It provides surveillance and control, and a disturbance in the module causes ataxia.

In most spinocerebellar ataxias (SCA), sporadic ataxia, and Friedreich's ataxia (FRDA), at least one component of the cerebellar module is destroyed. In SCA-1, SCA-2, SCA-7, and the most common form of sporadic ataxia, multiple system atrophy (MSA), an additional problem exists in the gray matter of the pons. The pons, literally the bridge, is a bulging part of the middle brain stem. It conveys abundant impulses to the cerebellum. When its nerve cells degenerate, the patient will have olivopontocerebellar atrophy (OPCA). In SCA-3/Machado-Joseph disease (MJD) and FRDA, the disease predominantly affects the dentate nucleus.

The principal investigator seeks to apply his experience with numerous tissue samples from

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patients with ataxia to an advanced study of the disturbed cerebellar module. The focus is on connections between nerve cells. When a nerve cell dies, it can no longer receive or issue signals. It can also not provide the normal nutrients that travel up and down nerve connections. However, in SCA-6, deprived nerve fibers can seek new connections with neighboring cells and find nutrients from an alternate source.

The investigator also believes that nerve cell loss in the dentate nucleus is due to an inappropriate proliferation of terminals. This phenomenon is especially prominent in the dentate nucleus of patients with SCA- 3/MJD and FRDA. If this research shows that abnormal nerve terminals proliferate and utilize an excess of an otherwise normal transmitter substance, such as glutamic acid, currently available drugs may be beneficial.

Parvoneh Poorkaj Navas, BS, PhD

University of Washington

Genomic mouse models of spinocerebellar ataxia

Summary: Dr. Parvoneh Poorkaj Navas of the University of Washington will develop genetically altered mice that will carry a mutated protein kinase C gamma (PKC gamma) gene. Mutations in PKC gamma are responsible for SCA14, a disease in humans that is characterized by progressive incoordination of gait, often associated with poor coordination of hands, speech and eye movements.

Dr Navas' goal is to study the pathogenesis of cerebellar dysfunction and neurodegeneration throughout the life cycle to aid in the development of treatments for SCA14 and related diseases.

Punett Opal, MD, PhD

Northwestern University

Understanding Spinocerebellar Ataxia Type 1

Summary: Spinocerebellar ataxia type 1 (SCA1) is an inherited disease that causes progressive instability of gait or ataxia. Unfortunately there is no treatment for this relentless disease and those afflicted succumb to complications of cerebellar and brainstem dysfunction. This disease is caused by an expansion of a stretch of glutamines (glutamine is an amino acid) in the disease causing protein, ataxin-l.

Using SCA1 as a model system, our long-term goal is to shed light on two questions pertaining to ataxias: 1) What is the basis for degeneration in cerebellar neurons, the neurons responsible for the co-ordination of movements, and 2) What are the subcellular pathways involved in toxicity? This study addresses both of these issues in SCA l by focusing on an ataxin-l interactor, the Leucine-Rich Acidic Nuclear Protein (LANP).

Based on our preliminary results, we hypothesize that LANP plays a role in SCA1 pathogenesis by serving as a mediator of toxicity in SCA l. Indeed, we have some tantalizing preliminary evidence that reducing LANP levels might prove ameliorative in SCA l pathogenesis. This grant probes the neuronal functions of LANP with the final aim of delineating its role in SCA l pathogenesis. We believe that our experiments will help us not only to understand this disease, but also provide clues to treat this otherwise incurable disease.

Susan L. Perlman, MD

David Geffen School of Medicine at UCLA

Web Access of the National Ataxia Database and a Pilot Epidemiologic Study

Summary: The Cooperative Ataxia Group ⏩

(CAG), a consortium of 38 North American clinical investigators, have developed a standard database for the ataxic disorders, to be used for a) studies of how specific genes affect cerebellar function and cause disease, b) the identification of new causes of ataxia (genetic and non-genetic), and c) the design of treatment trials for different types of ataxia.

This database has already been computerized and will now be made accessible on the web, for direct use by all ataxia investigators.

Stefan M. Pulst, MD

Cedars-Sinai Medical Center

Mutation Analysis of the KCNC3 Voltage Gated Potassium Channel in Sporadic and Familial Ataxias

Finding new ataxia genes is still important even if a dozen have already been identified. First and foremost, any new ataxia allows expanded genetic counseling. Equally as importantly, new ataxia genes tell us something about function and dysfunction of the cerebellum.

We have identified the gene for SCA13. Quite surprisingly, SCA 13 gene turned out to be a potassium channel. These had not before been considered as being involved in neurodegeneration when mutated.

Laura P.W. Ranum, PhD

University of Minnesota

Molecular Genetic Characterization of the spinocerebellar ataxia type 5 (SCA 5)

Summary: We recently identified the SCA5 gene and currently have a manuscript under review that indicates that the SCA5 mutations affect a protein that is highly expressed in the cerebellum. SCA5 is a slowly progressive disease that usually does not shorten lifespan.

Clinical, neuroimaging and pathological data indicate that SCA5 primarily affects the cerebellum with little or no brainstem involvement, at least for adult-onset cases. Although onset typically occurs in mid-life, a broad range in the age of onset has been observed (10-68 years).

The identification of the SCA5 gene provides a more comprehensive understanding of biochemical changes leading to this group of diseases and to the interdependence of the neuronal systems affected during SCA pathogenesis.

Chih-Cheng Tsai, PhD

UMDNJ-Robert Wood Johnson Medical School

Mechanisms of ataxin-1 mediated cytotoxicity

Summary: My research focuses on ataxin-1, whose glutamine-repeat expanded form causes SCA 1. Although researchers have long thought that insoluble ataxin-1 aggregates are the main culprits for bringing about SCA 1 symptoms, this view has recently been challenged by findings that the detrimental effects of ataxin-1 begin appearing before protein aggregates form, or even when aggregates do not form at all. These observations were made in mice or in fruit flies (Drosophila) that were genetically engineered to express mutant ataxin-1. Such evidence has led many researchers to look once again for what makes mutant ataxin-1 so toxic to certain cells.

We recently found that ataxin-1 binds an important nuclear protein called SMRT (Silencing Mediator or Retinoid and Thyroid hormone receptors) in vertebrate cells; it also binds to a SMRT-related factor, called

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SMRTER, in flies. Because the main property of SMRT and SMRTER is to help other proteins, such as thyroid hormone receptor in vertebrates or ecdysone receptor in flies, to shut down the transcription of their target genes, the physical interaction we observed between ataxin-1 and SMRT/SMRTER leads us to hypothesize that mutant ataxin-1 may damage cells because of its ability to perturb nuclear receptor signaling pathways.

Because ataxin-1 can interact with SMRTER, and because Drosophila nuclear receptors, like their vertebrate counterparts, use similar methods to regulate gene expression, we propose to use fly as a model system for investigating the relationships among ataxin-1, SMRTER, and nuclear hormone receptors in living organisms. If our studies in flies show promising results, it would help us to design better parallel experiments in vertebrate cells and in live vertebrate animals (where research is much more time-consuming) to see whether the cytotoxicity caused by mutant ataxin-1 is indeed due to disrupted nuclear receptor signaling. Many of these nuclear receptors bind steroid, thyroid, or retinoid hormones; if their properties are indeed affected by mutant ataxin-1, it is possible that drugs that affect the operation of these nuclear receptors could be used to counteract the damaging effects brought about by SCA 1.

George R. Wilmot, MD, PhD
Emory University

Cooperative Ataxia Registry

Summary: This registry is designed for patients with ataxia. Ataxia is a group of rare disorders that affect movement and coordination. Because these disorders are rare, it will require a collaborative effort between scientist across North America and patients across North America to complete sound research.

This registry will serve in matching patients interested in participating in research projects with researchers looking for eligible subjects to enroll in their studies. After signing an informed consent form and an authorization to obtain medical records form, potential subjects will complete a patient information form and mail them or fax them to the registry office. After review of the data, eligibility will be determined by the principal investigator. The data will be entered by hand and stored in a secure database on a computer.

The registry will support two different types of subsequent studies. First, patient data that is stripped of all identifying information can be accessed directly by researchers who have submitted qualifying study protocols to the registry. Second, ataxia researchers can submit research protocols requiring identifying information, and if a protocol is approved by the registry principal investigator, potentially eligible patients will be mailed information on the study. The information sheet will provide a brief description of the study and a phone number to contact the study coordinator. It will be up to the patient to determine if they are interested in calling to get more information about the study. At no time will patient contact information be provided to the researcher by the registry.

One purpose of the study is to collect data and personal contact information, on an ongoing basis, about patients diagnosed with ataxia. This identifiable data will enable us to contact patients to provide information on research studies available. Another purpose will be to use this data to study the natural history of these disorders and will allow identification of the features which may be most sensitive to change, and/or interventions that may be tested in collaborative studies in the future. ▸▸

Patients enrolled in the registry will have the opportunity to enroll in future treatment protocols, if they are eligible and so desire, but will sign a different, specific, consent form for those studies at that time. After the information listed above is obtained, it will be submitted to the cooperative registry. Patients can refuse any part of the data collection they do not wish to participate in.

This research may help us to learn more about this group of rare diseases and may help to form a basis for future treatment protocols that have not been available to date.

Young Investigator Award 2005-06

Armin Alaedini, PhD
Weill Medical College of Cornell University

Immune reactivity to synapsin in the ataxia associated with gluten sensitivity

Summary: Celiac disease is a complex autoimmune disease that is triggered by ingestion of gluten in genetically susceptible individuals. It is a common disease (prevalence of 1% in United States and Europe), which is associated with multiple extra intestinal manifestations.

Cerebellar ataxia is among the most common and debilitating neurologic complications associated with gluten sensitivity. The associated ataxia has been suspected to have an autoimmune component, with gliadin playing a central role in the pathogenic mechanism. In preliminary studies, we have found that antibodies to gliadin cross-react with and bind to a major protein of the nervous system, called synapsin 1. The synapsin 1 protein has a key role in the release of neurotransmitters in the nervous system. Our hypothesis is that such cross-reactivity of anti-gliadin antibodies against the synapsin 1 molecule plays a pathogenic role and is associated with neurologic manifestations, including cerebellar ataxia.

We propose to test this hypothesis as follows: 1) To determine whether there is an association between anti-gliadin antibody cross-reactivity with synapsin 1 and presence of gluten sensitivity in ataxia patients, 2) To map the cross-reactive amino acid sequences of the synapsin 1 molecule, and 3) To determine whether the cross-reactive antibodies exhibit pathogenic characteristics that have potential for causing disease.

The proposed studies are expected to shed light on how cerebellar ataxia may be associated with gluten sensitivity. They may also serve to provide a useful antibody marker for the diagnosis of gluten sensitivity-associated cerebellar ataxia, and offer a rationale for examining the efficacy of therapies that target autoimmune mechanisms in affected patients.

Research Fellowship Award

Kerri Carlson, PhD
University of Minnesota

Tools for SCA 1 Therapeutics

Summary : Spinocerebellar ataxia-1 type 1 (SCA 1) is a neurodegenerative, genetic disorder caused by a mutation in the SCA 1 gene. The SCA 1 gene codes for the ataxin-1 protein.

Recent studies using a mouse model suggest that therapies aimed at reducing the levels of the ataxin-1 protein in cells may be effective for treating SCA1. The phosphorylation of serine 776 in the ataxin-1 protein has been linked to the stability of the ataxin-1 protein in

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the cell and has been demonstrated to be necessary for disease to occur. We propose that strategies aimed at preventing this phosphorylation event from occurring may be lead candidates for SCA 1 treatments.

The aim of this proposal is to identify both chemical and genetic factors that regulate ataxin-1 S776 phosphorylation. First, we have screened a library of small molecules to identify chemical modulators of S776 phosphorylation. We will perform follow up studies on lead chemicals that were identified as hits in our primary screen. In these studies we will study the specificity of each compound for ataxin-1 phosphorylation as well as examine both their cytotoxicity and determine the effective dose of each compound.

Next, we will use a secondary screen to validate compounds that we determine are highly specific inhibitors of ataxin-1 S776 phosphorylation with minimal cytotoxicity. This secondary screen will be performed using a cerebellar slice culture system. In this system thin slices of the cerebellum from a SCA 1 mouse will be exposed to our lead candidate compounds and maintained for varying amounts of time. We will then assess whether our candidate compounds continue to affect ataxin-1 S776 phosphorylation in our slice cultures. Using a cerebellar slice culture system will allow us to validate multiple hits in an environment that more closely resembles the mammalian cerebellum. Compounds that are validated using our cerebellar slice culture system will become lead compounds to follow up on in I experiments using animal models.

The second part of this proposal is aimed at identifying the specific proteins (called kinases) that are involved in phosphorylating ataxin-1 S776. To accomplish this aim, we will use a technique called siRNA to decrease the expression of different kinases in the cell and then monitor the levels of ataxin-1 S776 phosphorylation. Through these experiments we will identify kinases that specifically regulate ataxin-1 S776 phosphorylation. The identification of these kinases will help us to better understand SCA1 pathology. In addition, these kinases will also become novel targets for the development of a SCA 1 therapeutic.

