Generations

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# Ataxia Research Review

*By Harry T. Orr, PhD, NAF's Research Director*

*The following was presented at the 2009 NAF Annual Membership Meeting in Seattle, WA and edited for publication in Generations.*

Over the years we've talked about research in ataxia as consisting of three major areas. The first area being the basic science of ataxia — [including] genes and gene discoveries and using genes to understand the pathways of disease. The next area of research is called translational research and this is basically taking the information from the basic science labs and trying to utilize that information to come up with novel therapeutic approaches, in our case, therapeutic approaches for ataxia. And then finally is the area of patient and clinical based research and the gold standard here would be clinical trials – testing various therapeutic modalities for their safety and effectiveness on ataxia patients.

Last year in Las Vegas I indicated it would be important to hold us, the researchers, accountable for meeting many of these goals. And I'd like to go through what I indicated last year as some important expectations for this year's ataxia research. In the context of basic research we needed to continue to identify additional pathways towards the disease and additional ataxia genes. In translational research, we needed to come up with some novel drug targets, new approaches for ataxias, and then finally we needed to begin to expand the number of actual clinical trials, testing for various therapeutic modalities for ataxia. In many of these areas, particularly in the latter area I think we are beginning to make substantial progress in meeting some of the expectations. The concept we need to keep in mind is that we really are all one family, we're in one boat. As we move things forward in one particular area we will indeed be moving things forward for all.

I want to talk a little bit about funding of ataxia research. I think a very important effort at the National Ataxia Foundation, particularly over the last couple of years is this concept of partnership. We can't do it all by ourselves, no one entity has the resources to meet the goal that we all want, that is treatment and cure for ataxia. NAF is very proud to have partnered with FARA and particularly in relationship to the Kyle Bryant Friedreich's Ataxia Translational Research Awards. This year's ride was incredibly successful and keeps growing and again we can expect an announcement for applications for research grants towards this translational research on Friedreich's ataxia. The SCA 1, 2, 3 and 6 compound trials initiated multi-centered across the country, funding of this trial was done in partnership with the Bob Allison Ataxia Research Center in Minneapolis. So again, the willingness of these various entities to work

*Continued on page 3*

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# Table of Contents

## Annual Membership Meeting

## Research

## Articles

## Articles (cont.)

## Membership Topics

## Personal Stories & Poems

*Ataxia Research Review*
*Continued from page 1*

together, to add our resources together is, I think, a very positive statement.

The National Institutes of Health (NIH) is, from my perspective, one aspect of the federal government that works well. This is the major funder of biomedical research in the United States. This is I think where hopefully we'd like to see as many of our tax dollars go as possible. The reality over the last eight years is that the NIH budget has been flat. There have been no increases in funding since roughly 2001. As the cost of research has increased due to inflation, due to the addition of new technologies that are more expensive, the increase of funds have not been there. However, the next two years looks to be considerably better. Congress has passed what is called the "American Recovery and Reinvestment Act of 2009" and in this act is $8.2 billion in research funding for NIH over the next two years. The annual budget for NIH at the moment is roughly $26 to 30 million. So this $8.2 billion really does represent a substantial increase. That's the good news; the bad news is it's there for only two years. Hopefully, as we move through subsequent legislative periods over the next few years, there will be more political incentives and budgetary incentives to perhaps stabilize the NIH funding so that this two year boost that we're going to get will last through subsequent years.


**Dr. Harry Orr**

So how might this stimulus funding help ataxia research? There are various funding strategies being developed by different institutes at the NIH and I've highlighted one called Challenge Grants. These are $1 million grants for two years (so $500,000 in each of two years). Applications are due this April. They'll be reviewed during June and July and will be funded by the end of September of this year. This is an incredibly rapid funding cycle. Typically it takes nine months from submission of a grant to NIH to getting the news that the application will be funded. Applications can fit into 15 different categories and I've highlighted three that as a result of my efforts and efforts of colleagues of mine that I know are being used to write grant applications specifically on ataxia research: clinical research, enhancing clinical trials, and translational signs.

The Challenge Grant is really targeted towards the early detection and treatment of rare diseases. Specifically they are asking for research projects on these rare diseases that will identify targets of these rare diseases, development of models of these diseases in animals (flies, fish or mice), screening or detection of rare diseases (in human populations), development of tools for drug discovery to treat these diseases, as well as clinical trials. Clearly on the NIH front there are a couple of important messages. There is at least for the next couple of years going to be a substantial increase in funds available for research. And there are some very substantive initiatives underway that will have direct impact on moving ataxia research forward.

At the NAF in 2007 we spent a little over $840,000 on research; in 2008 this went up to over $960,000; and at this point in 2009 we've committed $484,000 to research with additional sources yet to come down the pipe. Like everything else in this current economic climate we can expect the amount of funds that NAF will have to support research this year will be less than we've had in banner years such as 2007 and 2008. This funding of $480,000-plus is the result of NAF receiving 48 applications. We were able to enlist the efforts of 28 individuals to review these

*Continued on page 4*

*Ataxia Research Review*
*Continued from page 3*

applications, and based on these reviews and the funds available we were able to fund nine applications. This funding decision was made towards the end of December of 2008 with funding beginning for these grants in the beginning of 2009. Perhaps the important message is that there are a lot of people out there looking for support for ataxia research. We have a very dedicated panel of ataxia researchers that are willing, gratis, to put in time to review these applications. And I think the particularly important point is that what comes out of this pipeline is a high level of confidence that we're funding the best science available.

I would like to close with two points: first, if you're thinking of donating and I hope you are, I fully appreciate all the economic pressures that you're under constantly now. Second, if you're thinking of being able to support ataxia research I'd like you to think of considering donating your money to the General Ataxia Research Fund. What this allows us to do is to match the dollars to the best science. Many of you, when you donate, you donate to specific diseases (SCA1 or Friedreich's ataxia, or SCA3). I fully understand the impetus for that type of donation. But on our side, we're very committed to funding the best science. And we fully believe that progress in one area is going to lift all boats. Donating to the General Research Fund gives us the greatest flexibility to match our funds with the best science. Which we will argue will give us the greatest likelihood to getting where we want to get and that is new treatments and cures for ataxias. ❖

# Episodic Ataxia Patient Registry

The episodic ataxias are characterized by attacks of clumsiness and imbalance, often triggered by factors such as stress or fatigue. Episodic ataxia type 1 is characterized by episodes of imbalance with fine twitching or rippling of muscles, which is difficult to see except in small muscles of the hand and face but is detectable by electro-myography. Episodic ataxia type 2 is characterized by episodes of slurring of speech and gait imbalance and dysfunction of eye movements. Seven types of episodic ataxia have been identified.

Because of the disease rarity, researchers often have difficulty finding enough patients to study episodic ataxia in order to understand and cure it.

The Episodic Ataxia Patient Registry was created with the purpose of providing an opportunity for individuals with this rare disorder to register themselves to receive information about studies conducted by the Clinical Investigation of Neurologic Channelopathies (CINCH), a collaborative effort of doctors, patient organizations, including the National Ataxia Foundation, and federal health agencies that want to learn more about this disease so that ultimately they can offer better treatments to patients. CINCH is part of the Rare Diseases Clinical Research Network (RDCRN).

By joining the Rare Diseases Contact Registry you can help find the cure for episodic ataxia. You will be asked to provide information about you (or your child) and how you can be contacted. The registry will use that information to contact individuals who might qualify for participation in a research study. They may also use your contact information in order to communicate treatment information and sources.

Please visit *http://rarediseasesnetwork.epi.usf.edu/cinch/index.htm* for more information and to sign up for this registry on-line. If you do not have internet access, please contact the Foundation to receive a hard copy of the Rare Diseases Contact Registry Form which can be completed and returned by postal mail. If you have questions, you may contact the National Ataxia Foundation.

# Cognition, Emotion and the Cerebellum

*By Jeremy Schmahmann, MD*

*The following was presented at the 2008 NAF Annual Membership Meeting in Las Vegas, NV and edited for publication in Generations.*

We're going to talk about a topic that is somewhat new in the ataxia world, new to doctors but not new to patients. And this is the notion of cognition, emotion and the cerebellum. Emotion we all understand what that is – what makes us feel things. Cognition is intellectual function – planning, reasoning, forming strategies, language formation, finding our way in space. That's the large understanding of what cognition entails. What I'm going to go through with you is a brief background of what it is about the cerebellum that lends itself to playing a role in cognition and emotion. I'm going to talk about the clinical phenomena that are important in this scenario, and then end off with some comments about how you can be proactive in thinking about these aspects of your everyday function in the setting of cerebellar disorders.

The cerebellum looks the same everywhere when you look at it under the microscope, but the connections of different parts of cerebellum to different parts of brain are quite importantly distinct. The part called the anterior lobe is linked up with the part of the brain that's important for movement, and the posterior lobe is linked up to part of the brain that are important for planning, reasoning, thinking, understanding, language and so on, and the middle line of the cerebellum which is called the vermus, is linked up to parts of the brain that are important for emotional processing. So there is a way for cerebellum to talk to the big brain upstairs not just in motor regions but to areas involved in cognition and emotion as well.

A different place in the cerebellum is active when one doesn't just speak words, but does a manipulation to words when one has to think of another word. For example, if I show you the picture of a chair, you have to say the word "sit" you're generating a verb for a noun so there's a language component, an intellectual process, that activates cerebellum but in a different place than the part of cerebellum involved in the actual formation of the words. There's a difference between language and speech and they activate different parts of cerebellum. The cerebellum is [also] important for love and emotional expression and certainly intensely held emotions.

When I went to the bedside and examined some of my patients who had a stroke in the cerebellum they've had some kind of problem either in the blood vessels in the neck or a problem in the heart. A piece of something flew up into the brain and caused a blockage of blood vessels and they had a stroke. This is an old-fashioned way of comparing structure in the brain to function. Those who had a stroke involving the anterior lobe in a blood vessel called the superior cerebellar artery, these people had ataxia on the same side as where the stroke took place. In-coordination of the arm and the leg, that was what one expects in the old-fashioned view of cerebellum. But when the people who had a stroke that involved not the anterior lobe but the bottom part, the posterior lobe, when I examined them their ataxia rating scale score

*Continued on page 6*

*Cognition, Emotion and the Cerebellum*
*Continued from page 5*

was negative, was normal. And they didn't have problems with movement. So what was their problem? A number of patients who have strokes or tumors taken out or trouble in the back part of cerebellum called the posterior lobe, have a change in behavior.

When you look at this in a larger context, we described a syndrome in people who have cerebellar troubles which are called the cerebellar cognitive affective syndrome. And this is a constellation, a combination of troubles that include problems with executive function, spatial cognition, language deficits and personality changes. The executive function is what we think of generally as frontal lobe function (planning, organizing, strategy formation, verbal reasoning, holding something in mind and manipulating it). And it's also very important for multi-tasking, something that people consistently report to me as an issue when they have cerebellar difficulties. Spatial cognition involves awareness of where one is in space, ability to navigate in space. I've heard more than once from someone with a true motor ataxia who would report to me that they're bumping into the wall as they try to go into another room not because they can't control their motion, but because they seem to misjudge the distance. And that's a very interesting use of turn of phrase, to report what we see as motor in-coordination but what patients may describe as an inability to put together your sense of where the world is in terms of your own body. It has a sensory component to it.

Personality change happens (in the people that we saw in the clinic) when the mid-line of cerebellum was involved and this had a remarkable pattern. There was a blunting of their expression of emotion that made people look depressed and sometimes they in fact were, but at the same time they could be actually a little dis-inhibited in their behaviors, not quite checking their behaviors in a way one would expect in normal interactions. We found a similar kind of problem in children who'd had tumors taken out of the cerebellum. In the children that we looked at, there was a constellation of difficulties of failure to organize their own thinking, verbal and visual spatial material, their planning was impaired, language was troublesome, and memory for stories was troublesome. Again, when the mid-line was involved, some of these children had a dramatic change in their behaviors. Some of them (between 15 and 30% depending on the study) stopped talking, they get what's called cerebellar mutism – it's a posterior facisyndrome, which can go on for some weeks and even beyond that after a surgery taking a tumor out of the cerebellum. And in addition to that there's a change in their behavior, they can be impulsive and irritable and quite aggressive on one hand, and on the other hand sort of happy and giggly and playful – a marked change in their behavior from one moment to the next as you're with them in the room.