Irene De Biase, MD, PhD

Board of Regents of the University of Oklahoma Health Sciences Center

Somatic instability in the pathogenesis and treatment of Friedreich ataxia

Summary: Friedreich ataxia is the most common inherited ataxia. It is caused when patients inherit large expansions of a GM triplet-repeat mutation from either parent. Whereas everyone who inherits these mutations develops disease, patients show a remarkable degree of variability in clinical manifestations. Even though the size of the GM triplet-repeat mutation generally determines the severity of disease, frequently individuals with the same size of repeat show very different clinical severities. Moreover, individuals who inherit mutations are usually asymptomatic until their teenage years, at which time the disease initiates, and then progresses relentlessly. Another confounding feature is that some regions of the nervous system degenerate early in the disease process compared with other regions, and some regions remain normal throughout.

The causes of the individual variability despite inheriting similar mutations, the progressive nature of disease, and the selective damage to specific regions of the nervous system remain unknown. We believe that the reason stems from the behavior of the GM triplet-repeat mutation in specific tissues and ⏩

its alteration during the aging of patients.

We have found promising preliminary evidence to support our hypothesis and would like to comprehensively address this issue by analyzing the behavior of this mutation in various tissues derived from autopsies of 10 individuals who died of Friedreich 1 ataxia. Our ultimate goal is to develop strategies to alter the behavior of this repeat sequence, slowing or preventing further expansion, in patient cells as a potential mechanism to slow the progression of disease. We propose to test various chemotherapeutic drugs in patient cells cultured in the lab in order to test their effect on altering the behavior of the GM triplet-repeat I mutation.

We believe that our studies will help to better understand why the disease is progressive, and perhaps yield clues to the development of strategies to slow the progression of disease.

Gumei Liu, PhD

University of Iowa

Disease-regulated RNA interference for Spinal Ataxia Type 1 therapy

Summary: Spinal cerebellar ataxia remains a fatal, dominant neurogenetic disease. While supportive therapies exist, the development of an effective treatment is warranted. We previously showed that attacking the fundamental problem of mutant gene expression could be one approach to therapy. To accomplish this, we used a method called ANA interference, or RNAi. RNAi refers to a process whereby target genes are inhibited from being expressed. We showed, using a mouse model of SCA 1, that reducing disease gene expression improved the motor incoordination and improved the pathology in the cerebellum, the major site of disease in this model.

In our prior work, we accomplished RNAi using a system that would have it 'on' at all times. We do not know if such a system is needed or safe for a disease that can span decades. For this reason, I propose to develop an RNAi system that turns on when the cells are sick, and off when the cells recover. We know the cells can recover to some extent because of other mouse work done by Dr. Harry Orr, U of Minn.

How to accomplish this? I propose that this can be done using inhibitory RNA which are naturally expressed in brain cells. While we don't know what these naturally occurring RNAi are doing, we do know that some of them are expressed at higher levels in SCA 1 mice brains. We will use the elements that make them be expressed upon disease onset, and off in healthier brains, to drive RNAi specific for mutant ataxin-1. This system would take advantage of the cells natural ability to turn things on and off as needed, and represents a very novel approach to SCA1 therapy.

Greg Mayeur, PhD

University of California, Davis

Late Onset Ataxia Due to a CGG Repeat Expansion in the FMR1 Gene

Summary: Fragile X-associated Tremor/Ataxia Syndrome (FXTAS) is a recently discovered ataxia associated with Fragile X Syndrome (FXS). Both FXTAS and FXS result from an expansion of the CGG repeats located in the 5' untranslated region of the fragile X mental retardation 1 gene (FMR 1). FXTAS occurs in older patients classified as premutation for CGG repeat number (55-200 repeats), whereas FXS is found in childhood patients with greater than 200 repeats (full mutation). Despite being caused by the same gene, FXTAS and FXS are caused by entirely distinct molecular mechanisms. While FXS is

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a protein deficiency disorder caused by gene silencing, FXTAS is caused by elevated expression of expanded repeat mRNA, not lowered levels of the FMR1 protein (FMRP).

FXTAS appears to affect primarily older (>50 years) male carriers of premutation alleles, although some female carriers are also affected. The major clinical features of FXTAS include gait ataxia, and progressive intention tremor, with Parkinsonism, and peripheral neuropathy being more variable symptoms. Gait ataxia begins with balance problems, particularly with tandem gait. Walking difficulties progress to the point where successive use of cane, walker, and wheelchair is required. Based on results of ataxia/tremor screening of adult premutation carriers, and a premutation carrier frequency of 1:800 for males in the general population, an estimated 1:3000 males poses a risk of developing FXTAS over their lifetime. Additionally screens of ataxia populations have identified 2-5% as carriers of the premutation alleles.

Based on the current observations we hypothesize that FXTAS is likely caused by a RNA "toxic I gain-of-function." The four main arguments that support this are: 1) The ataxia is exclusively: confined to carriers of the premutation. 2) The dysregulation of transcription in the premutation: range. 3) A CGG repeat model of FXTAS upstream of a heterogous reporter in Drosophila melanogaster exhibits similar neuropathology. 4) The FMR1 mRNA is found in intranuclear inclusions found in FXT AS patients.

To examine this hypothesis we propose two specific aims: 1) To identify trans-acting factors that interact directly with the FMR 1 CGG repeat, and the potential neurpathologies of this interaction and 2) Identify the transcriptional regulatory factors that lead to elevated FMR1 mRNA levels.

Sokal V. Todi, PhD

The University of Iowa

Generating a conditional knockout mouse to investigate the functional necessity of MJD1, the causative gene for Spinocerebellar Ataxia 3, in mammals

Spinocerebellar Ataxia 3 (SCA3), also known as Machado-Joseph Disease (MJD), is the most common dominantly inherited ataxia. SCA3/MJD arises from the expansion of a region of the protein ataxin-3 from 12-41 to over 60 repeats of the amino acid glutamate. SCA3/MJD affects nervous system areas such as the basal ganglia, brainstem, cerebellum, and the spinal cord.

Not much is known about ataxin-3 functions in an organism. Studies conducted thus far have only shed light onto ataxin-3 interactions with other proteins and some of its enzymatic properties. As a matter of fact, we do not even know if ataxin-3 is an essential protein in mammals.

Research indicates that a considerable number of genes in our genome are not functionally necessary. In this proposal, we will investigate if MJD1, the gene which produces ataxin-3, is necessary for proper functioning of mammals. We aim to generate a mouse model where MJD1 is removed from the animal's genome, to understand functional necessities of ataxin-3 in otherwise normal animals.

The information gathered will be important in answering crucial questions, such as: Is ataxin-3 functionally necessary during development or in the adult mammal?; What are some possible functions it plays in the nervous system and other organ systems?; Can therapeutic techniques, which will properly combat deleterious effects of SCA3/MJD, be successfully designed and safely implemented? ▸▸

Natascia Venture, MD, PhD
University of Rome "Tor Vergata"

Experimental Medicine and Biochemical Science

Summary: This project is intended to provide insight into the molecular pathogenesis of Friedreich's Ataxia (FRDA), the most common inherited ataxia. FRDA is caused by the defective expression of the I FXN (FRDA, X25) gene, which leads to impaired expression of the encoded protein, frataxin.

We recently generated a new powerful genetic tool to gain insight into the molecular pathogenesis of Friedreich's Ataxia (1). Lowering C.elegans frataxin homologue by RNAi, unexpectedly, increases nematode life span. In C.elegans, nevertheless, this is consistent with inactivation or reduction of other proteins involved in mitochondrial metabolism.

Worms with low level of frataxin are smaller, paler, have lower brood size and affected sensitivity to oxidative stress compare to control RNAi fed worm. Since most of the pathways so far described in C.elegans are very well conserved in humans, our provocative finding suggest new appealing function for frataxin in pathways controlling cell growth, metabolism, aging and the stress response. Different hypotheses can be formulated with the purpose of uncovering a role for frataxin in these important biological processes. In the nematode C. elegans, mutations that impact on life span belong mostly to the dauer-specifying insulin/IGF-1-like pathway and to proteins affecting mitochondrial metabolism. In both cases though, increased longevity can be ascribed to alterations in energy metabolic pathways, eventually resulting in increased resistance to stress.

Understanding how C.elegans copes, and actually lives longer, with decreased frataxin could then shed lights on specific signal transduction pathways regulated frataxin.

We propose a model in which lowering frataxin affect mitochondrial metabolism and increase free radicals production within a certain level that early in life may still induce stress response pathways and alter specific genes to maintain energy metabolism and rescue cell viability. Once beyond the threshold, free radical may induce an oxidative damage no longer tolerated from cells, which will eventually degenerate. The early induction of protective pathways would account and be sufficient to prolong C.elegans life-span. More importantly, the same pathways, activated early in life in FRDA cells, will rescue cell degeneration if supported with specific therapy before cell physiology is completely dismantled.

The general aim of this project is then to shed light on premature signal transduction pathways affected by frataxin deficiency, which might be difficult to be recognized once the pathology is established. This will suggest new specific therapeutic strategies to prevent the diseases progression. ❖

2007 will mark the 50-year anniversary of the National Ataxia Foundation.

Watch for more details about the 2007 Annual Membership meeting in Generations and on www.ataxia.org.

Don't miss this milestone event!

NAF Research Fellowship Award 2004

Final Summary

Molecular and Genetic Characterization of SCA5

By Yoshio Ikeda, MD, PhD
Postdoctoral Fellow in the Laboratory of Dr. Laura Ranum
Department of Genetics, Cell Biology and Development, University of Minnesota

SCA5 gene identified

Spinocerebellar ataxia type 5 (SCA5) is a dominantly inherited form of hereditary ataxia which primarily affects the cerebellum. Dr. Laura Ranum and colleagues began working with members of a large American ataxia family related to President Lincoln in 1992, and reported the genetic localization of this disorder on chromosome 11 in 1994. Overall, the clinical picture of SCA5 is milder than many other forms of ataxia in that patients do not develop the severe swallowing or breathing difficulties that can be found in other forms of ataxia. I began working on this project in 2003, after moving from Japan to Minnesota to work as a Postdoctoral Fellow in Dr. Laura Ranum's laboratory at the University of Minnesota. The funding I received from the National Ataxia Foundation helped to pay for my support and allowed me and others in the lab to perform a series of experiments aimed at identifying the gene responsible for SCA5. Below is a research update on our SCA5 research, which I am very pleased to say has led to the identification of a new type of ataxia gene that changes a protein called spectrin. What we found and what it means are summarized below.

What is SCA5?

SCA5 is a dominantly inherited form of ataxia, which was first described in a large American family descended from President Lincoln's grandparents. After the discovery of this family, two other families were shown to have ataxia genes that also were located in the same region containing SCA5, one from France (reported in 1999 by Drs. Brice, Dürr and Stevanin) and one from Germany (reported in 2004 by Drs. Zühlke and Bürk). In all three of these families the disease primarily affects the cerebellum, the region of the brain that controls coordination of speech and movement, but spares regions of the brainstem and the cerebrum. Although disabling, overall the clinical picture of SCA5 is milder than many other forms of ataxia because patients do not develop the severe swallowing or breathing difficulties that are often found in patients with other types of ataxia.

Collecting DNA from the Lincoln Family

Dr. Ranum started this historical and scientific journey more than a decade ago. Her personal account of working with the Lincoln family follows.

***Dr. Ranum**: In 1992 I received a phone call from a neurologist with an ataxia patient that had a strong family history of the disease. Impressed upon hearing there were at least eight affected family members, I asked if I could contact the patient directly. After talking to this woman about her family history she paused and said "but you know, you really ought to talk to my mother … I think she knows of some more cousins."* ▸▸

The SCA5 odyssey began. I called her mother, then her mother's cousins, and their cousins. A common theme of these calls was that these family members all knew that they were related to President Lincoln, but not necessarily how they were related to each other or that there was so much ataxia in the family. After obtaining a few DNA samples and ruling out the SCA1 locus, Dr. Larry Schut, a neurologist working at the University of Minnesota, and I traveled to visit the family. Family members were very proactive, wanting to find the source of what they called "Lincoln's disease," and invited us into their communities and to family reunions, where we performed neurological evaluations and collected blood samples. Eager to brag about the family connection to Lincoln and also to increase awareness of ataxia, a family member arranged for the local newspaper to do an article about our research on our second of many trips. Although at the time we didn't know that the disease went back as far as President Lincoln's grandparents, because at that time we were only working with the branch of the family descended from President Lincoln's uncle Josiah, the reporter wrote that we had traced the gene back to President Lincoln's grandfather, Captain Abraham Lincoln. Embarrassing at the time, this inaccuracy proved serendipitous and fortunate because I was soon contacted by descendents of President Lincoln's aunt Mary, who also suffer from ataxia. Dr. Schut and I went out to collect this branch of the family. Using DNA from both branches of the Lincoln family, we mapped the ataxia gene to the centromeric region of chromosome 11, a novel ataxia locus. The disease was designated spinocerebellar ataxia type 5 and the results were published in 1994 in Nature Genetics.