We know from studies of people who have a variety of cerebellar degeneration disorders that there is a high incidence of what the group at Johns Hopkins called non-cognitive psychiatric disorders, the commonest of which was mood disorder. Depression is a major problem in people who have a variety of ataxias from the neurodegenerative disorders including the SCA's and sporadic ataxias and so on. We also know from a large body of literature now that autism, which is a common problem as you know, schizophrenia, attention deficit disorder, dyslexia, and even children who are born very pre-term when you study them with time, and you look at the brains of some of these folks who have passed on we see that there are changes in the cerebellum sometimes in conjunction with changes elsewhere. But we know that these are behaviorally defined disorders. Not ataxia, but problems in behavior in which there is a cerebellar abnormality. This relationship of cerebellum to behavior comes from both angles. ⏩

Over the last 15-20 years as people have come to spend time with us in the clinic they have reported a variety of impairments that I then looked at in a more systematic manner to see what is the nature of the affective change in the cerebellar cognitive affective syndrome? Cognition being intellect, affective being emotional expression and experience.

The symptoms together divide up into five major groups of difficulty: attentional control, emotional control, along the spectrum of autistic behaviors, psychosis spectrum, and social skill set which is actually quite a common issue. The symptoms in these categories can be divided as I've looked at them. In one category the symptoms are down or depressed; in another they're actually exaggerated or enhanced. And this is somewhat like the problem of movement control in cerebellum, the dysmetria of movement where there's an overshoot and undershoot in the movement domain. One tries to reach for something and you overshoot or you reach and you don't quite get there. The same thing seems to apply to the domains of cognition and emotion.

**Dr. Jeremy Schmahmann**

In the range of attentional control: distractibility, hyper-activity, compulsive behaviors, ritualistic behaviors, these can be problems that one experiences in some people who have cerebellar difficulties. Rumination is the opposite, getting stuck and set, staying with the same kind of thinking pattern, obsessional thoughts may be a problem in folks with cerebellar pathologies [as well as] emotional control, impulsive, dis-inhibition, sometimes in feelings being incongruence to the state of mind that you're in. This happens for example, in multiple system atrophy, probably 30 to 40 percent of patients who have cerebellar type MSA have what's called pathologic laughing and crying. Where there may be exaggerated expression of emotion even in the absence of the feeling state that goes along with that, crying or laughing when one doesn't feel sad or happy or doing it in a manner exaggerated or inappropriate to the context. There can be a sense of depression, sadness, hopelessness that goes along with this emotional control difficulty.

In the children that we've seen the autistic spectrum behaviors are really quite striking and they include just like autistic kids stereotypical behaviors head rocking and banging behaviors. They don't like sensory contact so you get this avoidant behavior and tactile defensiveness. A couple of cases I'll describe had this psychosis spectrum, illogical thought, paranoid thinking, a lack of empathy or an apathy, an inability to engage appropriately in emotional interactions. Then finally, the social skill set, where there can be difficulty in interacting with people in the playground that these children have. For example, inability to control the anger, irritability, sometimes overly territorial, overly possessive. On the other side of that, overly passive or immature, not understanding social boundaries and being too gullible and too trusting.

Where one takes all of this observation is that we hear from you, our patients, who teach us what it is that we need to understand about the cerebellum, is that the cerebellum is not involved only in motor control. Ataxia certainly is a movement disorder; it's a problem as nobody else can know better than you can. But in addition to that, it appears that different parts of the cerebellum regulate different kinds of functions. We know that the motor cerebellum is predominantly in the top part, the anterior lobe, and there's another part down at the bottom called lobial eight that also has a representation for

*Continued on page 8*

*Cognition, Emotion and the Cerebellum*
*Continued from page 7*

movement. But what are expanded massively through evolution are the lateral parts, the big posterior lateral parts of cerebellum [and] we now know from studies of imaging and anatomy, are important for higher order function. So the way that we think about this is the damage to the motor parts of cerebellum produces the dysmetria (Greek term for the in-coordination with timing) of movement, or the ataxia that you know well. The other aspect that we're learning more about as we go is that damage to the posterior lobe of the cerebellum the new part that's evolved with evolution, when that is damaged you get the dysmetria of cognition and emotion and that's the cerebellar cognitive affective syndrome. Now the reason that this seems to work and I've put this together as the dysmetria of thought theory, dysmetria again being the word we've used to describe movement in ataxia. In the same way that the cerebellum regulates all the movements that go on, rate, rhythm and the force and the accuracy of all of our movements whether it's breathing or speech or eye movements, so does it regulate the mental capacities (the way that we can think rapidly and clearly, how consistently, our capacity to think and to keep emotions in check and how appropriate are our interactions in the environment). This is the dysmetria of thought theory – that the cerebellum does. We think it optimizes behavior, it produces a behavior that is appropriate to context, and we can do it automatically without our awareness. So when you lose that, when you have to bring things to consciousness, and pay attention to what used to happen automatically without a conscious awareness but now is an issue where we need to change the way that we develop our strategies for managing that.

This results in a series of appreciations that have indications for therapy. It can be tough to say to folks who are dealing with ataxia there are emotional and cognitive problems and this is always a sensitive issue … but what it does is it empowers you to recognize that if these issues arise they are problems that are not in your head, they're in your brain. And that's the "need to know" imperative. So when you walk into your doctor's office and your doctor says "oh that's ataxia, it has nothing to do with emotion or intellectual function," you can take this information and say "I beg to differ."

One caveat here, bear in mind that some of these disorders like SCA 1 for example, would involve parts of the brain that are outside of cerebellum. So we have to be careful about how much we ascribe to the cerebellum in these particular disorders. That's why when I study this question I'm trying to focus on people who we know have problems confined to cerebellum because that then can inform our knowledge of other disorders that have cerebellum and maybe other problems as well.

So some aspects to bear in mind at the clinical level that matter for you in your daily lives – depression, anxiety and panic disorder may occur, [and] they're all treatable. There are medications for each of these symptoms and syndromes, they're not specifically for ataxia, but they're specific for quality of life improvement in problems that may be plaguing you or your family. Executive function, the planning, the organizing, the strategy formation, the multitasking that falls apart in many situations and people tell me of their stories, this is something that one can deal with [through] cognitive rehabilitation. [For example] taking one step at a time, focusing on one task at a time before moving onto the next. The multi-tasking applies as much to the motor domain as to the cognitive domain.

Memory impairment can be an issue, but this is not Alzheimer's disease. People do not forget who they are or forget what happened to them in the recent past. What the memory impairment consists of in folks who have cerebellar troubles is the ability to pull things up. The memories aren't gone, they're difficult ▸▸

to access, there is a tip-of-the-tongue phenomenon, trouble pulling things up but the information is still in there. Strategies to get around that can be helpful.

The MSA patients who kick and scream and shout in the middle of the night and throw their partners out of bed as a consequence with bruising and injury – there's a neurology behind that, they're not just being mean. That happens, and there are treatments for this, you can actually treat the REM sleep behavior disorders. This laughing and crying that can be embarrassing to MSA patients can be treated with medications.

Importantly for the children who have developmental abnormalities, or the kids who've survived tumors, or those who have onset of disease in early childhood where that affects the way the brain is developing, we need to recognize that the developmental and language delays need to be managed actively with physical therapy, occupational therapy, rehabilitation services, working with the school counselors addressing these issue head-on. And all the other aspects of autism spectrum disorders, psychosis spectrum disorders there have not yet been any studies that clearly identify which medications for which patients, for which symptoms. I think that having recognized this as an issue, you'll be able to move forward and come up with answers to these questions.

So recognizing the problem is a need to know imperative. We can bring actions to conscious awareness to try to minimize the difficulties that you're having. Use medications that are appropriate to each of the symptoms, and then consider sometimes the physical rehabilitation that you're engaged in may be helpful not only for the motor control but for its overflow affect on the rest of our mood and our general well-being. ❖

# TISSUE DONATION

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

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# CFC Number

The National Ataxia Foundation's Combined Federal Campaign (CFC) number is 10752. This program provides a convenient way to donate to the Foundation, and provides great benefit to those with ataxia.

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

# GoodSearch

Did you know that using GoodSearch for Internet searches provides donations to the National Ataxia Foundation? GoodSearch recently added online shopping to their site, with a donation made to the Foundation with every purchase.

Visit *www.goodsearch.com* today to see how easy it is to start making a difference.

# EMERGENCY EVACUATION GUIDE

According to the National Fire Protection Association (NFPA) publication *Emergency Evacuation Planning Guide for People with Disabilities*, "All people, regardless of circumstances, have some obligation to be prepared to take action during an emergency and to assume responsibility for their own safety."

The NFPA recommends that you use the following guidelines to help prepare for an emergency:

## CREATE A HOME PLAN

☐ You're on your own (YOYO).

☐ Meet with household members, neighbors or personal care assistant to discuss what would happen in an emergency.

☐ Remember, when creating a plan for an emergency, close proximity is important.

☐ Discuss different types of emergencies:

- Tornado
- Pandemic
- Flood
- Chemical spill

☐ Determine what you will need to do to respond to each type of emergency:

☐ Will you shelter in place or will you evacuate?

☐ Shelter in place – do you have enough water, food, medical supplies, Personal Care Attendant (PCA) support?

☐ Evacuation – do you have a transportation source, is the evacuation site accessible, do you have enough medical supplies, PCA support?

## CHECKLIST

☐ Post emergency telephone numbers where you can find them, near the telephone or programmed into your cell phone.

☐ Teach children and others in the household what to do, who to call and when.

☐ Listen to a battery or crank-operated radio for emergency information.

☐ Know where the flashlights are located.

☐ Know where the first-aid kit is located.

☐ Arrange for a relative, friend or neighbor to check on you in an emergency.

☐ Teach those who may need to assist you in an emergency on what to do:

- The best way to notify you of an emergency if you are deaf or hard of hearing
- How to assist with a transfer
- How to do a blood pressure check
- How to assist with an insulin injection
- How to operate necessary equipment, etc.

☐ Keep family records, medical records or other important documents in watertight, fireproof containers.

☐ Consider getting a medical alert system that will allow you to call for help if you are immobilized in an emergency.

☐ Consider getting a medical ID bracelet or medical dog tags that state your medical condition.

☐ Try to identify a second exit, in case the primary exit is blocked. At a minimum, have some ideas on how you would evacuate in this situation.

☐ **Consider your transportation options; do you have access to a vehicle?**

☐ Do you have a network of friends, family or neighbors that would be able to provide transportation in an emergency?

☐ Does your transportation provider have resources available during an emergency?

☐ Pick one out-of-state friend and one

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local friend or relative for family members to call if separated by disaster.

☐ Pick two meeting places:

- A place near your home in case of a fire.
- A place outside your neighborhood in case you cannot return home after a disaster.

☐ Learn how to turn off the water, gas and electricity at main valves or switches.

☐ Know how to connect or start a back-up power supply if needed.

☐ PLAN AND PRACTICE HOW TO ESCAPE FROM YOUR HOME IN AN EMERGENCY.

☐ If you live in an apartment, ask the management to identify and mark accessible exits.

☐ **Plan and practice.**

## LEARN YOUR COMMUNITY'S EVACUATION PLAN:

☐ Will your community have transportation options available?

☐ Are the shelters accessible?

☐ How will you secure a sign language interpreter?

☐ Will guides or assistants be available?

☐ Contact the emergency planner for your area and volunteer to serve on a committee that addresses disability issues.

## PREPARE A DISASTER SUPPLIES KIT

☐ Assemble supplies you might need in an evacuation. Store them in an easy-to-carry container such as a backpack or duffel bag.

Include:

☐ A battery or crank-operated radio, flashlight and plenty of extra batteries for them.

☐ A first aid kit, extra pair of glasses.

☐ **If you take medication or use supplies, make sure you have a week's worth, if not more, available and travel ready.**

☐ A supply of water – store water in a sealed, unbreakable container. Identify the storage date and replace every six months.

☐ A supply of non-perishable food and a non-electric can opener, plus any special food you require.

☐ A sturdy whistle.

☐ Cash or travelers checks.

☐ Soap and sanitation products.

☐ A change of clothing, rain gear, and sturdy shoes.

☐ Blanket or sleeping bag.

☐ Important family and medical documents that include:

- A list of family physicians and the relative or friend who should be notified if you are injured.
- A list of the style and serial numbers of medical devices such as pacemaker.
- Keep family records, medical records or other important documents in your disaster supply kit in watertight containers.

☐ An extra set of car keys.

☐ If you have a baby, include extra diapers and other infant care items.

☐ Extra wheelchair batteries, oxygen, medication, catheters, food for guide or service animal, or other special equipment you might need.

☐ Plastic garbage bags.

Also…

☐ Store back-up equipment, such as a manual wheelchair, at a neighbor's home, school or workplace.

*For more information about the National Fire Prevention Association, to download the "Emergency Evacuation Planning Guide" in PDF or Word format, or to sign up for "e-Access," the NFPA's quarterly newsletter designed to help reduce the worldwide burden of fire and other hazards on the quality of life for people with disabilities, visit www.nfpa.org/categoryList.asp?categoryID=824* ❖

## Deadline

The deadline for the summer issue of *Generations* is August 14. Contact information appears inside the front cover.

# NAF Merchandise

## BOOKS

**Summer Born** *by Cheryl Wedesweiler* **NEW!**
Fictional story of a teenager who courageously faces her diagnosis of cerebellar ataxia. Paperback. $15.95

**Three Wheels** *by Rebecca Cummings Baldwin*
True personal, heart-warming story of a woman with ataxia. A portion of the proceeds supports the NAF. Paperback. $15.99

**Ten Years to Live** *by Henry Schut*
The story of the Schut family's struggle with hereditary ataxia. Paperback, photos. $8.75

**Living with Ataxia** *by Martha Nance, MD*
Compassionate, understandable explanation with ideas on how to live with ataxia. Paperback. $14

**Healing Wounded Doctor-Patient Relationships**
*by Linda Hanner and contributor John J. Witek, MD*
Learn better ways to communicate with your medical care providers. Paperback. $10

**Friedreich's Ataxia Research Cookbook**
Julie Karjalahti published this cookbook to raise money for FA research. $12

**Recipes and Recollections** *by Kathryn Hoefer Smith*
Full of delicious recipes and recollections. Proceeds go towards FA research. Paperback. $10

**Managing Speech & Swallowing Problems**
*by G.N. Rangamani, PdD, CCC-SLP*
A basic guide to understanding and managing speech and/or swallowing problems. $7.50

**Evaluation and Management of Ataxic Disorders, an Overview for Physicians** *by Susan L. Perlman, MD*
A guide for physicians treating ataxia patients. Paperback. $5

## VIDEO / CD

**Ballads of a Family Man CD**
10 songs in memory of Billa Ballard. $5 of purchase price goes to support the work of the NAF. $13

**"Together There is Understanding" VHS or DVD**
Continuation and expansion of "Together There is Hope." 50 minutes. VHS $20 or DVD $25

## SHIRTS / MISCELLANEOUS

**2009 Annual Membership Meeting T-Shirt** **NEW!**
Gray, long-sleeved with "Climb Every Mountain" logo. Sizes medium to XXX-large. $10

**Past Annual Membership Meeting T-Shirts**
Meeting t-shirts from past annual membership meetings. Various styles, sizes and colors. $5

**NAF Shoulder Bag**
Blue with white NAF logo. 11 x 15 x 2 inches. $10

**NAF Polo Shirt**
Royal blue w/ white embroidered NAF logo. $27.50

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**"Ataxia is not a foreign cab" T-Shirt**
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# Update on the Ataxia Center at Johns Hopkins Medical Institute

In February of 2008, the inauguration of the Ataxia Center at Johns Hopkins Medical Institute in Baltimore was announced at the Chesapeake Chapter's Annual Medical Meeting. In August of 2008 Joseph M. Savitt, MD, PhD of the Johns Hopkins Department of Neurology Movement Disorders Division became the Director of the Ataxia Center.

Here are some excerpts from his recent progress report:

From May 1, 2008 to April 30, 2009 we saw 125 patients and our staff generated 167 encounters. The encounters include visits to ataxia physicians as well as to psychiatry, genetic counseling, and physical/occupational and speech therapy. Surveys given to a recent subset of patients asked them to grade us on several components of the visit…

**Dr. Joseph Savitt**

All patients said they would recommend our center. My general impression is that all of our patients were pleased to speak with someone who has an interest in their problems and an ability to share the experiences of others who are similarly affected. Advice, understanding, education, diagnostic testing and treatment options usually close out the visit with our patients during an appointment, but just the idea that a person with ataxia is not alone is an important part of the take-home message as well…

At the present time we are operating the clinic at near full capacity. As such I feel that our goal of establishing a center has been largely accomplished. We, of course, continue to try to encourage feedback from faculty, staff and patients to further improve our center…

The center has been able to attract a wide array of college students, medical students, residents and fellows to our clinic. In the end, I believe that our program will produce neurologists and other care and research professionals that are among the most experienced in diagnosing, understanding and treating ataxia…

I believe that we have accomplished a great deal with the generous gift provided by the National Ataxia Foundation and the Gordon and Marilyn Macklin Foundation. We have hired an exceptional coordinator and have been successful in providing outreach, quality care, and support to our patients and their families. We have taken up the cause of ataxia awareness and education, and continue to foster an extremely valuable relationship with the CC-NAF. Our center's website is up and running and referrals are accumulating faster than we could have hoped. I am very proud of the efforts of those at the center, and we have been able to accomplish all of this using fewer resources than anticipated…

My general plan in this regard is to continue to assemble the best Johns Hopkins faculty available to care for our patients, thus providing a rich environment that ultimately attracts more patients, more faculty and more financial support for the center.

Lastly, I wish to express my sincere gratitude for the opportunity you have given us to provide care for these patients.

Sincerely,
Joseph Savitt

❖

## — September 25, 2009 —

# International Ataxia Awareness Day

International Ataxia Awareness Day (IAAD) is celebrated around the world every year on September 25 to spread the word about ataxia and to raise awareness about the effects of ataxia.

There are many ways you can participate in IAAD. NAF has prepared an IAAD kit – filled with information and ideas on ways you can get involved. You can request a kit by contacting the NAF office. IAAD kits can also be found on our website at *www.ataxia.org/events/international-ataxia-awareness -day.aspx*.

**Members of the Seattle Support Group pose on the beach after their first annual Walk n' Roll**

You can help raise ataxia awareness by telling others about ataxia, getting people together at a picnic or barbeque, telling your story to your local media about how ataxia has affected you, requesting that your national, state, county, or city officials recognize IAAD by signing a proclamation, and by supporting or organizing other IAAD events in your area.

International Ataxia Awareness Day events can not only raise ataxia awareness, but can also raise funds to support important ataxia research and funds to support the important services that help the ataxia community. Ideas on IAAD fundraising events can be found in the IAAD kit. Popular IAAD events include: bake sales, garage sales, and Walk n' Roll fitness activities. Local eateries have been happy to host events in support of NAF and have included live entertainment, silent auctions, raffles, and lots of great food.

Last year the NAF San Diego Ataxia Support Group held their second Annual NAF IAAD Walk n' Roll in honor of Charlie McLaughlin. The Seattle Ataxia Support Group and the Northern CA Ataxia Support Group held their first Annual IAAD Walk n' Rolls. The 2008 Walk n' Roll events combined with other IAAD events held throughout the world raised more than $50,000 in support of NAF programs.

2009 IAAD events are listed on our website's calendar of events. If you are interested in participating in an IAAD event in your area keep checking NAF's website for the most complete list of events in your area. Let us know if you are organizing an IAAD event and we will be happy to add your event to our calendar. ❖

## Ironman for Ataxia

On September 13, 2009 National Ataxia Foundation member Joe Golminas will participate in the Madison Wisconsin Ironman competition – an event that pushes the boundaries of athletic endurance through a 2.4-mile swim, 112-mile bike, and a 26.2-mile run. Joe is competing in honor of his mother, and is raising funds for NAF for his participation in this event. To support Joe in his efforts, visit his fundraising web page at *http://januscharitychallenge.kintera.org/wi09/ataxia?faf=1&e=2283643993*. We wish Joe the best of luck in this event!

# NAF Needs Your Help

In these uncertain economic times, the National Ataxia Foundation more than ever appreciates your commitment and financial sacrifice in supporting the important work of the Foundation. Here are just a few ways in which you can help further the goals of the Foundation:

- Support the NAF Annual Ataxia Research Drive
- Become an NAF Member and encourage others to become members as well
- Support the NAF Annual Membership Meeting Fund
- Stock Donations: Directly donate appreciated securities such as stock to NAF
- Deferred Giving: Include NAF in your will
- United Way Giving: Designate your United Way gift to NAF
- Employer Matching Gift Program: Ask your employer to match your gift to NAF
- Combined Federal Campaign (CFC): NAF's CFC number is 10752
- Vehicle Donations: Donate your car, truck, or van to NAF. Contact NAF for details.
- Shopping on the Web: Designate NAF as your charity of choice on the online shopping mall *iGive.com* and a portion of each purchase will be donated to NAF
- Surfing the Web: Designate NAF as your charity of choice on *iSearchiGive.com* or *Good Search.com* and a donation will be made each time you make an online search from those sites
- Honors and Memorials: Remember and honor family and friends
- Online Donations: You can become a member, support research, make a gift "In Memory Of" or "In Honor Of," support the NAF Annual Membership Meeting Fund and much more by visiting *www.ataxia.org*
- Pledging: You can make monthly, quarterly, or annual pledges to NAF
- Local Support: Ask your local civic groups to help support NAF
- Host Your Own NAF FundRaiser: Contact NAF or go online at *www.ataxia.org* for a fund raising kit, guidelines, and an application form
- Individual Donations: Make a donation in support of NAF programs
- Family Funds: Families pool your money together to support NAF programs and research
- Volunteer: Volunteer to help through your local NAF ataxia support group or chapter for various events and activities
- Participate: Be part of a clinical trial or participate in a survey
- Gift Membership: Give a Gift Membership to a friend or family member
- Individual E-mail/Letter Writing Campaign: E-mail or write your friends, co-workers, family members and others to encourage them to support NAF
- Individual Ataxia Awareness: Set a goal to tell one person each day about ataxia and NAF
- Support NAF Walk n' Rolls: For more information, please visit *www.ataxia.org*
- Purchase and wear ataxia awareness apparel, see page 12 of this issue of *Generations* to place your order
- Designate NAF as a beneficiary on your insurance policy
- Getting Married? Register with the I Do Foundation to designate NAF as the recipient of your charity registry

These are just a few ways that you can help support the continuing efforts of the National Ataxia Foundation. If you have other ideas or opportunities to raise much needed funds for the Foundation or ataxia awareness, please call the NAF office to discuss the possibilities. NAF truly appreciates all that you doing in giving help and hope to the ataxia community. Thank you! ❖

# Carl J. Lauter – Chesapeake Chapter's President Emeritus

*By Glenn & Carolyn Davis*

After 14 years of dedicated service as President of the Chesapeake Chapter of the National Ataxia Foundation, Carl J. Lauter became President Emeritus on April 26 at a meeting of the Chapter's "A-Team."

Much has been accomplished under his inspired leadership during that long tenure. The chapter has grown to over 300 members. It hosted the NAF Annual Membership Meeting in 1998. The Ataxia Center at Johns Hopkins was established in Baltimore in 2008 with initial funding from the Macklin Foundation. Various support groups were established, and many chapter meetings were organized over those 14 years. An annual medical meeting has been held consistently for 26 years with speakers from NIH, FARA, A-T Children's Project, Johns Hopkins University, University of Maryland, other universities, and various private medical and physical therapy practices both locally and from around the country. Carl was uniquely suited to plan these meetings, with his professional career at National Institutes of Health positioning him to know those involved in ataxia research and patient care. The ataxia community was well served by his understanding of neuro-degenerative disorders as a result of his own studies and research.


**Carl J. Lauter**

Carl assembled an "A-Team" of chapter members and medical advisors dedicated to carrying out CC-NAF's mission. He oversaw fundraising to support NAF's mission and its research funds and to help sponsor an AIM meeting. He is editor of a comprehensive information booklet distributed by the chapter and updated annually with the latest information on ataxia research and care.

In 2003, unbeknownst to Carl, the chapter initiated the "Lauter Award" to be presented periodically to a member who has shown outstanding support and service to the Chapter. Of course, Carl was the first recipient because of his longstanding and dedicated service.

Carl was born and raised in Washington, DC. In 1955 he graduated from the University of Rochester in New York with a BA in chemistry. He continued with advanced courses in chemistry and biochemistry topics in a program at NIH in Bethesda, MD. His professional career was as a biochemist in medically related biochemical research at NIH with government service spanning 42 years. His projects involved lipid biochemistry, protein synthesis, carbohydrate studies, cell membrane enzymes, cell culturing, genetic manipulations, and glyco-protein components and structure of myelin and its relation to brain development and neuro-degenerative disorders. He has been an active member in several professional societies and community organizations.

Carl is married to Astrid Aarli from Norway and they are the parents of two children. Carl's association with NAF started when his wife was diagnosed with an unknown form of ⏩

hereditary ataxia and became involved with a clinical study at NIH. Learning of the local Chesapeake Chapter, they began attending meetings in 1992, and in 1995 Carl was "nominated" to lead CC-NAF.