Although we had collected DNA from a considerable number of family members, we had very few recombinants because of the suppressed recombination near the centromere, and so our gene-rich critical region remained frustratingly large. Over the next decade, we continued to work with both branches of the Lincoln family, taking field trips almost annually – in what seemed to be an eternal search for the "key" recombinant. Dr. John Day joined the research effort in 1999, as part of an ongoing collaboration involving SCA8 and myotonic dystrophy type 2. Over the ensuing years, with many trips to examine family members and refine the clinical features of SCA5 we were able to collect and examine 299 family members, including 90 affected individuals with this slowly progressive neurodegenerative disorder.

The SCA5 gene hunt

Finding a genetic mutation that causes a disease is often compared to finding a "needle in a haystack." The first step in trying to locate a gene associated with a disease is to determine what chromosome the gene is on or in other words determine what haystack on a farm the needle is in. Every cell in our body has 46 chromosome arranged in 23 pairs. Each chromosome has on average 130,000,000 letters of the genetic code. Because the SCA5 gene had been mapped to chromosome 11 we focused our search on that chromosome and honed in on the gene by figuring out what portion of that chromosome was shared among all of the affected family members. Unfortunately, the hunt for the SCA5 gene was more difficult than expected because the DNA change that causes ataxia, is located on a segment of chromosome 11 known as a "centromeric region" – a region more difficult to examine because the DNA tends to stick together. This made our gene hunt more difficult because instead of searching for a "needle in a haystack" we were searching for a needle in a haystack that was frozen in a block of ice.

To improve our chances of finding the mutation, Katherine Dick, Marcy Weatherspoon and I compared the DNA of the French, German and American pedigrees. Through these comparisons we identified a small section of DNA from chromosome 11 that was shared

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Molecular and Genetic Characterization of SCA5 Continued from page 15

by the French and American families. This region, which contains 17 genes, was prioritized for further analysis to identify any changes in the DNA sequence, or mutations specific to the SCA5 families. We performed a technique called DNA sequencing identifies each base pair within a stretch of DNA to make sure none of the base pairs are changed, missing or added. After persistently chipping away at the problem we found a genetic change in the "SPBTN2" gene encoding a protein called β-III spectrin.

β-III spectrin mutations cause SCA5

By sequencing the β-III spectrin gene in individuals affected with SCA5 we found three distinct mutations – a different one in each of three SCA5 families. The American SCA5 mutation is a short in-frame deletion with 39 letters of the code missing. This change causes a slightly shorter spectrin protein to be made. The French SCA5 family has a different in-frame deletion mutation at the position close to the American mutation. In the German SCA5 family, a single letter of the genetic code is changed. All three of these mutations cause the β-III spectrin protein not to work right.

Mechanism leading to neurodegeneration in SCA5

β-III spectrin is a protein which is abundantly produced in the brain, especially within a specific type of neuron in the cerebellum called the Purkinje cell. We know from studying autopsy tissue of an SCA5 patient that Purkinje cells are a major type of neuron that dies in SCA5 and that the death of these neurons causes patients to lose their ability to coordinate their movements. The β-III spectrin protein was initially described by Stankewich and others in 1998 and in 2001 Dr. Jeffrey Rothstein and colleagues showed that β-III spectrin helps to anchor another protein, a glutamate transporter protein called EAAT4, into the membrane of the Purkinje cell. In collaboration with Dr. Rothstein's group from Johns Hopkins we showed that the β-III spectrin protein containing the American mutation prevents β-III spectrin from anchoring EAAT4. The failure of β-III spectrin to anchor EAAT4 within the plasma membrane disrupts the ability of cells to communicate with each other through chemical signals which over time is likely to contribute to Purkinje cell death and the symptoms of SCA5.

A further implication of our discovery is that SCA5 mutations could affect the movement of proteins within the cell by disrupting interactions between β-III spectrin and the "motor complex" responsible for moving proteins from one part of the cell to another. Disruption of the movement of proteins within cells, or "protein trafficking" appears to occur in several neurodegenerative diseases, including amyotrophic lateral sclerosis (ALS), Huntington's and Alzheimer's disease.

What does our discovery mean now and for the future?

In the short term finding the gene that causes SCA5 means that there will be a genetic test available that people at risk for the disease can take. In the long term finding the SCA5 mutation is also important because for the first time this will allow scientists to begin to figure out how this disease really works which may provide us with important clues for the development of future treatment strategies.

Did President Lincoln have ataxia?

The history of ataxia in the Lincoln family raises the question of whether President Abraham Lincoln carried the SCA5 mutation. Historical descriptions of the President suggest that he had an uneven gait – an early sign of ataxia. On March 27, 1861, William Russell wrote of Lincoln, "Soon afterwards there entered, with a shambling, loose, irregular, ▸▸

A Special Thank You

The National Ataxia Foundation would like to extend a special thank you to all the attendees, speakers, facilitators, exhibitors and the numerous volunteers of the NAF's 2006 "Beacon of Light" Annual Membership Meeting in Boston, MA.

The NAF would like to especially thank the New England Support Group for all their efforts to make this conference truly memorable. It was a pleasure working with the New England Support Group on this conference because they brought so many ideas and so much energy and commitment to making this event an uplifting experience for everyone.

The New England Area Support Group takes time to pose for a picture at the Friday night reception.

The "Beacon of Light" conference had approximately 475 attendees! 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 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.

Thank you to the Quincy Marriott in Quincy, MA for their excellent service and hospitality throughout this event.

almost unsteady gait, a tall, lank, lean man..." The identification of the SCA5 mutation makes it possible to unequivocally determine if the President Lincoln carried the mutation using artifacts containing DNA that have been preserved. In 1991, the identification of a gene responsible for Marfan's syndrome sparked debate concerning the testing of President Lincoln's DNA to determine whether his tall stature could have resulted from that disease. Unlike the question of Marfan's syndrome, the Lincoln family history clearly indicates President Lincoln was at risk of having inherited SCA5, and because the mutation in that family is now known, a specific test could definitively determine whether he carried the SCA5 mutation.

The connection to President Lincoln has provided an opportunity to increase awareness of ataxia. To our amazement, the news of our discovery quickly traveled the globe in the popular press – the connection of this family to President Lincoln is clearly of interest to the world. Last November I had a chance to attend the Neuroscience Meeting in Washington D.C. and while there to visit the Lincoln Memorial. I was deeply impressed when I looked up at the statue of President Lincoln and happy to have had a chance as a visiting scientist from Japan to participate in a gene discovery study involving the extended family members of this tremendously important United States president.

I am very excited about finding the SCA5 mutation and eager to move forward with additional studies to understand how spectrin mutations cause disease and to relate these findings to mechanisms found in other neurodegenerative diseases.

Dr. Ranum and I would like to thank the families for their participation and all of the collaborators on this paper, especially Katherine Dick, a graduate student in the Ranum lab and co-first author on this study. ❖

Jackie: A Caregiver's Story

By Ron Lombard
Shrewsbury, MA

How do you say no to a woman who had been an outstanding mother and homemaker for the last 45 years? A beautiful spirit who always put her children's needs before her own? A devoted and compassionate spouse who made the world a better place to live for her whole family? After being diagnosed with a debilitating, degenerative, and ultimately fatal illness, it finally was her turn for somebody else to take care of her.

In May 2000, my wife Jacqueline (Jackie) was diagnosed with a form of Multiple System Atrophy (MSA) called Sporadic Olivopontocerebellar Atrophy (OPCA). This disease affects one out of every 100,000 people, so it is quite rare. She was 60 years old at the time and her diagnosis came after several years of feeling "unwell." Her initial symptoms included headaches, dizzy spells, fatigue, nausea, an overwhelming feeling of depression, and occasional bruises. Various trips to the doctor had revealed little other than H. Pylori (the bacteria that can lead to ulcers) and a urinary tract infection (UTI) that had given Jackie no symptoms. These were treated successfully, but UTIs kept recurring. During this time she also started seeing a therapist and taking medication. She knew something was wrong but her doctor could find no physical reason for her health complaints, she felt it might be depression that was causing her physical symptoms.

In hindsight, there had been some warning signs many years before the ataxia was identified. It was my youngest daughter who pointed out one day that Jackie was walking as though she were very drunk (she only had one glass of wine). It is easy to see why this disease was sometimes referred to as "Drunken Sailor Syndrome." I used to joke with Jackie about her driving, until one day she drove right up on a sidewalk. Jackie voluntarily stopped driving not too long after this incident because she realized that she was endangering others as well as herself.

Trying to determine the cause of Jackie's worsening symptoms was a long, exhausting, and sometimes painful process. We made numerous visits to physicians and neurologists. Jackie endured a battery of X-rays, MRIs, brain scans, physical and psychological testing, and blood work. Jackie had so many needles stuck in her that she often said her body felt like a pincushion. One year later, after seeking another opinion from a third neurologist who specializes in movement disorders, we finally had a diagnosis. The images taken of Jackie's brain indicated that portions of her brain were shrinking.

It was very traumatic for Jackie to have endured so much testing only to find out that there is no cure for OPCA and no definitive treatment for the many different symptoms that occur during the course of the disease. Much of what we have learned has been through trial and error, and approaches to managing symptoms in an ataxia patient need to be tailored to the specific needs of each patient and his or her support network.

Jackie's symptoms started out with the inability to completely empty her bladder when urinating, Parkinson-like trembling in her arms and hands, and 50% loss of mobility to the right arm and leg (which retrograded to 80% after one year), slurring her words, and impaired eyesight. Balance was bad from day one and she would get occasional headaches (which usually could be eased with aspirin). ▸▸

Finding the right medications and supplements to help manage Jackie's symptoms has been an ongoing process of seeing what works best. Building the body's resistance and controlling tremble were goals from the start.

Year One

During the year following her diagnosis, Jackie's ability to walk declined dramatically and she started falling down without any warning. Her neurologist ordered Jackie a walker. At first she used one without wheels but it was too difficult for her to maneuver due to her shaky balance. We replaced it with one that had wheels and brakes that went on when Jackie leaned forward on the handles. This was very effective at helping prevent falls.

Measures to reduce the risk of falling included pulling up all scatter rugs and runners and installing safety grab bars throughout the house, especially in the bathroom and most importantly around the toilet and in the shower. Going up and down stairs became increasingly risky .While our house is a ranch, the laundry area was in the basement and Jackie insisted she was still able to do the wash. She navigated the stairs using the railing and strategically placed grab bars but after awhile this became too dangerous. We installed a wooden railing across the top of the basement staircase to prevent Jackie from accidentally falling down the stairs.

As walking became more and more difficult, we obtained a portable wheelchair. It was strong and stable so Jackie could safely transfer in and out of it. It was relatively light and maneuverable. She could use it all around the house. It folded to fit in the trunk of our car, and made traveling to doctors' appointments and stores much easier for Jackie to endure.

Jackie no longer felt safe in her own home due to her occasional and unpredictable falling episodes. She also was worried about something happening to her when I was outside or away from the house, so we decided to install a Lifeline. While we have only had to use this service once, it was an invaluable asset in those early months for giving Jackie and I peace of mind.

Tremors started to interfere with Jackie's ability to write and perform small motor tasks related to dressing and feeding herself. To ensure her safety while Jackie was preparing food, we filed down the points on knives. We purchased pens and tableware with large grips and plates with lips around the edges so she could pick up her food more easily. Hot drinks were put into insulated mugs with covers to prevent Jackie from spilling hot liquids on her.

Ron and Jackie Lombard in their home in Shrewsbury, MA.

Another significant problem that Jackie experienced was the inability to completely empty her bladder when she urinated. Her neurologist determined that this could be the cause of her recurring UTIs and referred her to a urologist. He recommended that Jackie begin using catheterization as means to reduce the number of UTIs she was experiencing. Both Jackie and I learned how to insert a catheter into her bladder to empty the urine.

In order to maintain muscle strength for as long as possible, Jackie rode a stationary bicycle. She started physical therapy which provided her with various strengthening exercises and tools such as squeeze balls, soft putty,

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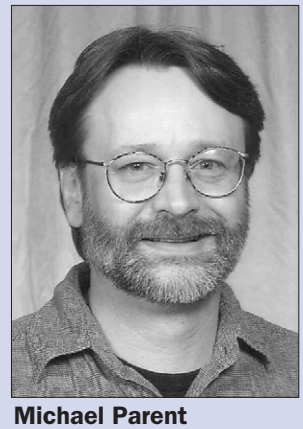
From the Desk of the Executive Director

These are very exciting times for the Foundation. Fresh off the 2006 NAF Annual Membership Meeting, plans are now underway for the 50th Annual NAF Membership Meeting in 2007. It was wonderful to see old friends and meet many new ones at the 2006 meeting, and I look forward in seeing you at the 2007 meeting.