With this change in leadership, Carl and Astrid will have more time to spend with their two granddaughters and to travel, a pastime they have enjoyed throughout their married life. We are grateful that Carl has promised to continue as a member of the "A-Team" with the well-deserved title of "President Emeritus." ❖

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# Request for Research Proposals

The National Ataxia Foundation (NAF) is requesting research proposals focusing on new and innovative studies that are relevant to the cause, pathogenesis or treatment of ataxia, both hereditary and sporadic.

The National Ataxia Foundation was established in 1957 by Dr. John W. Schut, the brilliant physician and researcher who was determined to find the cause, and cure for the ataxias. Dr. Schut lost his personal battle with ataxia before his dream was realized but his vision to improve the lives of persons affected by ataxia through support, education, and research continues to be the guiding light of NAF.

Due to the generosity of donors, NAF is pleased to provide funding to support research that will bring us closer to finding the answers needed to end ataxia. Research seed-money grants, the Young Investigator Award and Research Fellowship Awards make up the three research programs that the Foundation offers. Each grant is for one year and ranges in amounts of $5,000 to $50,000. Applications and deadline information are available at *www.ataxia.org/research/ataxia-research-grants.aspx* or you may e-mail questions to *naf@ataxia.org*. ❖

## SHOPPING on the WEB

What if you could shop at a wide variety of stores without leaving your home, get 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 there really is such a place! Simply visit **www.iSearchiGive.com** and you can shop for brand names you know and trust at hundreds of stores, and receive discounts. All 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 this fine shopping portal today!

## Thank You Athena!

Athena Diagnostics consistently supports the important work of the National Ataxia Foundation through its most generous support of the NAF annual membership meetings and as a sponsor of the NAF Ataxia Investigators Meetings (AIM).

The National Ataxia Foundation is truly grateful for Athena's continued support, including the 2009 NAF Annual Membership Meeting.

Athena Diagnostics is a leading provider of advanced neurological assays. Athena's expertise includes diagnosis in many areas including ataxia. Athena Diagnostics perform more than 200 assays for neurological disease using a variety of sophisticated laboratory methods.

# Chesapeake Chapter Medical Meeting:
# Full of Hope and Optimism

*By Carolyn Davis*

The annual medical meeting of the Chesapeake Chapter of NAF was held Saturday, February 21, at Montgomery College in Rockville, MD, with A/V help ably provided by Philip d'Souza of the college. About 140 people were in attendance, including chapter members, Macklin Fellows, and other representatives from Johns Hopkins University. One attendee was from the United Arab Emirates. Following Chapter President Carl Lauter's welcome, Libby Labash, Chapter Vice President, introduced the speakers and their topics.

**Members and guests enjoyed dancing following the February 21 meeting of the Chesapeake Chapter of the National Ataxia Foundation**

The presentation by one of the featured speakers, Dr. Thomas L. Clouse, spoke to the theme, "Walking with Ataxia – Are You Up for the Challenge?" Dr. Clouse gave a very motivational presentation, talking to the "patients" about "what you can do for you," with a strong belief that everyone can improve. Dr. Clouse has a lot of credibility, having been diagnosed with SCA14 in 1997. In 2005 he began a movement therapy program, learning dance skills because they are movement skills. The premise is that learning to dance is a fun way to learn to walk again. He and his partner, Tracy Wallace, danced during the morning break as a demonstration of what can be accomplished. Dr. Clouse is in the process of developing a Therapeutic Movement Program specifically for the ataxic person. Johns Hopkins University has expressed interest in collaborating in this effort.

Two speakers, Ron Bartek and Dr. Theresa Zesiewicz, spoke of clinical trials that are currently underway or in the pipeline. Mr. Bartek, President of Friedreich's Ataxia Research Alliance (FARA), reported that five drugs are currently in clinical trials for FA, each addressing different mechanisms of the disease. In addition to partnering with government, other foundations, scientists, and 1,600 registered patient families, drug companies have been deeply involved in identifying treatments for ataxia. Dr. Zesiewicz, Director of the Ataxia Research Center at University of South Florida, has been studying an anti-smoking drug that may improve the gait of ataxic patients. Though it has many side effects, it should be in clinical trials later this year. She reported on results of her initial studies.

Dr. Rebecca Spencer, Principal Investigator at the Cognition and Action Lab at University of Massachusetts, Amherst, presented her research on how an impaired cerebellum learns and how to improve learning. She is looking for ataxic patients in New England to be part of her study. Information can be found at *www.cognaclab.com*.

Dr. Amy Bastian, Director of the Motion Analysis Lab at Kennedy Krieger Institute in Baltimore, MD, is also looking for participants for her ataxia studies in home physical therapy exercise and strength training for balance and endurance. Learning new movement patterns ⏩

can improve coordination, balance, and stability. She also has a grant to study cerebellar stimulation for improved learning and movement control. More information is available at *www.kennedykrieger.org*.

Dr. Sarah Ying, Assistant Professor of Neurology and Ophthalmology at Johns Hopkins University and with close ties to the Ataxia Center, spoke about what one person can do. She paid tribute to Carl Lauter, who has been President of CC-NAF since 1995 and has planned these medical meetings annually. She mentioned the Macklin Fellows who are involved in research, outreach, and patient care.

Minnan Xu, one of the 2008 Macklin Fellows and PhD student at Johns Hopkins, presented her research on eye movements. The Ataxia Student Ambassadors can educate and inform, participating fully in ataxia awareness activities. Students have volunteered and teachers have inspired. And we, the ataxia patients, can participate in research, share experiences, and write our government leaders to let them know what is important to us.

Libby Labash, earlier in the day, paid tribute to Gordon and Marilyn Macklin whose Foundation, headed by Don Dawn, made possible the establishment of the Ataxia Center at Johns Hopkins.

These speakers, along with additional doctors and researchers, participated in an open forum panel discussion moderated by Bill Nye where meeting participants were able to ask questions. He also presented certificates and books to the Macklin Fellows in attendance. Following the formal part of the day, a jazz quartet made up of Hopkins faculty played while Dr. Clouse encouraged those who were interested to get up and learn to move through learning dance skills. The quartet also provided music during our lunch break, adding a fun, even celebratory, element to the meeting.

We extend a special thank you to all who made this meeting a success. ❖

# My Body / My Mind

***By Deborah McClain***
***Diagnosed with SCA 3 in 2004***

My body has a mind
Of its own
For if it used the mind
It was given,
All things would work
Together for
Good …

Unfortunately, my body
Has decided to go
Its own way

Forget synchronization
Forget participation
It does its own thing

My mind tells my body
Stand up straight
Walk a straight line

But my body says,
"I choose not to.
Straight lines are overrated
Walk diagonally, lean a little, head for the wall."

My mind tells my body
Pick up your feet
Step over that object in the floor

But my body says,
"I choose not to step over. Instead, let me introduce you
To the floor. Floor meet face."

My mind tells my body, RUN,
Your grandchildren want to play

But my body says, "I choose not to run, ever again.
I'd much rather use this nifty cane, or walker, or chair."

And then in a moment of defeat, my mind told my body,
What good are you? You can't do what I tell you to do.
You don't act like I want you to? What good are you?

And my body said, I chose not to listen to you.
I choose to have a mind of my own.
Because, even though I do my own thing
I still do
Even though I go my own way
I still go
Even though my pace is slow
It is still a pace
And even though sometimes I cry
I still live.

# American Association on Health and Disability (AAHD) Scholarship Program Applications Now Being Taken

In 2009, the American Association on Health and Disability (AAHD) created the AAHD Scholarship Program, which will support students with disabilities who are pursuing higher education. Preference will be given to students who plan to pursue undergraduate/graduate studies in the field of public health, health promotion, disability studies, to include disability policy and disability research.

The AAHD Board of Directors Scholarship Committee will evaluate each of the applicants and make a decision in December of each calendar year. The first AAHD Scholarship Award will be awarded December, 2009. It is the discretion of the Scholarship Committee to determine how many scholarships will be awarded each year and the amount of each scholarship, as well as final determination of the recipients.

The AAHD board and staff are excited to be able to launch this program and support the efforts and dedication of students who have chosen to pursue higher education in the field of disability.

**Scholarship Program Criteria**

– Applicant must be a high school graduate, have a documented disability and provide documentation of their disability.

– Applicant must be a U.S. citizen or legal resident living in the U.S. and enrolled in, or accepted by, an accredited U.S. four-year university or graduate school on a full-time basis.

– Preference will be given to students majoring in public health, disability studies, health promotion or a field related to disability and health.

**Application Requirements**

– Applicant must provide a Personal Statement (maximum three pages – double spaced), including brief personal history, educational/career goals, extra-curricular activities, and reasons why they should be selected to the AAHD Scholarship Committee. This Statement must be written solely by the applicant.

– Applicant must provide three Letters of Recommendation (One must be from a teacher or academic advisor).

– Applicant must provide an official copy of high school transcript as well as college transcript (if applicable).

– Applicant must agree to allow AAHD to use their name, picture and/or story in future scholarship materials.

Please mail applications to:
AAHD
Attn: Scholarship Committee
110 N. Washington St., Suite 328J
Rockville, MD 20850
(301) 545-6140 *www.aahd.us*

Only completed applications will be considered and need to be postmarked by October 15, 2009.

Please e-mail Roberta Carlin, AAHD Executive Director, at *rcarlin@aahd.us* or call (301) 545-6140 ext. 206 if you have any questions. ❖

# Dr. Susan Perlman Appointed as Medical Director of NAF

Susan L. Perlman, MD has been the Director of the Ataxia Center and Huntington's Disease Center of Excellence at UCLA since 1983. During her career she has provided excellent care for hundreds of ataxia patients.

**Dr. Susan Perlman**

Dr. Perlman has offered her expertise to the National Ataxia Foundation by presenting important medical and research information at the last nine annual membership meetings, assisting in writing ataxia fact sheets and authoring the booklet, "Evaluation and Management of Ataxia Disorders: An Overview for Physicians."

Dr. Perlman has recently been appointed to the role of Medical Director for the Foundation, replacing Dr. Lawrence Schut who has served in this position for more than 25 years.

We are grateful to Dr. Schut for his commitment to the Foundation, which was established by his family 52 years ago. Dr. Schut will continue to serve on NAF's Board of Directors and Medical and Research Advisory Board as Medical Liaison. ❖

## NAF Represented at American Academy of Neurology Meeting

*By Milly Lewendon*

The Seattle Ataxia Support Group supported the National Ataxia Foundation by volunteering at their exhibit booth at the American Academy of Neurology Meeting held at the Washington State Convention Center in downtown Seattle on April 20-23.

Over 12,000 people attended this meeting. What a wonderful opportunity to meet individuals from all over the world and share information about NAF!

**Seattle Support Group Leader Milly Lewendon helps staff the NAF booth at the American Academy of Neurology meeting in Seattle**

The NAF booth was situated in the sky bridge area of the convention center right between the two huge exhibit areas. The sky bridge is all glass and we were most fortunate to have sunny, beautiful weather every day for the week-long meeting. Volunteers included Trinity Falk, Shelly Hersman, Gloria LaBelle, Milly and Tony Lewendon, and Margaret Way.

We were able to distribute NAF literature, obtain names and addresses for the mailing list and Tony personally went around to the vendors and gave them a copy of *Generations*.

By having NAF represented at this meeting, exposure was provided to the neurologists who see patients with ataxia so that they can refer them to the Foundation for support services.

In addition, because of this meeting, we received requests from neurologists to be added to NAF's mailing list, which will keep them updated on the Foundation's activities and provide NAF with neurological resources. Thanks to our local volunteers, the Foundation was able to save hundreds of dollars that can now be used for important ataxia research.

# Caregiver's Corner

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

## Incontinence & Personal Hygiene

### A Common Little Secret

Incontinence is a problem that involves the leakage of urine or feces over which the person has no control. Bladder management medications are available; other possible treatments include bladder training, exercises to strengthen the pelvic floor (Kegel exercises), biofeedback, surgery, electrical muscle stimulators, urinary catheters, prosthetic devices, or external collection devices.

A precise diagnosis for incontinence must be made in order to come up with an effective treatment plan. If the primary care doctor cannot solve the problem, consult an experienced urologist.

### Managing Incontinence

- Avoid alcohol, coffee, spicy foods, and citrus foods, which may irritate the bladder and increase the need to urinate.
- Give fluids at regular intervals to dilute the urine, which decreases irritation to the bladder.
- Provide clothing that can be easily removed.
- Keep a bedpan or a portable commode nearby.
- Use adult diapers under clothes.
- Keep the skin dry and clean. Urine on the skin can cause pressure sores and infection.

Your patience and understanding will help the person maintain confidence and self-respect.