Another exciting development is in the Foundation's acceleration of its important ataxia research efforts. Over a 12-month period, December 2004 to December 2005, the Foundation has made more than a $1,000,000 funding commitment in supporting promising worldwide ataxia research.



Michael Parent

In December 2005, for fiscal year 2006, the Foundation awarded funding to 18 vital ataxia research studies. These current studies focus on dominant ataxia (including many SCAs), recessive ataxia (including Friedreich's ataxia) and sporadic ataxia. You will find a summary of each of these studies in this issue of Generations.

The Foundation is also excited about a new publication called "Managing Speech and Swallowing, A Guidebook for Persons with Ataxia." This publication offers the reader current and invaluable information on improving and managing speech and swallowing issues. Much care and compassion was given by the author, Dr. Rangamoni, a speech pathologist, in the writing of this book and we are eternally grateful for Dr. Rangamoni's kindness in sharing her wisdom with us. To find out more about this book, please go to page 26 of this publication or page 24 to order.

The Foundation is developing a number of new ataxia fact sheets and updating other publications. In addition, as part of a comprehensive educational plan, the Foundation is developing a physician's guidebook on ataxia. This book, which is being written by Dr. Susan Perlman, will better inform general practitioners and neurologist alike about current information regarding ataxia. We are truly grateful to Dr. Perlman for again sharing her vast knowledge and insight with us. This book will be available later this year.

These efforts and others have been made possible through contributions made by you. Through your support of the annual ataxia research drive, the Foundation was able to fund many promising ataxia research studies. Through your membership support, the Foundation is able to develop and provide important programs and publications. We humbly thank you for your support and ask for your continued financial commitment to help in the important work of the Foundation.

Matching Gifts Provide Important Funding

Many companies will match your contributions made to the National Ataxia Foundation. Please ask your employer if they provide an employee matching gifts program. Also, please encourage your co-workers to support the Foundation. You and your co-workers gifts will double because of the generosity of your employer. The Foundation has seen companies match gifts up to $5,000 or more.

Each and every dollar helps significantly in providing important programs for ataxia families. Many people have taken advantage of this program and we are truly thankful to them and their employers. ❖

Jackie: A Caregiver's Story
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and exercise band to use each day. The fact that she never seriously hurt herself when she fell is due in large part, we believe, to her strength which is why exercise is so important!

Year Two

In the second year of her illness, Jackie's condition declined at a much faster rate than her family and doctors expected. Her muscles became more rigid, her tremors worsened, her eyesight diminished, and her speech became slurred. Her neurologist ordered a muscle relaxant, to calm down the trembling. In the fifth year it was moved to a higher dose per day.

She had more and more difficulty with dressing, bathing, and toileting. She required assistance getting dressed and could only do so while in bed. She needed to use a bath safety chair in the shower because she could no longer take a bath. I took over her dental care because she was no longer able to hold her electric toothbrush or floss. We placed a commode next to the bed to make toileting more convenient (especially in the middle of the night). Jackie was no longer able to get in and out of bed by herself due to the increased trembling and her right leg had become completely rigid and immobile. At first we simply removed the wheels from the bed frame so the mattress would be at a height that was easier for Jackie to reach. We also placed a bedside support rail for Jackie to grip when she was being transferred.

Jackie also began voiding less and less on her own, and we needed to increase the number of catheterizations from one to three per day to keep her comfortable. We began using waterproof bed pads that lay atop the sheets to reduce the number of linen changes needed. Increasing the number of catheterizations cut down on amount of transfers needed between bed, commode, wheelchair, and toilet, but it also increased the risk of UTIs by introducing a foreign object into the bladder. We tried medication to slow down the bladder spasms so we wouldn't have to catheterize so often. This worked well at reducing the number of catheterizations needed per day but it dehydrated Jackie. Then we were faced with the problem of softening and loosening the stool. A good rapport with our pharmacists has been very helpful because they usually have a strong knowledge of how each drug works and have given us very good feedback on regulating Jackie's needs.

Walking with the walker became ever more difficult and she started falling more and more often. She began spending a great deal of time in bed, not only to keep herself from falling but she was exhausted from the huge amount of effort required to do everything. When she was no longer able to go up and down the three steps leading in and out of the house we installed a wheelchair ramp. This was essential for preventing Jackie from becoming homebound at this relatively early stage of the disease. We were fortunate to have a friend whose family had a wheelchair ramp that they no longer used and were happy to pass on to someone else who needed one. Portable wheelchair ramps also are available, which can be useful when visiting other peoples' homes.

We acquired an electric wheelchair when Jackie was no longer strong enough to maneuver the manual wheelchair on her own. Having an electric wheelchair was a bonus that gave Jackie a small but much-needed dose of freedom because she could now go outside in the yard on her own and even take strolls around the block with me if she felt up to it.

As Jackie's need for assistance increased, I began to have some difficulty keeping up with all that needed to be done. Not only was I spending more time helping Jackie but I had taken over all of her share of the work around

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Jackie: A Caregiver's Story
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the house. My elderly mother also lives with us, and although she requires minimal care, it was yet another responsibility for me. We contacted our local senior center to see what assistance might be available to people in our situation, and they referred us to the Worcester Area Council on Aging. After reviewing our situation, they determined that we were eligible for some services such as Meals on Wheels and housekeeping. At this point, Jackie was still able to feed herself using weighted forks and spoons and adaptive bowls, plates, and cups. We also tried the housekeeping services but I eventually decided I would rather do this myself.

Another difficulty during that second year was that Jackie began having sleep disturbances. She would have very vivid dreams and nightmares, and act out physically in her sleep. Behaviors such as talking, yelling, hitting, flailing, and pinching were common. She also developed insomnia and often would go an entire night without sleeping. Her neurologist started her on medication for this which successfully alleviated these symptoms.

When she was no longer able to catheterize herself due to the severity of her tremors (she could not void more than 10% of her urine on her own at this point) I, upon her request, became her primary caregiver. We have been in the fortunate position of being able to keep Jackie at home for the entire duration of her illness because I was retired when she became ill and was willing and able to care for her. However, I cannot emphasize enough the important roles that Elder Services and Mass Health (Massachusetts' Medicaid Program) have played in facilitating Jackie's home care.

Years Three and Four

As Jackie's ataxia progressed into the third year and fourth years, she became almost completely bedridden. The only times she would leave her bed during the day were for breakfast, dinner, bathing, toileting, and occasional outings. We invested in an electric hospital bed so she could sit up comfortably and change positions whenever needed or desired. Getting a change of position is essential for someone who is immobile. The electric bed also made transferring from bed to wheelchair or commode easier for us both. I requested a trapeze for over the bed, which was very useful in helping Jackie maintain grip and upper body strength, improve her lung capacity making breathing easier and less lung rattle (and enjoy some welcome stretching). We installed a wall-mounted television stand at the foot of her bed, and placed a small television/VCR combo, a DVD player, and a five-disc CD player (all with remote controls) in the bedroom to make her space more pleasant.

In the later years it was becoming increasingly clear that if we wanted to keep Jackie at home, we were going to have to make some modifications to our house in order to care for her properly. We hired a contractor with significant experience in home remodeling for handicapped persons. Although we did not have a great deal of space to work with, we were able to add on a large handicapped bathroom with a roll-in shower, a raised toilet surrounded by grab bars on the walls, a utility sink for easy clean-up, and a laundry room. I installed a full-sized, stackable washer and dryer so laundry wouldn't have to be done in the basement. This has been a real time-saver for me. We also added a two-car garage and a wheelchair ramp that leads from the new bathroom directly into the garage. This made leaving the house much easier (especially in inclement weather). Last but not least, we built a three-season porch that Jackie also can enter from the bathroom. Before that she didn't really have any place to sit out in the yard, because it's so hard to move a wheelchair on grass. Another adaptation that has been very ⏩

helpful for taking Jackie out of the house is a handicapped-equipped van that was retrofitted for use with a wheelchair. However, we did need to upgrade Jackie's electric wheelchair in order to fit into the van's locking mechanism.

Jackie experienced major loss of physical capability during this time period. Her speech worsened dramatically, and her legs became so rigid that she experienced a complete loss of dexterity. She could no longer walk with the walker and she was not strong enough to hold on to the grab bars and hold or pull herself along. Jackie started wearing a gait belt around her waist, which is a strong, locking canvas belt that I grasped to help her move from place to place. One that automatically opens with one touch is especially useful for mealtime, because it can be loosened easily so as not to restrict breathing and then buckled back up again after eating without fumbling with the old buckle types. I continued to help Jackie walk by using the walker and gait belt to walk down the hallway to the kitchen for breakfast I believed that movement was still important). I also found Tai Chi to be very useful for me, because it gave me good balance to aid in transferring an immobile patient.

Jackie Lombard

Years Five and Six

After five years, Jackie's ataxia has been retrograding so fast that it is almost impossible to keep up with it. I thought it had reached a worst-stage scenario after two years, but then each month or two the retrograde would continue. I think all caregivers must be prepared for this decline, as we have had to complete all the legal paperwork, such as Power of Attorney, Health Care Proxy, Last Will and Testament, Do Not Resuscitate (DNR) forms, and affidavits signed by doctors, lawyers, and witnesses. As difficult as it is to know that Jackie wants no medical intervention to prolong her life, I will honor her request so as to not delay the inevitable.

Dysphasia is now a real problem. I started pureeing all of Jackie's solid food and thickening all her drinks to the consistency of honey. These measures are needed not only to make it easier for Jackie to swallow but also to stop any small pieces of food from wedging in the epiglottis or aspirating liquid, either of which might cause food to go into the lungs and cause pneumonia. I purchased a hand-held mixer for a reasonable price, which is great for pureeing soft foods and for mixing thickener into juices and coffee. I also purchased an inexpensive food processor, which is great for pureeing dinner meals and works better than a blender. Jackie's speech therapists recommended "sippy tips" to put on straws, which makes it easy to take in liquid without the straw going too far into the palate. This saves a lot of choking and doesn't allow her to draw liquid too fast.

For large vitamins, I use a simple mortar and pestle to grind them to dust. I add them to Jackie's pureed fruit, which makes it a lot easier for her to swallow. Most medications and supplements that are not time-released can be crushed. I recommend doing this whenever swallowing is a problem.

Jackie has experienced a nearly total loss of speech, and she started speech therapy during this time period. A good speech therapist is most helpful for advice regarding equipment to aid the OPCA patient in communication. Jackie's therapist introduced a little electronic panel box with four large square buttons. We can program it with words to communicate

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NAF Merchandise

BOOKS

"Ten Years to Live" *by Henry Schut*
The story of the Schut family's struggle with hereditary ataxia and the impact it had on this extended family. Paperback, photos. $8.75 (includes S&H)

"Keep A Goin'" *by Jeff and Melinda Cromwell*
Fifty stories about ataxians around the world. A portion of the proceeds goes to NAF's research program. Paperback. $13 (includes S&H)

"Living with Ataxia" *by Martha Nance, MD*
New second edition! A compassionate, easy to understand explanation and ideas on how to live with ataxia. Paperback. $14 (includes S&H)

"Healing Wounded Doctor-Patient Relationships"
by Linda Hanner and contributor John J. Witek, MD
Offers demonstrations of how effective dialog can help move patients and doctors to productive relationships. Paperback. $10 (includes S&H)

Friedreich's Ataxia Research Cookbook
Julie Karjalahti, of Savage, MN, has published this cookbook to raise money for FA research. Recipes from around the United States. $12 (includes S&H)

"Recipes and Recollections" *by Kathryn Hoefer Smith*
Full of delicious recipes and recollections. Perfect for fund raisers. Proceeds go towards FA research. Paperback. $10 (includes S&H)

Managing Speech & Swallowing Problems
by G.N. Rangamani, PdD, CCC-SLP
NEW!
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All events are wheelchair accessible.

Jackie: A Caregiver's Story
Continued from page 23

whatever Jackie needs most, such as "bathroom," "pain," "catheterize," or just "yes" or "no." A second box was added with eight squares and a remote device so Jackie does not have to reach for the buttons. We also had a book made up for Jackie that allows her to point to a square for many different subjects as well as letters to spell out words. I believe losing the ability to talk has been the most difficult part of OPCA.

Physically, Jackie is now totally bedridden except for occasional short trips to visit her neurologist, our son's family who lives close by, or the dairy for an ice cream. She has a total loss of movement in her right leg, and only five percent use of right arm. A lift was essential in order to transfer her to the bathroom for showers. We invested in a high-end wheelchair that can recline and has a tray to allow her to sit comfortably when she is not in bed. Her primary care physician now comes to the house whenever Jackie has an appointment. Her failing health prompted us to start in-home hospice this past August. We have been very impressed with the quality of the hospice staff and the compassionate care they provide to Jackie as well as their attention to other household and family members. Hospice has been invaluable for providing medications and solutions to make Jackie more comfortable and my job easier. While we were reluctant about starting hospice, our doctors advised us to bring in hospice sooner rather than later, and our experience definitely supports their recommendations.