### Toileting and Alzheimer's Disease (AD)

Incontinence usually begins in the late part of the middle stage of AD. Most AD caregivers fear they will not be able to handle this condition, but many learn to take it in stride and find that it is not as awful as they expected. Knowledge of the appropriate products and how to use them will help relieve any discomfort you may feel.

Incontinence in AD may be caused by confusion in finding the bathroom, inability to get there on time, or a urinary tract infection. Be sure to ask the doctor if there could be a physical cause to the problem, rather than the progression of AD.

A regular toileting schedule and reading the signals when the person needs to go to the toilet may help the person to continue to use the toilet for a longer time. However, you will probably need to use protection for the bed, since the person may sleep through the urge to go.

### Note

Be sure the person in your care goes to the bathroom regularly, ideally every two to three hours. Use an alarm clock to keep track of the time.

### Catheters

A urinary catheter is a device made from rubber or plastic that drains urine from the body. It is inserted by a nurse through the urethra (a tube that connects the bladder to the outside of the body) into the bladder (an organ that collects urine).

A Foley catheter stays in the bladder and drains into a bag attached to a person's leg, the bed, or a chair.

A Foley catheter greatly increases the risk of infection. It is chosen as a last resort to manage incontinence.

### Bathing & AD

Bathing is often called the most challenging activity for both the person with dementia and the caregiver. Standing naked, afraid of falling, in a room that may be drafty, with water ⏩

coming from all kinds of unexpected places may result in pain, fatigue, weakness, confusion, and anxiety for the person with AD.

To make bathing easier:

- *Let the person feel in control.* Does he prefer showers or a tub bath? At what time of day?
- *Create a safe atmosphere.* Put non-slip adhesives on the floor and bottom of tub, install grab bars to prevent falls, test the water temperature in advance.
- *Use a bath bench.* Respect the person's dignity. Allow the person to keep a towel around him both in and out of the shower, if necessary.
- *Don't worry about bathing.* It doesn't have to be done every day. Sponge baths can be used in between showers and baths.
- *Be gentle.* The person's skin may be sensitive. Avoid scrubbing. Pat dry. Use lotion.
- *Be flexible.* If the person does not want a shampoo, use a wash cloth to soap and rinse the hair, or a shampoo in a cap or no rinse shampoo can be substituted for a regular shampoo.
- *Talk with the person.* Tell him what you are going to do next, encourage him to wash areas that he can and watch that the flow of water is not too strong. A person can also be washed in bed, if showers or baths are not comfortable or feasible.

**Inspiration**

Although the world is full of suffering, it is also full of the overcoming of it.

— *Helen Keller*

**Urinary Tract Infection**

Urinary tract infection may be present if the person has any of the following signs or symptoms:

- Blood in the urine
- A burning feeling when voiding
- Cloudy urine with sediment (matter that settles to the bottom)
- Pain in the lower abdomen or lower back
- Fever and chills
- Foul-smelling urine
- A frequent, strong urge to void or frequent voiding

**Diarrhea**

Diarrhea (loose, watery stools) can be caused by viral stomach flu, antibiotics, or other medications, or stress anxiety.

Diarrhea in people who are immobile is often caused by impaction. This is a blockage formed by hardened stool, with liquid stool passing around it. This must always be taken into consideration, because the usual treatments for diarrhea would be extremely dangerous if the diarrhea is being caused by impaction.

The doctor should be consulted if there is any sign of a urinary tract infection or prolonged diarrhea.

❖

## Donate a Vehicle to Benefit NAF

Do you have a spare car or truck sitting unused, or know someone who does? The donation of a vehicle will help support the important work of the National Ataxia Foundation.

To donate your car, truck or motor home, please call the NAF office at (763) 553-0020. Your vehicle will be picked up at your home, office or other place that you designate. Be sure to have the certificate of title with the vehicle.

## E-mail Addresses Wanted!

E-mail blasts from the National Ataxia Foundation are sent out periodically on ataxia research, events and other timely issues of interest regarding ataxia.

Please email your e-mail address to *julie@ataxia.org* so you don't miss out on receiving important information!

# From the Desk of the **Executive Director**

Each of us has an opportunity to make a difference. I see it time and time again by individuals and families who have made a commitment to support the important work of the National Ataxia Foundation.

These families and individuals have dedicated themselves to join the Foundation's important efforts in supporting promising ataxia research and programs which serve ataxia families. They are my true heroes and they come from many backgrounds and throughout the nation and beyond.

Some are persons with ataxia, while others have a family member or friend affected with ataxia. Through local fund raisers and awareness initiatives, donations, volunteering for clinical trials, and alike, they are all making a significant difference in the fight against ataxia. The National Ataxia Foundation is truly grateful for all their efforts and extends to all of you our sincerest and heartfelt thank you.

**Michael Parent**

I have had the opportunity to speak with many of these wonderful people; each has a very important story to tell on how ataxia has impacted their lives. There is one common thread which weaves this very diverse group together and that is collectively they are making a difference in finding answers to stop ataxia.

Each year, through the National Ataxia Foundation's ataxia research programs, scientists around the world are learning more about ataxia each and every day. The tools provided to these scientists are the research dollars which are made available because of your support and commitment of the National Ataxia Foundation's research efforts.

Too often, however, some of these crucial, support-worthy studies are not funded, not necessarily because of lack of funds, but because those research dollars were designated to other forms of ataxia. The National Ataxia Foundation takes seriously its obligation to honor those who designate their research dollars to a specific type of ataxia and will continue to do so. However, sometimes a designated fund may not be used immediately because of a lack of qualified research applications for that specific form of ataxia. In other cases the fund amounts are too small to support any significant research project.

Time is crucial in ataxia research. Many times what we learn from one form of ataxia can have a profound impact on other forms of ataxia. Therefore, I am not discouraging you from designating your research dollars to a specific type of ataxia, but rather I encourage you to designate your research dollars to the "General Research Fund" to allow for greater flexibility and efficiency in finding answers more quickly which may impact many more forms of ataxia in bringing us closer to treatments and a cure.

During the 2009 Fall NAF Annual Research Drive you will still have the same opportunity to designate your research gift to a specific type of ataxia. However, please consider designating your gift to the "General Research Fund" or perhaps splitting your gift between the two categories. Each year the National Ataxia Foundation sees an increase in the number of qualified ataxia research proposals from around the world. NAF is able, because of your generous support, to fund many of these outstanding studies. Your designation to the "General Research Fund" provides the Foundation with a better pathway to fund cutting edge ataxia research which could have an impact on many other forms of ataxia.

The National Ataxia Foundation is truly thankful for your continued support in these most important efforts. Together we are making a difference. ❖

*The NAF Board of Directors along with the*
*Chicago Ataxia Support Groups would like to invite you to attend the*

# National Ataxia Foundation
# 53rd Annual Membership Meeting

## March 12–14, 2010
(Leadership Meeting March 11)

## *Join us in Chicago for the Annual Membership Meeting!*

The Hyatt Regency O'Hare Hotel is pleased to provide the facilities for the 2010 National Ataxia Foundation Annual Membership Meeting. Rooms are available at the **special group rate** of $149 per night. Please be sure to make your reservations by **February 15, 2010** in order to secure the special group rate. If rooms are available, the special group rate will be extended three days before and three days after the meeting dates.

**There were a limited number of ADA rooms available in our group block, but all of these rooms are now reserved. If you are interested in putting your name on our ADA room waiting list, please contact the National Ataxia Foundation at (763) 553-0020.**

If you need ADA equipment be sure and mention this when making your room reservation. Shower chairs, tub bars and toilet frames will be available on a first-come, first-served basis by contacting the Hyatt Regency O'Hare Hotel front Desk upon check in.

**To book your stay online**, go to *https://resweb.passkey.com/Resweb.do?mode=welcome_ei_new&eventID=779322&fromResdesk=true* or if you would prefer to make your reservations by phone, please call 1-888-421-1442 or (847) 696-1234 and ask for the **National Ataxia Foundation Conference special rate**.

Watch for the 2010 AMM Registration Form in the Winter 2009-10 issue of *Generations*. Keep checking our website, *www.ataxia.org*, for the latest information about the meeting.

**We look forward to seeing you in Chicago!**

# Managing Ataxia and Managing Your Neurologist

*By Susan Perlman, MD, NAF's Medical Director*

*The following was presented at the 2009 NAF Annual Membership Meeting in Seattle, WA and edited for publication in Generations.*

Very few physicians know about ataxia. It may take a long time to be diagnosed and there's often a lot of frustration because many times after spending a lot of money and a lot of time going through a lot of procedures you still don't have a diagnosis. These factors are remediable through education and more research. If you know where to get information, you can share it with your doctor and if you know where research is being done you can stay informed about that and reduce that level of frustration. I think other problems that are less easy to understand, to rationalize, is how little neurologists have to offer after they've given a diagnosis and then when they do get a diagnosis the hopelessness that may sometimes be communicated. We need to know how to manage those factors as well.

Diagnosing ataxia is not simple. Ataxias are rare diseases and your doctor is probably going to be unfamiliar with them. Alzheimer's disease affects 1,600 patients for every 100,000 individuals in the country, Parkinson's 180 patients for every 100,000, the ataxias one to three patients for every 100,000. *Many physicians and many neurologists may go through many years never seeing somebody with ataxia.* The true nature of an ataxia may not reveal itself for up to a year or two. So if you are newly symptomatic, your first visit may not give an answer. You may have to go back a couple more times, you may have to plan a visit a year later if it's a slowly changing ataxia.

At best only 50 percent of ataxias are inherited and this is going to vary between parts of the country and clinics. There are only a few genetic tests available, some insurance companies don't pay for them, and getting a genetic diagnosis can be hard. Very few non-genetic causes are known. In my personal clinic of my genetic cases only half actually have a genetic diagnosis and of the non-genetic cases only half have an explanation (thyroid, immune system etc.). The other half, we're still looking. This does limit your doctor's ability to offer treatment, you may not get answers to all your questions, but you should get some guidelines for what to do when you leave that office. When a patient leaves my office, I like them to leave with at least one concrete thing that I have given them to do – something they can take with them that will be useful.

What can you do to help your doctors help you? Your health is a valuable resource you need to treat it like any other investment. You need to pay attention to what's going on with your health and your health care. Treat your doctor as an ally not an adversary. If you have a personality problem with your doctor, find another doctor. Establish a continuing relationship with your doctor, don't go doctor hopping. Find one that you can work with, and continue to work with that person. Know when to ask for a second opinion. If your doctor seems stuck it's reasonable to get a second opinion even if it's just a one-time consultation with somebody who might be a little more knowledgeable.

Keep organized records of your medical history and tests that you have done. Certainly if you're going to get a second opinion or go to a consultant it would be nice for you to have a

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notebook with your important medical information in it.

When you come to a visit, bring a written list of questions, a handful of questions that are most important to you. Write them down so you don't forget and then check them off as you discuss them with the doctor.

*Be proactive* – if you hear something, see an article, send it to your doctor, bring it into the doctor, at least he'll glance at the headline, get a sense of the things that you're thinking about and the things that are important to you. If there are too many questions or too many articles, prioritize them and save some for the next visit. Less urgent concerns may be able to be handled by e-mail if your doctor is into e-mail. It's an efficient way – some places require that you sign a consent form to have your private health information go over the internet on e-mail but most e-mail servers are confidential and it's treated just like your medical record.

> **"Ataxias are rare diseases and your doctor is probably going to be unfamiliar with them."**

Use your primary care doctor to help sort out problems that may relate to your ataxia or may not. Everything that happens to you is not necessarily from your ataxia. You're not immune from other problems and a good local primary care doctor is an invaluable resource. If an explanation is not clear- ask for clarification, don't just sit there and nod. Ask the doctor to clarify. Don't leave the doctor's office confused. Ask for explanations, they don't have to be long explanations – key points, key words that you can then go back and it'll jog your memory about what you discussed.

*Communicating with your insurance company* – Your doctor may find it easier now to justify getting certain tests covered, including genetic testing and even off-label use of drugs because there is a growing literature, not necessarily FDA approved stuff, but if you can present two articles from the medical literature supporting the drug you want to use or the test you want to have, often the insurance company can look at this and agree to fund whatever the particular need is. Your doctor is going to have to convince the insurance company that these things are necessary – that you will benefit from those things, but then he's going to have to convince you also- that you're going to benefit from those things. I think it's a good partnership there.

*Seven habits of living with ataxia* – Information, explanation, evaluation, rehabilitation, symptom relief, access to research, and then somebody to pay it forward to. I think the approach at the National Ataxia Foundation, in the past has been hope and cope (hope for benefits, hope for new research breakthroughs, and then cope with what you've got), but I believe now we're more on an advance and attack mode. There is active research funding – one research project directly leads to another, people are actively helping each other cope with symptoms and know what questions to ask. So I don't think we're sitting by passively – we're a very active organization and a very active group.