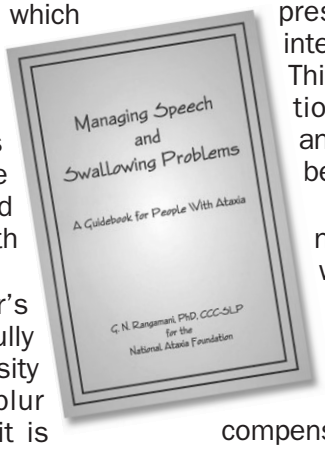
In closing our prayers and admiration reach out to all the doctors, nurses, therapists, social workers, pharmacists, caregivers and everyone else whose compassion and dedication help make life bearable for Jackie and me. We are truly grateful for all that has been done. ❖

FEATURED BOOK

Managing Speech and Swallowing Problems: A Guidebook for People with Ataxia

By G.N Rangamani, PhD, CCC-SLP

This book is intended to serve as a basic guide for understanding and managing the speech and/or swallowing changes which can occur in the person with an ataxic disorder. In no way does this information replace the directions or program set up by one's physician and/or speech language pathologist; rather it is a guide and resource to use in conjunction with one's total health care plan.



Often what one is told in a doctor's office or therapy session is not fully remembered. The stress and intensity of the situation can frequently blur the information given. Therefore, it is important to have a concise reference that provides basic facts about speech and swallowing disorders in the ataxias.

By understanding the effects of the disease, the person so afflicted and the caregivers can more confidently manage the preservation of the person's speech intelligibility level as long as possible. This guidebook also provides information regarding communication aids and how to use them if speech does become completely unintelligible.

The sense of understanding the nature of the speech problems and what to do about speech changes also holds true for knowing about, and being able to manage, the disturbances of the swallowing mechanism. The use of simple, compensating eating methods can allow a person to eat by mouth for many years.

To order, please use the Merchandise order form on page 24 or visit *www.ataxia.org*.

Making a **Difference**

On Nov. 19, 2005 the Jordan C. Hubbard Foundation made a $10,000 donation to the National Ataxia Foundation. The presentation was the fulfillment of a dream that one day, Jordan's life would make a difference.

Jordan was born Dec. 31, 1998, the first child of Jason and Sherri Hubbard. In his 18th month Jordan was diagnosed with Spinocerebellar Ataxia 7 (SCA7) and at the age of three, on March 29, 2002, he lost his battle due to complications from the disorder.

Throughout his brief time, Jordan touched the lives of many people so it was a natural decision to create a foundation in his memory; one that would continue to touch the lives of others. On Sept. 11, 2002 the Jordan C. Hubbard Foundation was established as an official 501(C) 3, tax-exempt organization. The mission of the foundation is to:

1) Bring awareness to Spinocerebellar Ataxia

2) Raise money to find a cure

3) Offset the expense of durable medical equipment for children with movement disorders.

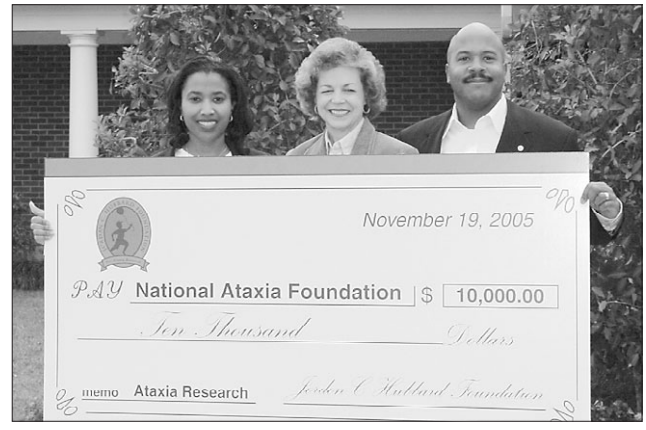
To achieve its goals, the foundation has two annual events and has formed two partnerships.

Annual Events

In September the foundation hosts two events, the Jordan C. Hubbard Bowl-A-Thon and the Jordan C. Hubbard Memorial Fun Walk. The Bowl-A-Thon serves as the primary fundraising event in addition to contributions made throughout the year, making it possible for the foundation to donate money to its partners. The Memorial Fun Walk is a free, family-oriented event that is open to the public and serves as the community outreach event in an effort to educate others about ataxia – the first part of the mission statement. Both events are held in Dallas, TX, however, the foundation is supported by people across the country.

Partnerships

The Jordan C. Hubbard Foundation (JCHF) has established a successful partnership with two organizations, the National Ataxia Foundation (NAF) and Texas Scottish Rite Hospital for Children (TSRHC). Through these organizations the JCHF can realize the remaining two elements of its mission. Joining in the fight to find a cure, the JCHF has made its first donation to the National Ataxia Foundation in the amount of $10,000.



(left to right) Sherry Hubbard, Camille Daglio and Jason Hubbard

To help offset the expense of durable medical equipment for children with movement disorders – the third and final part of the mission – the JCHF supports TSRHC. Through a past donation, the JCHF assisted a young boy by purchasing a wheelchair to provide him much needed mobility. This assistance is given to children that lack the insurance coverage and financial means to purchase adaptive medical equipment.

The Jordan C. Hubbard Foundation remains committed to its vision and it values the financial support of the many contributors that help Jordan's life continue to make a difference in the lives of others. For more information about the foundation and Jordan, please visit the official website at *www.4Jordan.org*. ❖

Generations Word Find

Please see directions and terms at right. Answers appear on **page 40**.

S	Q	P	I	W	B	V	A	E	R	T	Y	U	O	L	H	G	K	F	A
Y	E	F	O	C	U	R	N	T	V	M	G	W	N	B	X	C	Z	W	U
M	C	X	F	L	I	G	H	T	A	B	O	S	T	I	N	W	A	K	T
P	V	O	E	A	C	W	J	C	A	X	E	H	R	O	U	G	H	R	O
A	Y	L	D	H	D	O	U	B	L	E	H	E	L	I	X	F	B	E	N
T	T	M	T	O	U	I	N	Y	J	U	B	T	W	I	T	A	D	C	O
H	Z	B	P	N	N	H	G	W	I	G	E	Q	A	U	N	Z	N	O	M
E	S	O	V	A	E	A	D	E	R	S	H	I	P	K	B	E	A	M	I
T	R	A	N	S	C	R	I	P	T	I	O	N	Y	O	U	X	K	B	C
I	C	T	R	G	L	H	F	W	B	V	Q	A	Z	F	L	Y	I	I	N
C	K	O	D	O	N	S	E	G	H	P	V	T	N	W	T	O	R	N	E
N	O	M	L	E	T	I	N	T	Z	E	M	A	T	A	Z	I	C	A	R
E	U	Z	A	I	S	J	H	R	I	A	W	X	B	R	C	L	K	T	V
R	E	N	E	B	V	Y	W	Q	V	C	Q	I	X	A	T	A	F	I	O
V	C	I	E	N	C	E	E	G	E	O	N	A	G	V	M	C	Y	O	U
O	J	T	Z	M	Y	O	C	L	O	N	U	S	R	A	L	L	H	N	S
U	I	S	T	R	A	N	S	E	L	M	S	S	R	V	W	D	M	J	S
S	W	O	R	G	K	B	C	R	F	L	P	W	S	H	V	E	L	R	Y
S	H	E	L	P	W	L	O	D	S	C	O	R	E	Y	R	T	E	X	S
Y	L	L	E	J	B	R	A	I	N	W	T	S	X	E	S	L	P	F	T
S	R	E	P	E	A	T	E	T	O	P	J	L	Q	Z	D	T	J	Z	E
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E	N	E	U	R	O	T	R	A	N	S	M	I	T	T	E	R	T	M	C
M	I	R	I	S	H	L	U	C	K	R	Y	B	A	D	G	E	O	L	D
P	O	L	Y	G	L	U	T	A	M	I	N	E	D	I	S	E	A	S	E

Word Find Directions: Circle the terms defined below when you find them. The terms can be found across, down, and diagonal. The answers can be found on **page 40**.

Ataxia: Poor coordination. It can be used to refer to a neurologic symptom which can have many causes or to denote one of several degenerative diseases that cause poor coordination.

Autonomic Nervous System: A part of the peripheral nervous system responsible for regulating the activity of internal organs. It works automatically. It includes the sympathetic and parasympathetic nervous systems.

Codon: The nucleotide triplet in messenger RNA (mRNA) that specifies the amino acid that should be inserted in a specific position when forming a polypeptide.

DNA: DNA (Deoxyribonucleic acid) is the genetic material of most organisms. Two strands make up the DNA thread which winds around each other so that it resembles a twisting, turning ladder. Each strand is composed of nucleic acid, (A, C, G, and T). The shape of a DNA molecule is called a double helix.

Double Helix: Describes the coiling of the two strands of the DNA molecule, resembling a spiral staircase in which the paired bases form the steps and the sugar-phosphate backbones form the rails.

LOD Score: A number representing the likelihood that any two genetic markers are located on the same chromosome. The LOD score represents a power of the 10. A larger LOD score implies that the two genetic markers are close to one another on the same chromosome.

Myclonus: Sudden spasms of muscles.

Neurotransmitter: A chemical released by neurons at a synapse, (space between neurons) for the purpose of relaying information via receptors.

Olive: Also termed as the oliva. It is technically termed as the olivary body, a rounded mass located in the anterolateral (in front and to the sides) portion of the medulla oblongata. It consists of a convoluted sheet of gray matter enclosed by white matter.

Polyglutamine Disease: A segment of ataxic diseases where the trinucleotide repeats within a gene are not within acceptable limits of what an unaffected gene presents.

RFLP: Restriction-fragment-length polymorphism. A variation in the size of DNA segments cut by restriction enzymes, in different individuals within the same population. Molecular genetics can use many of these variations to specify locations on genetic linkage maps.

Recombination: The genetic process that occurs during conception where the formation of the offspring has a genetic make up not present in the parents. When the sperm or eggs are being made, each pair of chromosomes interlocks, and genes are swapped from one chromosome in each pair to the other.

Sympathetic Nervous System: A branch of the autonomic (self-controlling) nervous system, responsible for mobilizing the body's energy and its resources during times of stress and arousal.

Transcription: The process of forming a complementary RNA molecule upon a DNA template. It is the necessary process of the copying of information from DNA to messenger RNA (the carrier of genetic information).

NAF's Pen Pal Program

Many new National Ataxia Foundation members may not be aware of a program specifically designed for you. Many years ago, the Foundation established a Pen Pal Program for persons with ataxia to communicate and share with others.

If you would like to communicate either by e-mail or mail with persons confronting the same disease, this international directory is for you.

Many friendships have developed over the years through the Pen Pal Program. In fact, many times people who have communicated for years through this program meet their pen pal for the first time at an NAF Annual Membership Meeting. Life-long friendships develop as one learns from one another.

Sharing and caring is all part of being involved with the NAF Pen Pal Program. Please contact the NAF for a Pen Pal Program application today.

National Ataxia Foundation Membership FAQ

Who Are NAF Members?

NAF members are a diverse group of people who have an interest in ataxia. They are persons with ataxia, ataxia families, friends of ataxia families, members of the medical community, NAF board members, persons interested in ataxia, and others.

NAF members are people who show their support by making a financial commitment to the Foundation through membership. They are people like you and me who want to help make a real difference in the lives of ataxia families.

Our members come from all walks of life… young, old, rich, or poor, each giving through membership to help support important programs for ataxia families. NAF members come from around the world, as far away as Australia and as close to home as your next-door neighbor.

What Does an NAF Membership Provide?

In many respects, membership is the basic building blocks to maintain an organization and to help secure a sound future. Membership also gives a strong and united voice in issues which affects the ataxia community.

Membership allows the Foundation to publish and distribute many publications, including *Generations*. It is through membership that enables the Foundation to attend important medical conferences and ability expos to get the word out about ataxia.

It is through membership that the Foundation is able to maintain and update its web site, bring people together through annual meetings and conferences, and develop books and videos on ataxia.

Membership provides an avenue by which others view the strength of an organization. The argument that *why should the corporate world support an organization's cause if the people you serve do not support you* is a very strong argument. Membership shows others the validity of a cause and a unity of purpose.

Membership fuels program development and expansion, and supports the day-to-day operations of the Foundation. It is through membership that allows us to help people every day by providing current and accurate information with care and compassion.

As an NAF member you receive uninterrupted issues of the quarterly news publication, *Generations*. You also receive discounts in attending the annual membership meetings. Most importantly, your membership dollars give ataxia families help and hope.

How Can I Become an NAF Member?