*Information* – It's at our fingertips. I think we all know the resources that we have, certainly we should be able to get answers to these questions.

*Explanation* – you need a health care provider that you can trust and you can talk to, to answer these very personal questions that may impact you. Each of these questions can be answered, even if the answer is "you can't get involved in research right now until we take care of your pnemonia" or "yes you will probably get worse, but we don't know how much worse you will get, let's work together on that." Some things have very straight-forward answers. Some we

Continued on page 28

*Managing Ataxia…*
*Continued from page 27*

just have to respect that we may have to wait another few months or another few years to get the complete answer.

*Evaluation* – Everybody needs to be evaluated for common acquired causes of ataxia, even if you have a genetic ataxia, you could have a thyroid problem on top of it that's making it worse, you could have a vitamin deficiency, you could have other things going on that, if treated, would make your genetic ataxia symptoms better. So I think there's kind of a minimum evaluation that we're still trying to flesh out that everybody should have done at least once.

*Rehab* – Demand it. It definitely helps. Goals, safe mobility (which includes driving), independence and activities of daily living, speech and swallowing, and then dealing with symptoms of de-conditioning, fatigue and pain. Many resources that we work with in our ataxia clinic and I think most ataxia specialty clinics and movement disorder clinics have good relationships with physical therapy, occupational therapy, home health, and genetic counseling groups – everybody on this list has been helpful to my patients at one time or another.

*Symptom relief* – Every one of these symptoms has recognized treatment protocols that will help. Maybe you won't take them away completely, but can bring significant relief. So maybe your list will include your five top symptoms and you can come away with a list of medications – one for each symptom that might help or non-medication strategies that might help. Typically if you're going to be treating more than one thing at a time, you start the treatments one at a time. So if you've been given a medication for tremor and you've been given a medication for bladder function and a medication for sleep, you'll start them one at a time in case there's a side effect, you'll know which one is the culprit.

*Access to research* – NAF, FARA, the AT Children's Project have a lot of research money that they have raised, they are funding a lot of research, they know where the studies are being done. Being members of these organizations I think puts you in the front of the line to get this information directly. The NAF website is developing links which will actually link you to lists of active studies that are recruiting and information about how to get in touch with them. So access to research is really only a mouse click away, a phone call away. The National Ataxia Registry is going to make it even easier. I think at next year's meeting we're going to have more than just one or two drug trials to report on. There are now comprehensive ataxia programs for diagnosis, treatment, and research in 20 states, united under the Cooperative Ataxia Group and there's also a link to those on the NAF website.

**Word of caution** – As accessible as many of these ataxia experts are via mail, phone and e-mail, and as good as the various ataxia websites are, electronic medicine is never going to replace a good personal relationship with a real flesh-and-blood health care provider. You've got to have at least one real health care provider who can look at you and to work with you.

*Someone to pay it forward to* – Ninety percent of what I know about ataxia I've learned from my patients. This is starting from when I was a resident in my last year of residency and I saw my very first patient, an adult patient in his early 30's, with Friedreich's ataxia. He had heart problems, had had a stroke, and had so many disabilities that I had never seen before. I had never seen an ataxia patient before. Since then I've seen many more ataxia patients and I have a better sense of what to look for, what not to do, when to wait, when to move ahead. But your own primary care doctor, when you roll or walk into his office for the first time, may have that same reaction. And you have to calm him down so that he can focus on your issues of the day and then come back again to focus on broader issues. You have to cultivate your doctor if he's not already knowledgeable. The other 10 percent of what I know I've learned from my colleagues.

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We all need to share questions, concerns, ideas, information with all of us – with people who haven't been able to come to the meetings and we can win the little war, and the big one – which is the cure.

Research will not happen without your involvement. It's a war, people make sacrifices in war. If it means you have to plan travel that's going to be difficult especially in winter, if it means that you have to work something out with your boss to get a little extra time off so you can go to an extra clinic appointment to participate in a study, that's how research can happen.

We all have to work together to make that easy because without your help, research is never going to get farther than those little involuntary rat "volunteers" that are involved in the basic science. ❖

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# Hereditary Ataxia and Genetic Testing: A Family Affair

*By Christina Rakshys*

When I was given the diagnosis of "Spinocerebellar Ataxia, type unknown" in 2005 by a local neurologist (based on my neurological exam results, MRI test results which showed cerebellar atrophy and family history), my medical journey began. It has been a long and complicated journey, filled with lots of uncertainty and angst. But I'd like to focus on the part that seems to be the most potentially promising for us – and that is genetic testing.

The starting point for me, as is for many ataxians, was to test for the full panel of Spinocerebellar Ataxias via blood draws. I did so, and a few weeks later when the office called with results, it came as no surprise to me that my results were negative. My family has been dealing with this "mystery illness" for a long time, and our diagnoses have ranged from such neurodegenerative disorders as MS, Parkinson's, ALS, Alzheimer's, and more. And so, I had to choose to stop with my search or to continue with further testing. Fortunately, I was physically, mentally and financially able to carry on with the continued research, and so I opted for the latter. I am still in the mild to moderate stages of our disorder, and I was more than willing to take on the role of "head guinea pig" for my living symptomatic family members (my aunts, mother, brother and me). Months and years passed – once I received second and third opinions from prominent ataxia specialists, I continued testing – this was between 2006 and 2008. After over 19 tests, results have still been negative for any testable type of SCA.

And now to the present state of my journey … I have enrolled in a clinical research study conducted by the National Institutes of Health. The medical team has suggested additional research, and my testing has changed from individual to group (family) testing – we are in the midst of a family linkage analysis study. Simply stated, linkage analysis is where blood samples are obtained from two groups of family members: *affected* and *unaffected*. The team then compares the two groups' samples, and ideally a mutation is discovered.

When genetic testing turns into group (family) testing, it gets very hairy. Attempting to gather estranged family members from a few generations is definitely no easy task! Also, testing

Continued on page 30

*Hereditary Ataxia and Genetic Testing…*
*Continued from page 29*

results may or may not be wanted by some family members, especially by those who are in denial or who have been misdiagnosed in the past. Another complication with linkage analysis is that it requires samples from many family members to be collected. And unfortunately, if a family does not have enough living *affecteds* on hand, and from at least three generations' worth, then the study may not be feasible.

True, genetic testing has been very time-consuming, expensive and emotionally draining for me. However, the potential medical and scientific knowledge gained from it far outweighs the small sacrifices that I've had to make. Most importantly, I'm sure that my son and his cousins will be grateful to know the hand they've been dealt, if anyone becomes symptomatic in the future.

I guess the reason that I am so passionate and driven to find out as much as possible about our disorder and the research process is relatively simple – when I became symptomatic in my late 20's, I had no idea whatsoever what was happening to me, and why – and I certainly do not want to pass that ignorance on to future generations. Unfortunately, medical technology wasn't nearly as available and advanced in the 1970's and 1980's for my mother's generation – but it is for my generation. Also, it's such a relief to finally have government support on our side (Genetics Information Nondiscrimination Act, aka GINA), so as to fight discrimination in the workplace and or help with insurance coverage (some types, not all) down the road. And so I feel safe in my efforts.

My membership with the Foundation has truly been a God-send. Thanks to them, I've finally been able to break through to my family members and to convince them that ours is something much bigger than what happens to our bodies. The shared information (from current research, to medical management tips, to Caregiver's Corner, to the listing of Medical Advisory Board members, etc.) enables me to keep on keepin' on. I am also an active member of the electronic bulletin board — where there is much support, both given and received.

Knowledge truly is power, and this belief has given me the powers of acceptance and relief. Having to deal with such ambiguities, uncertainties and confusion have been very tough at times. And so I am eternally grateful to the National Ataxia Foundation for all of their background support!

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## Summer Born: A Life with Cerebellar Ataxia

Mandy Wheeler had been living a teenage life filled with school, friends, and her first love. Her increasing poor coordination causes concern among family and friends so she goes to see a neurologist. She learns that she has a progressive neurological disorder called Cerebellar Ataxia: a progressive degeneration of the cerebellum which impairs coordination. The news leaves her frustrated and frightened, but the support of friends, family, and The National Ataxia Foundation eases her anxiety. She journeys through life, love, and a dream on her way toward the acceptance of her disability. Over 150,000 people in the United States have an ataxic disorder. This novel sheds light on a little known debilitating condition.

Cheryl Wedesweiler grew up in Southern California and dreamed of becoming a writer. She graduated from California State University, Fullerton with a degree in psychology. As a young adult, she learned to live with her hereditary disability, Cerebellar Ataxia.

*Summer Born: A Life with Cerebellar Ataxia* is available for purchase by using the NAF Merchandise page 12 or by going to NAF's secure on-line store at *www.ataxia.org*.

# Caregiver's Corner

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

## Falls & Home Safety

### *Things You Can Do*

Falls can occur any time, any place and to anyone while doing everyday activities such as climbing stairs or getting out of the bathtub. Simple safety modifications at home – where 60 percent of seniors' falls occur – can substantially cut the risk of falling. Protect the person in your care and yourself from falls with simple changes in furniture arrangement, housekeeping and lighting.

### *Risk Factors*

The causes of falls are known as risk factors. Although no single risk factor causes all falls, the greater the number of risk factors, the greater the probability of a fall and the more likely the fall will threaten personal independence.

Some people believe that falls are a normal part of aging, and as such are not preventable. But many risk factors are preventable. As obvious as it may sound, a lack of knowledge about risk factors and how to prevent them contributes to many falls.

Falls are the leading cause of injuries to older people in the United States. The number of falls and the severity of injury increase with age. While some risk factors for falls, such as heredity and age, cannot be changed, several risk factors can be eliminated or reduced.

### *Home Adjustments*

Make the home safe by following as many of these steps as possible:

- Remove unnecessary furniture. Place remaining furniture so there's enough space for walkers or wheelchairs. This avoids the need for an elderly or disabled person to move around coffee tables and other barriers.
- Once the person in your care has gotten used to where the furniture is, do not change it.
- Make sure furniture will not move if it is leaned on.
- Make sure the armrests of a favorite chair are long enough to help the person get up and down.
- Have a professional carpenter install railings where a person might need extra support. (A professional installation ensures that railings can bear a person's full weight and not give way.)
- Place masking or colored tape on glass doors and picture windows.
- Use automatic night-lights.
- Clear fire-escape routes.
- Place nonskid tape on the edges of stairs (and consider painting the edge of the first and last step a different color from the floor).
- It is easier to walk on thin-pile carpet than on thick pile. Avoid busy patterns.
- Be sure stairs have even surfaces with no metal strips or rubber mats to cause tripping.
- Tape or tack electrical and telephone cords to walls.
- Adjust rapidly closing doors.
- Provide sufficient no-glare lighting (indirect is best).

### FAST FACT

More than one-third of adults 65 and older fall each year in the United States.

Among older adults, falls are the leading cause of injury deaths. They are also the most common cause of nonfatal injuries and hospital admissions for trauma. Many people who fall, even those who are not injured, develop a fear of falling.

*Continued on page 32*

*Caregiver's Corner*
*Continued from page 31*

This fear may cause them to limit their activities, leading to reduced mobility and physical fitness, and increasing their actual risk of falling.

Women are 67% more likely than men to have a nonfatal fall.

### *Reducing Risk Factors*

Older adults can take several steps to reduce their risk of falling.

*Exercise regularly.* Exercise programs like Tai Chi increase strength and improve balance.

*Ask a doctor or pharmacist to review medications*, both prescription and over-the-counter, to reduce side effects and interactions.

*Have vision checked* by an eye doctor at least once a year.

*Get up slowly after eating, sitting or lying flat.*

*Dress Appropriately*

- Wear properly fitting shoes with nonskid soles.
- Tie your shoe laces.
- Replace loose, shapeless slippers.
- Use a long-handled shoehorn if you have trouble putting on your shoes.
- Avoid high heels and shoes with smooth, slick soles.
- If unsteady, use a cane or walker.
- Never walk in your stocking feet.

*Source: National Center for Injury Prevention and Control, Division of Unintentional Injury Prevention. www.cdc.gov/ncipc/factsheets/adultfalls.htm*

### *Taking Care of Yourself – Get a Pedometer*

Pedometers – simple devices costing around $25 – are surprisingly effective at motivating to become more active, which pays big health dividends including weight loss, reduced stress and cholesterol levels, and lower blood pressure. Studies show that sedentary adults given a pedometer walked more than 2,000 extra steps a day – roughly a mile – and lost weight and blood pressure fell enough to significantly reduce the risk of stroke.