Becoming a member of the National Ataxia Foundation has never been easier. On the back of this issue, you will find a membership application. Simply fill it out and return it with your membership payment to the NAF. ▸▸

Thank You Athena

Athena Diagnostics, Inc. is a leading provider of diagnostic testing for neurological disorders, including many of the ataxias. Athena has been a generous donor over the years in support of the National Ataxia Foundation's Annual Membership Meetings, including the 2006 NAF meeting in Boston. Thank you for your continued support in helping the National Ataxia Foundation!

For more information about Athena Diagnostics, Inc., please visit their website at *www.athenadiagnostics.com*.

In loving memory of Diane Marriott

Lemonade from Lemons

By Bob Marriott

Diane never quit! She was given extra time to be with us because she had a special purpose which wasn't fully understood until her passing. How she lived her life was heroic in the eyes of those around her. This is written in memory of a sweet lady, a wife of more than 34 years, a mother of two daughters and grandmother to five grandchildren.

Diane was diagnosed with Friedreich's ataxia at the age of 13 and she tested that at every opportunity (but the diagnoses never changed). She raised two beautiful children from a wheelchair. Those girls never knew what quitting was all about. Diane instilled in all of us strong values, hope rather than defeat and love instead of bitterness. She didn't protest on the state capital or wasn't an activist for the disabled community. Her fight was on a personal level. Diane's life was a living example of how to make the best out of every situation.

She quoted "Lemonade from Lemons" whenever circumstances seemed stacked against her. Diane's strong faith in God sustained and prospered her. She pushed through life despite the struggles with a disease that eventually left her quadriplegic, claimed her vision, speech, and hearing. Friends and family passed along her story which is still told today to people all over the world. After her passing, we received cards from people in Israel, Ireland and New Zealand (just to mention a few places).

Let this message bless you because we all have a fight to fight. Diane never purposed to have notoriety. She simply but steadfastly "fought the good fight" to make the most out of everyday. Her only defense was her attitude … "Lemonade from Lemons." ❖

There are various levels of memberships. A lifetime membership is a one-time membership payment, which entitles you to be an NAF member your entire life. There are also Individual, Household, Professional, and Patron Memberships. These categories of memberships are annual memberships and are renewed each year on the anniversary date.

There are also members who pledge monthly or quarterly to help support the important work of the Foundation throughout the year. You may also give a Gift Membership on behalf of a friend or relative.

Your membership support is important to us. If you are already a paid member of the Foundation, we sincerely thank you for your important support. If you are not yet a paid member and are a person with ataxia, an ataxia family, a friend of someone affected by ataxia, a member of the medical community, or would just like to help, please become an NAF member today. Thank you. ❖

Thank You Donna

In December of 2005, at the National Ataxia Foundation Board of Directors meeting, NAF President DeNiece Roach presented a plaque to former Executive Director Donna Gruetzmacher for over 30 years of service to the NAF.

Although Donna is retired, she still plays an active role in the Foundation, acting as adviser to *Generations* and to the committee for the NAF Annual Membership Meeting.

Donna's dedication through the years has been an inspiration to us all. Thank you for all you have done for the National Ataxia Foundation!

Caregiver's Corner

NAF has permission to reprint the following excerpts from the "The Comfort of Home" series.

Caregiving After a Stroke

Patience and Understanding is Needed

Stroke is the third leading cause of death in the U.S.

Recognizing the Signs and Symptoms of a Stroke

These signs and symptoms should be considered a life-threatening medical emergency.

- Sudden and severe headache with unknown cause (frequently stated as the worse headache ever experienced)
- Sudden vision loss or changes
- Sudden loss of balance, unsteady gait or coordination (especially when accompanied by another sign or symptom)
- Sudden confusion or trouble understanding when spoken to
- Suddenly incontinent
- Sudden trouble forming words (droopy on one side of the face)
- Sudden trouble using the correct words or repeating the same words
- Sudden numbness or weakness of the face, arm or leg (especially if on one side)
- Trouble swallowing

A person who is experiencing a stroke may not realize what is happening to them or appear to be confused by what they are feeling. Stroke victims have the best chance of survival and/or recovery if someone around them recognizes the symptoms and acts quickly by calling 911.

Every minute counts when someone is having a stroke. The longer the blood flow is cut off to the brain, the greater the damage and disability. Time is even more critical today because now there is a treatment for ischemic stroke, but it must be started within three hours of when symptoms start. Immediate treatment can not only save their life but increase their chance of recovery.

Source: The National Institute of Neurological Disorders and Stroke, National Institutes of Health (www.ninds.nih.gov or 1-800-352-9242)

Better Communication

Communication is affected by a stroke because it affects a person's ability to form sounds or speak. Here are a few tips on communicating:

- Limit distractions, turn off radio or TV
- Speak slowly. Use short direct phrases. Do not use baby talk
- Make and keep eye contact
- Get the person's attention by touching his arm (if acceptable)
- Speak in a relaxed, casual manner (avoid increasing the stress level)
- Do not speak loudly unless the individual is hard of hearing as well
- Use pictures or an alphabet board

Caregiving after a stroke:

- Don't treat them like a victim but a survivor
- Do all you can to encourage rehab
- Avoid doing for them, struggling will make them stronger eventually
- Go to therapy before rehab discharge, talk with each therapist
- Learn about the affects of a stroke – educate yourself
- Get connected – Stroke Connection Magazine
- Find a support group to learn and share ideas
- Do all that you can to prevent another stroke
- Allow the person to grieve their loss of function and independence
- Be supportive and encouraging (share ▸▸

your anger with someone else)

• Look for signs of depression (high risk of depression after stroke)

• Be patient with emotional outbursts and mood swings

• Fatigue is a common issue, build frequent rest periods into activity

Why Worry About Frequent Handwashing?

Mom Was Right – Wash Your Hands!

Because of an increase in infectious diseases and a growing resistance to antibiotics, caregivers must be aware of effective cleaning techniques and basic health practices. One of the most important germ-fighting methods is also one of the simplest. Frequent hand washing is the single most effective way to prevent spreading germs.

Stop the Spread

To minimize the chance of spreading germs always wash your hands:

• Before and after contact with the person in your care and with other people

• When you come home

• Before preparing medications, doing a procedure or preparing food

• After you go to the bathroom

• After blowing your nose or coughing

• After touching a pet

• When cleaning, work from the cleanest to the dirtiest area and always wear gloves when giving personal care.

It's Easy – Do It Right!

• If the person in your care has an infection, use a bottle-dispensed antimicrobial soap.

• Rub your hands for at least 30 seconds (about the time it takes to sing Happy Birthday slowly) to produce lots of lather. Lather up away from running water so the lather is not washed away.

• Use a nailbrush on your nails; keep your nails trimmed and free of chips.

• Wash front and back of hands, between fingers and at least two inches up your wrists.

• Rinse well under warm running water. Repeat the process.

• Dry your hands on a clean cloth or paper towel.

Handling Soiled Laundry

As a caregiver, soiled laundry is part of your life. Follow these tips to make it safe:

• Always use gloves when handling soiled laundry.

• Carry dirty linens away from your body. Use a basket.

• Never shake soiled linens. (Germs may contaminate the floor and be spread throughout the house on the soles of shoes.)

• Use a leak-proof plastic bag, tied shut, for linen that contains body fluids or waste.

• Bag soiled laundry in the same place where it is used. Don't carry it to another room.

• Wash soiled linen separately from other clothes.

• Fill the machine with hot water, add 1/4 cup bleach and detergent rinse twice, and then dry.

• Clean the washer by running it through a cycle with one-cup bleach or other disinfectant.

Remember; wash your hands before going on to another task!

Germs such as bacteria and viruses can be transmitted several different ways, especially by touching dirty hands or changing dirty diapers. Germs also spread through:

• Contaminated water and food

• Droplets released during a cough or a sneeze

• Contaminated surfaces

• A sick person's body fluids

Sterilization

If several people are sharing supplies or equipment, sterilization will cut down on the spread

Continued on page 34

Caregiver's Corner
Continued from page 33

of germs. If only one person is using the equipment, keeping it clean and simply wiping it with a cotton ball soaked in a disinfectant is adequate. Never use the microwave oven to heat a non-food item. It may catch fire or explode.

Preventing Odors

Germs need moisture, warm temperatures, oxygen, darkness, and nourishment to grow. When the germs are happy, the result can be unpleasant smells. To eliminate some strong odors try:

- Keeping all storage areas dry and disinfected.
- Leaving a half can of finely ground coffee open under the bed.
- Using a few drops of mouthwash in commodes and bedpans.
- Placing mouthwash-saturated cotton balls in a bowl in the room.
- Spraying a fine mist of a solution of white distilled vinegar mixed with a few drops of eucalyptus or peppermint essential oil.
- Saturating cotton balls with vanilla extract and placing them in containers that retain strong odors.
- If all else fails, use electrical and mechanical devices for removing odor.

Stopping Avian Flu

Frequent hand washing will help stop the spread of this potentially dangerous strain of flu.

Keep it Clean!

Once a sterile package is opened to the air, it is no longer considered sterile.

When Using a Wheelchair:

- Wear leather gloves.
- Wash your hands frequently, and in-between washings, use pre-packaged cleansing towelettes.
- Keep the wheelchair clean and free from grime buildup. ❖

SHOPPING on the WEB

What if you could shop without leaving your home, have a vast array of stores to choose from, no waiting in lines, no parking problems, no transportation issues or costs, special discounts, and for each purchase you make a donation would be made to the National Ataxia Foundation?

It might sound too good to be true, but in fact, there really **is** such a place. If you visit **www.GreaterGood.com** or **www.iGive.com**, you will be able to shop at hundreds of stores, find brand names you know and trust, and many times receive discounts. And all of this without leaving your home! There is one more advantage ... With each purchase you make, **a donation will be made** to the National Ataxia Foundation. Try these fine shopping portals and **have fun shopping**.

Quotes from the 2006 NAF Annual Membership Meeting

Great job! Thank you!

General Sessions on three days – very good.

I was very impressed with the comprehensive scope of this meeting. The planning was excellent but the depth of presentation, the medical expertise of the medical community, the willingness of the speakers to share and answer questions, and the attitude of caring and openness was extraordinary.

The change in the format were good: Q&A each day, business meeting on Saturday a.m., and General Session Speakers each day.

I was very impressed with the organization of the meeting in general and the registration process was flawless. The first-time ribbons and identification labels are so helpful.

The silent auction was fun and profitable a good time for all!

I liked the assigned seating at the banquet – allows different and new friendships to develop.

Registration – excellent.

I was very impressed with my first meeting and if funds allow, will attend another meeting.

Everyone brought his or her uplifting spirits to the conference!

Speech and Swallowing was excellent.

Very informative (Breakout Sessions).

Nutrition was excellent

Fundraising – great!

Planning for the Financial Future – excellent.

Speech and Swallowing – offered practical information.

Coping Program was very good. It was very easy to relate to the speakers. Included the audience, I liked that.

Dr. Perlman – always good info and always presents well.

Computer adaptations was informative and gave resources.

Financial Future was excellent! Thanks Arnie for sharing information that I need to take action on soon!

As a first timer I really appreciated meeting each of the individuals in the room and hearing their stories and connecting with them. I was amazed and heartened by the openness of the conversations and the willingness to address usually unspeakable subjects. This group has courage in many ways (Birds of a Feather).

DeNiece was one of the highlights of the conference for us. She took special interest and made sure we were able to meet with Dr. Pulst. Thank you DeNiece!

My mom danced at the banquet for the first time in five or six years. This was excellent.

I so much appreciate the efforts that went into organizing this weekend and that goes into running the NAF. I was great to hear about the research dollars and how they are organized and strategize.

My top three were: 1) The doctors and researchers presentations during General Sessions; 2) Dr. Day's summary of Top 10; and 3) Birds of a Feather.

My top three were: 1) Meeting other Parents; 2) Banquet and Entertainment; and 3) Getting information on the latest research.

My top three were: 1) Knowledge of speakers; 2) Wheelchair accessible aisles; and 3) Host.

My top three were: 1) Access to wealth of information; 2) Meeting people with same concerns; and 3) The different exhibitor booths so you can learn.

Letter to the Editor

by Myrtle Puckett, East Bend, NC

My name is Myrtle Puckett and I have SCA 6. I inherited ataxia from my father, however, I knew very little about this disease. My family knew something was wrong with my daddy, but we didn't talk about it.

When I turned 46 years old I had surgery. The surgery went fine but afterwards I had symptoms that could not be explained. I was having trouble with my balance, weakness in my legs, eye movements and coordination of my hands and feet. I was sent all over from doctor to doctor each saying that there was nothing wrong with me (one doctor sent me to a psychiatrist). My friends wondered why I was walking the way I did. I had no explanation to give them.