As adults, Americans gain an average of two pounds a year. Two-thirds of U.S. adults are overweight. Half don't get the minimum 150 minutes a week (30 minutes, five days a week) of moderately intensive exercise recommended for a healthy heart.

Walking 10,000 steps a day can help. To reach this daily goal, you'll need to take a few brisk walks on top of your regular activities. Walking can rack up 3,000 to 4,000 steps in 30 minutes. The web site *www.pedometers.com/reviews.asp* offers detailed reviews of pedometers. AARP members chart their step count online at *www.aarp.stepuptobetterhealth.com*.

### *Inspiration*

"Everything is so dangerous that nothing is really very frightening."

— *Gertrude Stein*

### *Home Safety – Quick Check*

**Bedroom**

✔ Place a lamp, telephone and flashlight near the bed.

✔ Make sure beds are easy to get into and out of.

✔ Replace satiny sheets and comforters with nonslippery.

✔ Arrange clothes in the closet so that they are easy to reach.

✔ Keep clutter off all floors.

**Kitchen**

✔ Non-skid mats or rugs only.

✔ Clean up spills immediately.

✔ Store food, dishes and cooking equipment within easy reach.

✔ Don't stand on chairs or boxes to reach upper cabinets.

✔ Use nonskid floor wax.

**Bathroom**

✔ Place rubber mat in shower and tub.

*Source: The American Academy of Orthopaedic Surgeons (AAOS).*

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# Discovering and Developing New Medications – The Long and Challenging Journey

*By William T. Andrews, MD, FACP,*
*Vice President, Medical Affairs, Santhera Pharmaceuticals (USA), Inc.*

Developing a new drug for the treatment of human disease is a highly regulated undertaking, requiring years of research and a huge investment of time, money, and people. In the United States, the journey from promising compound to approved drug often takes 10 to 15 years, and the vast majority of compounds investigated never make it that far. The slow pace of drug development can prove frustrating for patients and families, doctors, and drug companies alike, but there is broad agreement among all stakeholders that all drugs require rigorous scientific evaluation.

The Food and Drug Administration (FDA) is responsible for ensuring that drugs are safe and effective before approved for use in the U.S. Pharmaceutical companies follow FDA guidelines and work closely with the FDA while developing and testing a possible new drug treatment. The long road in developing a new medication involves many research trials over many years. Much of the time required to conduct clinical trials is devoted to patient recruitment. If the targeted disease is rare, as is ataxia, recruitment can be challenging and slow. Also, the FDA can halt a drug research program at any stage if the risks of treatment appear to outweigh the potential benefits.

Drug development starts with the discovery or invention of a compound that has a good chance of treating a disease. Next, this compound needs to be tested in the laboratory in cells, tissues, and animals. These are called preclinical trials and a compound has to be proven safe here before testing in humans, in clinical trials. Many compounds never make it to this stage, but those that do need to be approved by the FDA for first-time testing in humans. Phase 1 clinical trials are small, closely monitored trials in healthy volunteers that primarily evaluate how a drug is absorbed and broken down inside the body and side effects of the drug. Phase 2 clinical trials are larger, often up to several hundred patients, and for the first time include patients with the targeted disease. These trials also directly compare patients randomly assigned to receive the test drug versus patients receiving placebo. This is known as a placebo controlled trial. The purpose of Phase 2 trials is to test whether the drug helps patients with the target disease (efficacy), and also to evaluate the drug's safety and proper dosing. Phase 3 clinical trials involve even more patients and are the main evaluation of drug efficacy and safety. In Phase 3 trials, patient selection must be representative of the target population, efficacy outcomes must be clinically relevant, and the evidence must be statistically significant. These are usually conducted at multiple clinical trial sites. Doctors can prescribe a drug for patients in the U.S. only if the FDA approves the medication after thorough review of the Phase 3 trial results and confirmation of drug efficacy and safety in the population studied.

Successful drug development relies on the coordinated efforts of many contributors: the investment of time, money, and human resources by the pharmaceutical company; the expert knowledge and devotion of clinical investigators, health care providers, and laboratory researchers; the oversight of regulatory authorities and research institutions; and the generosity of patients who participate in clinical trials. Working together to study new potential therapies can help yield the ultimate fruit: new or improved treatments that can offer hope to patients and their families.

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# Chapter and Support Group News from Around the Country

## Los Angeles Ataxia Support Group

*By Cherilyn Mclaughlin and Sid Luther*

On May 9, members of the Los Angeles Ataxia Support Group (LAASG) met at the Westside Center for Independent Living. We were happy to welcome Sherry and Randy Dombrouski, who were visiting from Michigan.

Group leader Sid Luther reported on the membership meeting and the spectacular Ride Ataxia III. He also reported on some International Ataxia Awareness Day fundraising opportunities, including a possible Orange County/ Los Angeles Walk n' Roll.

LAASG is keeping up with the times with a new Facebook account. You can link to it from the LAASG web page.

Social activities are plentiful this year. Sid reported on new Casa Colina outdoor adventure dates, including sailing and camping. The group will also attend the Hollywood Bowl on Sept. 13 to hear a concert of Brazilian music and see fireworks. Prior to the concert will be a group picnic and pictures.

The November cruise to Mexico is set with new sign-ups continuing. If you want to join us, please contact Debra Kerper at *www.easyaccesstravel.com*. Anyone is welcome to join us, so please invite your friends and family (remember to tell Debra you want to join the Ataxia support group).

Our next meeting will be the annual July barbecue at the home of Thom Fritz on July 11 at 2 p.m. Please bring a main dish for yourself and a side to share. Beverages and paper goods will be provided. Please contact Sid Luther or Jim Fritz, or visit the support group web page for details and directions.

## N.E. Florida Ataxia Support Group

*By June McGrane*

Our group met on May 9 at the Baptist South Medical Center in Jacksonville. We discussed the March NAF Convention in Seattle, the new research group at the University of South Florida and I handed out copies of the book "Ataxia Tactics" by Peter Meyerhoff (the book is very helpful to ataxians). Our members enjoy the breakaway sessions we have at each meeting where caregivers and ataxians can discuss their concerns separately.

I started this group four years ago (as there was no group in this area), when my son was diagnosed with sporadic SCA. I have met some wonderful people and appreciate all the help they and the NAF have given me. I am now retiring, and John Richwine is taking my place as President. We all spoke of the coming year and plans. I'm sure John will do a wonderful job and introduce new ideas.

Our next meeting will be August 8 at the Baptist South Medical Center at 1 p.m.

## Alabama Ataxia Support Group

*By Becky Donnelly*

Our Support Group met on Saturday, April 25, at Covenant Presbyterian Church with 17 members present. We enjoyed a time of greeting, refreshments and fellowship and then had reports from Cell Group leaders who gave updates on those absent. The Group was saddened to hear of member Jeff Scheffler's recent death and will send a memorial to NAF in his memory.

Our speaker was pharmacist Alex Sproule, who spoke on drugs and interactions. Afterwards,

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he answered many questions from members. Alex stayed for lunch, interacting with members, and learned much about the different types of ataxia.

The Group will meet in July in Clanton, AL, for a social and will have a luncheon together, followed by delicious homemade ice cream at Peach Park.

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## Western Michigan Ataxia Support Group

*By Lynn Ball*

Our first Support Group meeting was held Saturday, April 12, at the Donnelly Center at Aquinas College. Dr. James Garbern, a neurologist from Wayne State's Medical College, spoke from the heart as he addressed the group of ataxians and their guests. All benefited from his program on this rare disease.

The next meeting will be scheduled in the near future. It will be an informal gathering allowing ataxians to share and get more acquainted and to discuss possibilities for IAAD.

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## West Central Florida Ataxia Support Group

*By Crystal Frohna*

We most recently met at the Feathersound Community Church in Clearwater with 30 members present. After a sub sandwich lunch and some camaraderie we saw a presentation from New Horizon Service Dogs.

A service dog is a dog that has been professionally trained to assist a person with a disability by performing specifically needed physical tasks. Patti and Brian Goffee came to show us a black lab, Piper, and two golden retrievers, Jordan and Kanuka.

The dogs were amazing! Patti uses a wheelchair and relies on Piper to perform tasks like picking up objects that have been dropped, opening cabinet doors and room doors, even bringing her the phone if she has fallen. Just having a service dog for companionship can raise a person's spirits. Kanuka is learning sign language and will follow a verbal or gestured command.

To get on the waiting list, contact Janet Severt, Executive Director of New Horizon Service Dogs, at (386) 456-0408. Their website is *www.NewHorizonServiceDogs.org*.

**Brian Goffee with service dogs Piper, Jordan and Kanuka at the West Central Florida Ataxia Support Group meeting**

Afterwards, we discussed the fundraiser program at Sweet Tomatoes for non-profit organizations and decided to set up a date to meet there. They will donate 15 percent of the profits to your group.

We also discussed the new Our GV Rewards toolbar. Our GV Rewards is devoted to raising money for non-profit organizations. They have a shopping mall where members can shop on-line and vendors donate proceeds to the non-profit organization of your choice. We thought this was a good method to try to raise money for ataxia research. Any support groups wishing to participate, please contact me for information.

*Continued on page 36*

*Chapter and Support Group News*
*Continued from page 35*

Our next meeting will be July 11 at Feathersound Community Church in Clearwater and our featured speaker will be Dr. Theresa Zesiewicz, the head neurologist of the Ataxia Research Center at the University of South Florida. We are very excited to have her speak to us about her research. Currently she is doing a study with FA patients and in August plans on a study with SCA 1, 2, 3 and 6 patients. Members wishing to participate in the study should contact Amber or Kelly at (813) 974-5909 or e-mail Kelly at *kbarber@health.usf.edu*.

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## Metro Area Chicago Ataxia Support Group

*By Christopher Marsh*

At our meeting on April 25 at the Chicago Public Library - Edgewater Branch, Mary Anne Ehlert, founder and CEO of Protected Tomorrows, gave a very thought provoking and interesting presentation, discussing topics like future care planning, and financial and legal issues for disabled individuals. She has more than 20 years of experience in this field and demonstrated her vast knowledge of these issues when answering our questions. If Ms. Ehlert can assist you or answer any concerns that you might have, feel free to call her at (847) 522-8086, or drop her a note at *info@protectedtomorrows.com*.

……

## Maine Ataxia Support Group

*By Kelley Rollins*

The Maine Ataxia Support Group met April 25 at the Casco Bay Freeport YMCA. This meeting was most requested by our group. We had two speakers for a break-out session. Doreen Stone LMSW-CC and Kate Dulac LCPC were the speakers. We divided into separate groups, caregivers and ataxians. We spoke freely and listened to our speakers, I feel many left the meeting with hope and encouragement.

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## Chesapeake Chapter News

*By Carolyn Davis*

In March Jenean McKay represented CC-NAF at the annual meeting of ASENT, the American Society for Experimental Neuro-Therapeutics. ASENT was organized to advance the development of improved therapies for diseases and disorders of the nervous system and to facilitate the process by which new therapies are made available to patients with neurological disorders. In that regard, advocacy groups are an important partner in the organization and in moving research forward. About 40 participants stopped by the booth with an interest in ataxia.

The Ataxia Center at Johns Hopkins University sponsored an Outreach/Support/Information Meeting on March 28. More than 40 people attending the meeting had an opportunity to interact and share ideas and concerns with Dr. Joseph Savitt, Center Director, with Dr. Sarah Ying, one of the forces behind the establishment of the Center and a researcher at Johns Hopkins, and with Katie McGuire, Center Coordinator.

Dr. Ying spoke briefly about a proposed movement study research program with Dr. Tom Clouse. Interest was high, and funding is being sought. Dr. Savitt presented the three-fold mission of the Ataxia Center – patient care, education, and scaffolding for research. Attitude and exercise were emphasized, involving both the mind and the body. Several suggestions were made for topics and presenters for future meetings, the next one being scheduled for Saturday, June 27, from 12:30 to 2:30 p.m.

A group of 20 researchers, clinicians, and CC-NAF leaders were privileged to attend a dinner meeting with Dr. Susan Perlman on March 30 at Johns Hopkins in Baltimore. It was a wonderful chance to visit with her in a smaller setting, to understand the emphases she will pursue ⏩

as NAF's Medical Director, to explore collaborative opportunities, and to have a voice in the discussion of ideas and goals. It was a very pleasant evening – many thanks to the Ataxia Center for facilitating this exchange.