Two to three years went by without a doctor visit. I had no intention of going just to be told I was fine and there was nothing wrong with me. My daughter, who is a nurse, encouraged and convinced me to get another option. My new doctor sent me to a neurologist at Wake Forest University Baptist Medical Center. After three clinical examinations and a MRI, my neurologist thought I had ataxia. I decided to get the genetic blood test which finally gave me an answer, Spinocerebellar Ataxia Type 6 (SCA 6).

The National Ataxia Foundation was very helpful to gain information from leaflets, books and the *Generations* newsletter. In October of 2004 I had requested the Pen Pal Directory. Out of all the names listed only two people were listed with SCA 6 (myself and Kay). As fate would have it, the day I started writing to Kay I received a letter from her! It did not take long to learn we had a lot in common. We have SCA 6, are widows, breast cancer survivors, about the same age, and are both mothers and grandmothers. We also shared some of the same hobbies like gardening and just sitting outside in the sunlight.

One day Kay wrote that she had attended the 2004 NAF Annual Membership Meeting in San Diego, CA and asked if I was planning to attend the 2005 meeting in Tampa, FL. At that point it had not entered my mind but the more I thought about going the more convinced I was that it would be a good thing to do. I responded back to Kay and she made our reservations so we could room together.

Thursday, March 3, 2005 is a day I will never forget. It was a first in many ways for me. It was my first trip to Tampa, FL, my first NAF Annual Membership Meeting and the first time I met my pen pal. Meeting Kay for the first time was so much fun. We attended meetings together, ate our meals together and shared how ataxia has effected our lives and the lives of our family members. It was so encouraging to talk to someone who was going through the same experiences and who understands the feeling I was having. I found that the people I met at the NAF meeting had a positive outlook on life.

Meeting Kay was worth the trip. Learning more about ataxia from speakers and other ataxians was an added bonus. Kay and I realize that our faith in God and His love has giving us a "Ray of Hope."

We welcome your letters and comments. See the inside front cover for contact information.

Chapter and Support Group News from Around the Country

Alabama Ataxia Support Group

By Becky Donnelly

The Alabama Ataxia Support Group met in January in Birmingham with 24 members and guests present. Debra Eddins Laken of UAB spoke on and demonstrated CPR procedures. The group then enjoyed a lunch prepared by Pat Gercio and a period of fellowship together. After lunch, a business meeting was held and meetings, programs and socials were planned for the year. Afterwards, Rita and Pratt Dean, missionaries and members of our group, shared how they have continued their work and overcome the obstacles of ataxia. Pratt gave a condensed version of the story of the Trinity Sansai vase (see *www.trinityvase.com*).

Chesapeake Chapter

By Carl Lauter & Carole A. Connor

As this issue of *Generations* goes to press, our Chapter will have held its Annual Medical Meeting on February 11 at Montgomery College in Rockville, MD. Topics included some recent biochemical findings regarding neuroprotection and links to ataxia, inclusion bodies in one ataxia type, research on and clinical management of ataxic dysarthria (swallowing and voice and speech improvement), and understanding the role of emotions in coping strategies of both the afflicted and the caregiver. An open forum session was scheduled in the afternoon for questions and answers from the audience. Speakers scheduled were from the NIH, the Johns Hopkins University, the University of Maryland Dental School, and from the rich local community of independent professionals.

The chapter set up a literature information booth on behalf of NAF at the Society for Neuroscience Meeting, held at the Washington DC Convention Center November 12-16, 2005. This was an extremely large conference of research scientists, including neurologists, geneticists and biochemists, with world-wide representation. A total of 28,193 scientific members were in attendance (34,881 total attendance, including exhibitors, staff, guests and press) for the all-day seminar sessions, poster sessions, and the exhibits. This was a great chance for exposing ataxia to the scientists. Many who stopped by for information were interested in the research grants which NAF awards to researchers with qualified protocols. Having several people at the booth provides an opportunity to let one person browse the exhibits to see what others are doing in almost any field of neuroscience. We want to extend thanks to the CC-NAF volunteers who committed time and effort to staff the booth throughout the week.

Contributions to CC-NAF, and thus those transmitted to NAF, were at a record high this year, but this record comes sadly because of the loss of seven of our own chapter members who valiantly struggled against this awful disease. Thus, it has been a long and difficult year for CC-NAF. This loss of some of our most courageous and beloved members saddens us. Yet through our sadness, and from our loss, we will continue the fight to find a cure.

We wish to thank the families and friends who lost a loved one this year. Generosity shown at such a difficult time is the most heartfelt. The number and generosity of the donations alone shows just how many lives

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these people have touched and how much they will be missed.

All together, the Chapter is proud to have been able to contribute $26,180 to NAF for research and operations. We are grateful for all the generous personal contributions of many of our members, several small businesses and civic organizations, special fund-raisers, and the generous "Challenge Grant" of Marilyn and Gordon Macklin, two of our members, to help the CC-NAF maintain its activities and educational pursuits and importantly, to help fund NAF research. NAF research is so important to the goal of finding treatments and cures for the ataxias. We are pleased to announce that the Macklin "One-for-Two Challenge Grant" (wherein for every $2 contributed to CC-NAF, the Macklin Foundation contributes $1) is continued throughout 2006.

We always welcome new people from the area. For further information about the Chesapeake Chapter, please contact Carl Lauter at (301) 530-4989 or visit our website: *www.geocities.com/HotSprings/Oasis/4988/*.

Maine Ataxia Support Group

Submitted by June M. West

Below are remarks given by Nancy Dominy to the Ataxia Group of Maine on June1, 2005. Nancy was part of a panel discussion on the topic "What Is Working With Me in Dealing with Ataxia." Her comments were in response to questions asked her by the group. The Ataxia Group of Maine admires Nancy and Pat's ability to cope with any situation and their positive approach to life. They have been an inspiration to our group. We thought Nancy's comments would be helpful to all.

"My sister Pat and I were diagnosed with ataxia at the Lahey Clinic in Boston in 1980. After a detailed neurological exam and several lab tests, Pat and I were told that we had a progressive disorder referred to as 'Cerebellar Atrophy of the Holme's Type.'

For us, the biggest help since we have been diagnosed is living in an assisted-living residence where we don't have to cook or perform housework. I no longer drive. I stopped driving after a policeman pulled me over when he thought I had been drinking after my coordination had gotten worse.

With many helpful and willing friends, we go to various church activities, enjoy shopping and eating out. I love therapeutic horseback riding where wonderful volunteers help us ride.

The most important thing that we have discovered in dealing with ataxia is to be part and attend support meetings. Here we learn how to adapt to make life easier and see our friends. The most frustrating thing about having ataxia is having to use our walkers every time we move. We realize that it is better than falling so after much prayer and more patience, we keep on 'trucking along.' If something comes up that we can't handle, we call our sister Sally, who is in good health, to help us.

We have ataxia; it does not mean the end of the world. With God's help, we take one day at a time. We appreciate the National Ataxia Foundation and those organizing the national convention in Boston. They are so active that they give us the prod to do likewise."

The Greater Jacksonville Ataxia Support Group

By June McGrane

The second ataxia support group meeting for the Jacksonville and Northeast Florida area was a success. We increased our group to 19, which included those with ataxia as well as caregivers and family. We all spent a wonderful Saturday afternoon together, on January 28.

A formal meeting started things off with a speaker, Barbara Solin, a fitness and health instructor from our local YMCA, who stressed the importance of exercise. The YMCA schedules many different ⏩

Greater Jacksonville and Northeast Florida Ataxia Support Group at their Jan. 28 meeting.

activities daily, with some catering to people with disabilities. Each one of us realized we needed to start or increase some activity.

We then discussed NAF as a group, the different literature and videos available to us and the annual convention in Boston. Everyone's input was addressed and we voted on our next meeting and the "when and where's."

A social hour followed with refreshments and a chance for all to mingle. It was wonderful for us to be together and to share and enjoy each other's company.

We all scheduled the next meeting for April 8, a Saturday afternoon, same time and same place. June McGrane will continue to organize and lead the group. "If it's not broken, don't fix it." Our hope is that more people with ataxia and their caregivers and family, from Northeast Florida, will join us as we grow and strengthen our support with each other and the National Ataxia Foundation.

Los Angeles Ataxia Support Group

By Sid Luther

We gathered at the WCIL on Saturday, March 11, and watched the NAF video "Together there is Hope." We discussed meeting options for either bi-monthly or quarterly get-togethers. We voted to stay with our bi-monthly schedule with our next meeting on May 13. Darrell is going to try and arrange for a speaker.

The group discussed improving the newsletter. The new changes may include the previous months minutes, more details on WCIL (fully accessible facility with ample parking), adding a website for disabled programs, and a column for used walkers, wheelchairs or other items available. Ken is going to try to get information in the newsletter looking into a television spot.

The final announcement was that the July picnic is moving to Jim's backyard. If anyone is interested in joining the Los Angeles Support Group contact Sid Luther.

Kansas City Support Group

By Jim Clark

The Kansas City Support Group met December 4, 2005 for our annual Christmas dinner at the Northeast Library meeting room. Everyone contributed to the dinner. Good food, good conversations and a good time were had by all.

The Kansas City Support Group at their annual holiday dinner.

Our group is small with 12 members: FA, SCA 3, SCA 6 and many unknown forms of ataxia. Our door is open to any ataxia patient or any concerned person who is a friend or a family member of a person with ataxia in our area.

We meet the second Saturday of each month at the Northeast Library from 2 to 4 p.m. The meeting room is donated by the library.

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Tampa Bay Ataxia Support Group

By Charlie Kirchner

Our group was involved with Macy's Charity Shopping Event, held on October 29, as a fundraiser. Because of its success, we hope to participate again in April.

Our November meeting was two-fold. Instead of a light lunch at the beginning of the meeting, we had an all-out, sit down, Thanksgiving Dinner with everyone bringing a specified dish. In addition, we invited Cheryl Paul, MS., CCC-SLP, Clinical Instructor/Speech Pathologist at University of South Florida along with three graduate students to join us and follow up with a few remarks. This was followed by a lengthy question-and-answer session, which was most informative.

Our January meeting was devoted to discussing Athena Diagnostic and The Emory Ataxia Registry. We are attempting to have all members participate. We had about 10 members wanting to sign up. We welcomed a new member and we remind everyone that we always welcome new members. Check our web site for more information.

Our April meeting, which is our annual picnic, will be held on April 22 at Philippe Park, in Safety Harbor, from 11 a.m. to 3 p.m. ❖

Quilt for Ataxia

At the 2007 National Ataxia Foundation Annual Membership Meeting, NAF will be celebrating their 50th anniversary. This is a great accomplishment!

We are putting together a quilt to represent all of the Chapters, Support Groups, and Ambassadors. Together we have made the Foundation a success for 50 years!

Requirements: A square is 9½ x 9½ and must be 100%-cotton material.

How to make it:

1) Be creative
2) You can use fabric paints
3) Patchwork square
4) Iron-on transfer of photo of your group
5) Screen print using your computer

Resources:

1) Quilting magazines
2) Your local fabric store
3) Go to *www.quilting.com*

Due Date: The squares must be received by October 1.

Please mail to:
National Ataxia Foundation
Attn: Quilt for Ataxia
2600 Fernbrook Lane, Suite 119
Minneapolis, MN 55447

Questions: Contact Char Danielson by phone at (952) 934-0899 or e-mail *rdanie6401@aol.com*.

Word Find Answers

Here are the answers from the puzzle on page 28.

S	Q	P	I	W	B	V	A	E	R	T	Y	U	O	L	H	G	K	F	A
Y	E	F	O	C	U	R	N	T	V	M	G	W	N	B	X	C	Z	W	U
M	C	X	F	L	I	G	H	T	A	B	O	S	T	I	N	W	A	K	T
P	V	O	E	A	C	W	J	C	A	X	E	H	R	O	U	G	H	R	O
A	Y	L	D	H	D	O	U	B	L	E	H	E	L	I	X	F	B	E	N
T	T	M	T	O	U	I	N	Y	J	U	B	T	W	I	T	A	D	C	O
H	Z	B	P	N	N	H	G	W	I	G	E	Q	A	U	N	Z	N	O	M
E	S	O	V	A	E	A	D	E	R	S	H	I	P	K	B	E	A	M	I
T	R	A	N	S	C	R	I	P	T	I	O	N	Y	O	U	X	K	B	C
I	C	T	R	G	L	H	F	W	B	V	Q	A	Z	F	L	Y	I	I	N
C	K	O	D	O	N	S	E	G	H	P	V	T	N	W	T	O	R	N	E
N	O	M	L	E	T	I	N	T	Z	E	M	A	T	A	Z	I	C	A	R
E	U	Z	A	I	S	J	H	R	I	A	W	X	B	R	C	L	K	T	V
R	E	N	E	B	V	Y	W	Q	V	C	Q	I	X	A	T	A	F	I	O
V	C	I	E	N	C	E	E	G	E	O	N	A	G	V	M	C	Y	O	U
O	J	T	Z	M	Y	O	C	L	O	N	U	S	R	A	L	L	H	N	S
U	I	S	T	R	A	N	S	E	L	M	S	S	R	V	W	D	M	J	S
S	W	O	R	G	K	B	C	R	F	L	P	W	S	H	V	E	L	R	Y
S	H	E	L	P	W	L	O	D	S	C	O	R	E	Y	R	T	E	X	S
Y	L	L	E	J	B	R	A	I	N	W	T	S	X	E	S	L	P	F	T
S	R	E	P	E	A	T	E	T	O	P	J	L	Q	Z	D	T	J	Z	E
T	B	I	W	C	Y	Q	U	I	N	C	Q	A	R	R	I	E	E	E	M
E	N	E	U	R	O	T	R	A	N	S	M	I	T	T	E	R	T	M	C
M	I	R	I	S	H	L	U	C	K	R	Y	B	A	D	G	E	O	L	D
P	O	L	Y	G	L	U	T	A	M	I	N	E	D	I	S	E	A	S	E

NAF Chapters & Support Groups

This is a list of NAF chapters and support groups. The use of these names, addresses and phone numbers for any purpose other than requesting information regarding NAF or joining a chapter or support group is strictly prohibited. We encourage you to contact the chapter or group nearest you.

Chapters

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or Tim Daly, (410) 715-1241
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Web: www.geocities.com/hcasg/

(b) **Northern Virginia S.G.**
Dick Sargent, (703) 321-9143
Web: www.geocities.com/nvasg

(c) **ALLegHAny (WV, MD, PA) S.G.**
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Chapters and Support Groups
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Web: www.geocities.com/alberrtta/

Edmonton Ataxia S.G.
Jody Stuchbury
Box 4470
Barrhead, Alberta T7N 1A3
(780) 674-8874

British Columbia

Ataxia Society Vancouver, BC
Shannon Connors
275-7000 Minovu Blvd.
Richmond, B.C. V6Y 3Z5
(604) 279-7037
E-mail: info@bcataxia.org
Web: www.bcataxia.org

New Brunswick
Rose Gallant
Loch Lomond Villa Inc.
185 Loch Lomond Rd. #E5
Saint John, N.B. E2J 3S3

Ontario
South Central Ontario
Cathy Chamberlain
551 Vermilyea Rd.
Belleville, Ontario K8N 4Z5
(613) 962-9623

Korea

Keun-yong Kim
Green 304-103, Jigok, Nam-gu
Pohang, Kyungbuk, Korea
(017) 811-2382
E-mail: mosun@postech.ac.kr

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

Arnulf Koeppen, MD
Professor of Neurology
VA Medical Center
113 Holland Ave., Albany, NY 12208
Phone: 518.626.6373 Fax: 518.626.6369
E-mail: *Arnulf.Koeppen@med.va.gov*

Ambassador Listing

The following is a list of NAF Ambassadors. Ambassadors are often in areas not served by a support group or chapter. Please get to know your Ambassadors, and if you would like to become an Ambassador please contact the NAF office for an application.

Alabama

Dianne Blain Williamson
123 Leigh Ann Rd.
Hazel Green, AL 35750
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E-mail: millard@alaweb.com

Arkansas

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California

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E-mail: droopydog36@hotmail.com

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107 Barton St.
Torrington, CT 06790
(860) 489-5092

Florida

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E-mail: csugars@cox.net

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Brownsville, KY 42210
(270) 597-3854

Albin Douglas Johnson
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Louisville, KY 40272
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Michigan

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E-mail: lynnkball@aol.com

Clare and Patricia Greene
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Laingsburg, MI 48848
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Minnesota

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Rockingon, NC 28379
(910) 895-3902

Ohio

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North Canton, OH 44720
(330) 499-4060
E-mail: jkardos@juno.com

Nancy Reid
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Geneva, OH 44047-9804
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61-8-9404-7052
E-mail: moorear@westnet.com.au

Canada

Terry Greenwood
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Winnipeg, Manitoba R3K 0T8
(204) 885-3955
E-mail: tgreenwood6@shaw.ca

Prentis Clairmont
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Ottawa, Ontario K2P 2L3
(613) 239-0452
E-mail: prentman@rogers.com

NOTE: Please help us keep our listings complete and up-to-date. If you see an error, let us know!

Calendar of Events

May

6 Pennsylvania S.G. Luncheon

6 Denver Area Ataxia Support Group Meeting from 1 to 3 p.m. Potluck at the Swedish Hospital Medical Conference Center in the Spruce A/B Meeting Rooms.

13 Tampa Bay, FL S.G. Meeting from noon to 3 p.m. at the Feather Sound Community Church in Clearwater

13 Northern Texas S.G. Meeting at Las Colinas Medical Center at 10 a.m. See website for complete meeting information.

20 Orlando, FL S.G. Meeting from noon to 3 p.m. at Dr. Philips Library

21 Chicago Area S.G. Meeting from noon to 4 p.m. at the Good Samaritan Hospital White Oak Room

25 BC Ataxia Society S.G. Meeting from 7 to 9 p.m. at The Caring Place in Richmond

27 Alabama Ataxia S.G. Social Outing from 10 a.m. to 2 p.m.

June

10 Northern Texas S.G. Meeting at Las Colinas Medical Center at 10 a.m. See website for complete meeting information.

10 Pennsylvania S.G. Meeting

24 Alabama Ataxia S.G. Meeting, Luncheon and Program from 10 a.m to 2 p.m. at Covenant Presbyterian Church in Birmingham.

29 BC Ataxia Society Annual General Meeting from 6 to 10 p.m. at The Caring Place in Richmond

July

8 Northern California Ataxia S.G. Meeting

8 Northern Texas S.G. Meeting at Las Colinas Medical Center at 10 a.m. See website for complete meeting information.

8 Los Angeles Ataxia S.G. BBQ at Woodley Ave. Park

16 Chicago Area S.G. Meeting from noon to 4 p.m. at the Good Samaritan Hospital White Oak Room

July *(cont.)*

16-18 Abilities Expo-Southern California. Anaheim Covn. Center, Anaheim, CA

29 Alabama Ataxia S.G. Social Outing

August

12 Greater Atlanta S.G. Meeting

12 Northern Texas S.G. Meeting at Las Colinas Medical Center at 10 a.m. See website for complete meeting information.

18-20 Abilities Expo – Metro Detroit at the Novi Expo Center in Novi, MI

26 Alabama Ataxia S.G. Meeting, Luncheon and Breakout Sessions from 10 a.m to 2 p.m. at Covenant Presbyterian Church in Birmingham.

September

9 Tampa Bay, FL S.G. Contact Charlie Kirchner for meeting time and location.

9 Northern Texas S.G. Meeting at Las Colinas Medical Center at 10 a.m. See website for complete meeting information.

9 Pennsylvania S.G. Meeting

17 Chicago Area S.G. Meeting from noon to 4 p.m. at the Good Samaritan Hospital White Oak Room

25 Ataxia Awareness Day

Attention Chapter and Support Group Leaders

Please remember to send us your Chapter and Support Group News articles!

Your information helps others know what is happening in their area and inspires them to get involved. Don't forget to include photographs!

The deadline to get your news into the fall issue of Generation is May 26, 2006.

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 from November 2005 through February 2006. 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.

Alexander Family
M/M A. Alibrid
Maria Alioto
Jody Ames
M/M D.A. Bagwell
June Bailey
Vicki Balogh
Herman Bard
Brandon Barker
Lucile Barnett
Alva Beam
Jeannette Beaulieu
Bart Beck
Betty Beck
Clair Beck
John Berg
Audrey Billmeyer
M/M E. Birdsong
Kim Bishop
Joe Black
M/M James Black Family
George Boucher
Matthew Bouma
Muriel Breland
Jody Brennan
John Brennen
Charles Brooks
Jamie Brooks
Nancy Brooks
Dr. Willes Brown
Donald Browning Family
Joseph Burda
Edward Callis
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Richard Carr
Terry Carroll
Peter Castaneda
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Page Davis
Robert Davis
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Mary Delaurenti
Cathy Denadel
Diane Deniger
Dr. & Mrs. John Diamond
Sandy Dudzic
Richard Dunning
Diane Dusbiber
Robert Eisenhaur
Robert Emerson
Shirley Fields
Charles Fisher
Lisa Fountain
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Dr. Paul Genilo
Howard George
Bill Gill
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Jacqueline Gray
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George Happel
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Amy Keller
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Jamie Kosie
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Max Lanzendorfer
Irene Lanzendorfer
Peter Lanzendorfer
Gerald Laukhuf
Lorrie Laukhuf
Louis Lee
Stacy Leger
Johna Leidholt
Ken Leidholt
Joan Lepek
Neil Levin
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Scott Lund
Mary Lynch
M/M R. Macedonia
Gordon Macklin
Marily Macklin
David Marcy
Scott Marqua
Bradley Masserant
Bradley Masserant Family
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Maury McDonald
M/M J. McDonough
George McMillian
Russel Meek
James Meek
Kevin Meek
Reggie Melon
Harvey Millburg
Billy Miller
Dorothy Miller
Refiye Miller
Milton Miro
Garren Mizutani
Herb Moen
Minnie Molini
Eileen Monteleone
Mrs. Jack Moon
Earl Moore
Dolores Morello
Joy Morrison
Michael Nagle
Bill Nichols
Thelma Nichols
Kenneth Nicholson
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Carol Nolan
John Norton
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Patricia O'Brien
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Roseann O'Connell
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Bruce Olson Family
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Cathryne Overstreet
Laura Owens
Rhonda Pagel
Irvin Parce
Hazel Parsons
Julia Passarelli
Trent Pavelec
Tyrell Pavelec
Bryan Peterson
Greg Pettit
Marisa Pisano
Amanda Poon
Jeannie Price
David Price
Scott Quinn
Edward Reed
Patrick Reed
Allison Ridgely
Janet Riley
Mary Rizzuto
Nathan Robinson
M/M R. Rocca
Don Roemke
Ken Roemke
Walter Roemke
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Dolly Sachs
Santa Croce Family
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Nanette Santa Croce
Rev. Herbert Schaal Family
Doris Kiel-Schaal
Edith Schless
Ron Schneider
Diane Schneider
John Schooley
Nancy Schuback
Sally Shabaker
Hunter Shankle
Robert Shelquist
Donna Shelquist
Linda Simon
William Simpson
Siracusa Family
Patti Skorupka
Richard Skotske
M/M D.A. Slingerland
Doyle Smith
Michele Smith
Marvin Smith
Robin Smith
Leon Spears
Buford Speer
Abbie Spellman
Joey Staiger
Joseph Stamler
Dawn Stewart
Pearl Straub
Windy Stroschein
Larry Swier
Tifinay Talarico-Compiano
Kim Taylor
James Terry
Gerald Tremblay
Robert Trotti
Jesse Tucker
Phil Turnbull
Thomas Turnbull
Virginia Turner
Phyllis Underkoffler
M/M R. Van Horn
Jesse Vandergriff
Antoinette Varron
Donald Walker
Guy Watkins
Carolyn Watkins
Jennie Weist
Daniel Werdell
Dianne Williams
Mike Williams
Betty Williford
Jeanette Wilson
Linn Wilson
Teresa Woods
Thomas Wooten
Arthur Workley
Clarence Workley
Harry Workley
Joanne Workley
Larry Workley
Anne Wynne
Thomas Wynne ❖

Have You Written Your Will?

Most of us have not yet written a will. It is something many of us put off and do not want to think about. However, a will is really your last wishes and your last chance to let others know how you want to spend your assets once you are gone. A will is your last testament and is a testimony to you.

The Foundation has been honored over the years by individuals who have named the National Ataxia Foundation as a beneficiary of their estates. Through their kindness, the Foundation is able to support promising ataxia research and provide meaningful programs for ataxia families.

It is important for all of us to write a will and we are hopeful that you will consider the Foundation included in your list of beneficiaries.

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

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Is your address correct? Are you receiving more than one issue of *Generations*? If there are any changes that need to be made, please call NAF at (763) 553-0020. Thank you!

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

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

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

My contribution is:

❑ In Memory ❑ In Honor ❑ Gift Membership

Name _____

Occasion _____

Send Acknowledgment Card to:

Name _____

Address _____

City/State/Zip _____

From:

Name _____

Address _____

City/State/Zip _____

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Yes, I want to help fight ataxia! Enclosed is my membership donation, which enables NAF to continue to provide meaningful programs and services for ataxia families. (Gifts in US Dollars)

❑ Lifetime membership	$500 +
Annual memberships:	
❑ Patron membership	$100-$499
❑ Professional membership	$45 +
❑ Individual	$25 +
❑ Household	$45 +

❑ Addresses outside the U.S. please add $15

Your Name _____

Address _____

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PAYMENT INFORMATION

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

❑ Check. Please make payable to the National Ataxia Foundation.

Total Amount Enclosed $ _____

Credit Card: ❑ Visa ❑ Master Card

Name on Card _____

Card # _____

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