At a meeting of the Chapter's "A-Team" on March 26, Carl J. Lauter passed the baton of the chapter presidency to Carolyn Davis. Carl became President Emeritus; other board members will remain in their current positions. Dr. Joe Savitt and Katie McGuire represented the Ataxia Center at this meeting. There was much discussion on the future course of the chapter with regard to support group and chapter meetings, fundraising, and working with the Ataxia Center. We also honored Carl for his 14 years of capable, dedicated leadership.

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## Detroit Area Ataxia Support Group

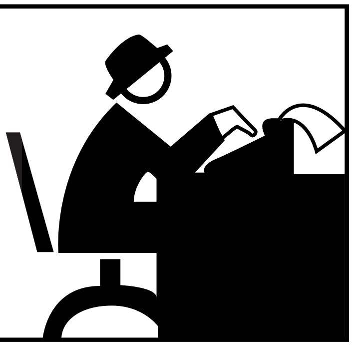
*By Tanya Tunstull*

On March 28 the Greater Detroit Area Ataxia Support Group had a great meeting – our first meeting of the year after a brief break during the winter. We welcomed several new members, and had two wonderful speakers – Margit Burmeister, PhD, Professor of Psychiatry and Human Genetics from the University of Michigan Hospital, along with her colleague, Karen Majczenko, MD, Neurologist. The presentations lasted for a couple of hours and were followed by questions from the group. Both speakers were very knowledgeable and informative.

Our next meeting was held on May 16. We had a potluck lunch and two speakers – Julie Campbell, Health Coordinator, and her colleague Kathleen who is a specialist in speech therapy and swallowing issues. We discussed problems that may occur in people who have ataxia.

Both speakers were very good and we had a very good meeting. Our next meetings will be July 18 and on the first Saturday in August. We are always happy to see new faces and hope they will continue to come! ❖

The deadline for the Fall issue of Generations is August 14



## 'Project: Cure' – Fighting for a Cure Through Music

*Project: Cure* is a new collaborative music project that aims to use music to make a difference in the lives of individuals and families facing chronic, life-threatening conditions.

The collaborative recently released a compilation CD that is full of inspirational music that *Project: Cure* founder Stefani Bush hopes will provide strength and encouragement for families and individuals during their time of need.

Stefani and her husband Ralph Bush have two children with chronic illnesses, including ataxia, and it was through their family's experience that they became inspired to use music to reach out to others facing similar situations.

Proceeds from the sale of *Project: Cure* CD's will be donated to the National Ataxia Foundation, the Immune Deficiency Foundation, and the United Mitochondrial Disease Foundation. NAF would like to thank all the individuals involved in *Project: Cure* for their hard work and generosity.

*Project: Cure* music is currently available at AmazonMP3, iTunes, Rhapsody, Napster, emusic, and *www.projectcuremusic.org*.

# Chapters, Support Groups and Ambassadors

*The following is a list of National Ataxia Foundation chapters, support groups and ambassadors. 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.*

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*Continued on page 40*

*Chapters, Support Groups and Ambassadors*
*Continued from page 39*

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## Social Networks

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

**NAF CHAT ROOM**
**Moderator - Blonde**
*www.ataxia.org/connect/chat-rooms.aspx*

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

**NAF MYSPACE GROUP**
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*Continued on page 42*

*Chapters, Support Groups and Ambassadors*
*Continued from page 41*

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*www.ataxia.org/chapters/Spokane/default.aspx*

## International Ambassadors

### American Samoa

**Bob Coulter**
PO Box 9062
American Samoa 96799
(684) 688-2437
*www.ataxia.org/chapters/BobCoulter/default.aspx*

### Australia

**Renee Moore (Nee McCallum)**
44 Lotherton Way
Hocking, W. Australia 6065
61-8-9404-7052
E-mail: moorear@bigpond.com
*www.ataxia.org/chapters/ReneeMoore/default.aspx*

### Canada

**Susan M. Duncan**
#401-1330 Richmond Rd.
Ottawa, Ontario K2B 8J6
(613) 820-7990
E-mail: smduncan1@sympatico.ca
*www.ataxia.org/chapters/SusanDuncan/default.aspx*

**Prentis Clairmont**
299 Somerset West, Apt. 402
Ottawa, Ontario K2P 2L3
(613) 864-8545
E-mail: prentis.clairmont@qmail.com
*www.ataxia.org/chapters/PrentisClairmont/default.aspx*

**Terry Greenwood**
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Winnipeg, Manitoba R3Y 1G8
(204) 488-4155
E-mail: magic1@mts.net
*www.ataxia.org/chapters/TerryGreenwood/default.aspx*

### India

**Abhinav Kedia**
207 L Model Town
Near Hero Ground
Panipat–132103
Haryana, India
Phone: 0091-0180-2681157
Mobile: 0091-0-9466355238
E-mail: kedia.abhinav@gmail.com
*www.ataxia.org/chapters/AbhinavKedia/default.aspx* ❖

## Planning Your 2010 AMM Trip?

Request an “Access Chicago” guide book to help you plan your 2010 National Ataxia Foundation Annual Membership Meeting journey!

The free book, provided by the Illinois Bureau of Tourism, is filled with information about the city including a list of accessible tours, local accessible transportation, a database of accessible hotels and restaurants, and a listing of key disability-related services and resources, including pharmacies, medical care facilities, lift, scooter and wheelchair rental and repair services, and even veterinarian services for assistance animals.

This free book can be requested by calling (800) 226-6632 or (800) 406-6418 TTY. You may also request or download a copy by visiting *www.enjoyillinois.com/brochures*.

To find out more about the 2010 AMM, see the announcement on page 25 or visit NAF’s website, *www.ataxia.org*.

# Calendar of Events

### *Thursday, June 25, 2009*

**Abilities Expo – Chicago**
June 25-27, 2009 at the Schaumburg Convention Center in Chicago, IL. *www.abilitiesexpo.com*

### *Saturday, June 27, 2009*

**Chesapeake Chapter Support Group Meeting**
12:30 – 2:30 p.m. Johns Hopkins Outpatient Center, 601 N. Caroline St., 2nd Floor Conference Room, Baltimore, MD. The Caroline St. parking garage in front of the Outpatient Center is available for a cost of about $5. Featured speaker and a break-out session for spouses/significant others. For more information or to RSVP, contact Katie McGuire, Ataxia Clinic Coordinator, at (410) 955-4894 or *ataxiaclinic@jhu.edu*. *www.ataxia.org/chapters/Chesapeake/default.aspx*

**Iowa Ataxia Support Group Meeting**
2 – 4 p.m. at Urbandale Public Library in Meeting Room B in Urbandale, IA. Dr. Robert Rodnitzky from University of Iowa Health Care Movement Disorders Clinic will be the guest speaker. For more information please contact Emily Medina at (515) 633-8620 or *emily061578@yahoo.com*. *www.ataxia.org/chapters/EmilyMedina/default.aspx*

### *Wednesday, July 8, 2009*

**Willamette Valley Ataxia Support Group Meeting**
11:30 a.m. – 1 p.m. at Albany General Hospital, 1046 Sixth Ave. SW, Albany, OR. For more information contact Malinda Moore, CCC-SLP at (541) 821-4162 or *malindam@samhealth.org*. *www.ataxia.org/chapters/Willamette/default.aspx*

### *Thursday, July 9, 2009*

**Tri-State Ataxia Support Group Meeting**
6:30 p.m. at Phillips Ambulatory Care Center (PACC), 10 Union Square E. New York, NY. To RSVP or for more information Contact Jeannie Soto-Valencia at (212) 844-8711. *www.ataxia.org/chapters/Tri-State/default.aspx*

### *Saturday, July 11, 2009*

**Kansas City Area Ataxia Support Group**
2 – 4 p.m. at the Northeast Library, 65 Wilson Ave., Kansas City, MO. For more information contact Lois Goodman (816) 257-2428 or Jim Clark at *clarckstone9348@sbcglobal.net*. *www.ataxia.org/chapters/KansasCity/default.aspx*

**Los Angeles Area**
**Ataxia Support Group Annual BBQ**
We meet every other month on the second Saturday at the Westside Center for Independent Living at 12901 Venice Blvd., Venice Beach, CA. Contact Sid Luther for more information at *harryluther@sbcglobal.net*. *www.ataxia.org/chapters/LosAngeles/default.aspx*

**North Texas Ataxia Support Group Meeting**
10 a.m. – noon at the Los Colinas Medical Center located at 6800 MacArthur Blvd. at Hwy 161, Irving, TX. Parking is FREE. Enter through the main building and follow the signs to the class rooms. Contact David Henry Jr. at *cheve11e@sbcglobal.net* for more information. *www.ataxia.org/chapters/NorthTexas/default.aspx*

**Northern California**
**Ataxia Support Group Meeting**
11:30 a.m. – 3 p.m. at Our Savior's Lutheran Church, 1035 Carol Lane, Lafayette, CA. For more information contact Deb Omictin at *rsisbig@aol.com* or (510) 783-3190. *www.ataxia.org/chapters/NorthernCalifornia/default.aspx*

**SE Pennsylvania Ataxia Support Group Meeting**
You must RSVP to the meetings. To RSVP to this meeting or for more information please contact Liz Nussear at (610) 272-1502 or *lizout@aol.com*. *www.ataxia.org/chapters/SEPennsylvania/default.aspx*

**West Central FL Ataxia Support Group Meeting**
1 – 3 p.m. at Feathersound Comunity Church, 13880 Feathersound Dr., Clearwater, FL. Contact Crystal Frohna at (813) 453-1084 or *flataxia@yahoo.com* for more information. *www.ataxia.org/chapters/TampaBay/default.aspx*

### *Saturday, July 18, 2009*

**Detroit Area Support Group Meeting**
Noon – 3 p.m. at Harper's Hospital in the Wertz Classroom 1237. For more information please contact Tanya Tunstull at *tinyt4822@yahoo.com*. *www.ataxia. org/chapters/Detroit/default.aspx*.

### *Sunday, July 19, 2009*

**Chicago Area Ataxia Support Group Meeting**
1 p.m. at the Good Samaritan Hospital – White

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Oak Room, 3815 Highland Ave., Downers Grove IL. For more information contact Craig Lisack at (847) 496-7544 or *caasg2@aol.com*. *www.ataxia.org/chapters/Chicago/default.aspx*

### *Tuesday, July 21, 2009*

**Twin Cities Ataxia Support Group Meeting**

7 p.m. at the Presbyterian Homes of Roseville at 1910 West County Road D, Roseville, MN. For more information contact Lenore Schultz at *lschultz@bitstream.net*. *www.ataxia.org/chapters/TwinCities/default.aspx*

### *Saturday, August 8, 2009*

**Detroit Area Support Group Picnic**

1 – 5 p.m. at Sherry's House in Brooklyn, MI. For more information please contact Tanya Tunstull at *tinyt48221@yahoo.com*. *www.ataxia.org/chapters/Detroit/default.aspx*

**Kansas City Area Ataxia Support Group**

2 – 4 p.m. at the Northeast Library, 65 Wilson Ave., Kansas City, MO. For more information contact Lois Goodman (816) 257-2428 or Jim Clark at *clarckstone9348@sbcglobal.net*. *www.ataxia.org/chapters/KansasCity/default.aspx*

**North Texas Ataxia Support Group Meeting**

10 a.m. – noon at the Los Colinas Medical Center located at 6800 MacArthur Blvd. at Hwy 161, Irving, TX. Parking is FREE. Enter through the main building and follow the signs to the class rooms. Contact David Henry Jr. at *cheve11e@sbcglobal.net* for more information. *www.ataxia.org/chapters/NorthTexas/default.aspx*

**Northeast Florida Ataxia Support Group Meeting**

1:00 p.m. at Baptist South Hospital in Jacksonville (off I-95) in the Azalea and Begonia rooms. For more information please contact June McGrane at (904) 273-4644 or *jmcgranepvb@bellsouth.net*. *www.ataxia.org/chapters/NortheastFlorida/default.aspx*

### *Wednesday, August 12, 2009*

**Willamette Valley Ataxia Support Group Meeting**

11:30 a.m. – 1 p.m. at Albany General Hospital, 1046 Sixth Ave. SW, Albany, OR. For more information contact Malinda Moore, CCC-SLP at (541) 821-4162 or *malindam@samhealth.org*. *www.ataxia.org/chapters/Willamette/default.aspx*

### *Saturday, August 15, 2009*

**Orange County Ataxia Support Group Meeting**

1:30 – 4 p.m. at the Orange Coast Memorial Medical Center (in the basement, next to the cafeteria), 9920 Talbert Ave., Fountain Valley, CA. For more information contact Daniel Navar at *dnavar@ucla.edu*. *www.ataxia.org/chapters/OrangeCounty/default.aspx*

### *Tuesday, August 18, 2009*

**Twin Cities Ataxia Support Group Meeting**

7 p.m. at the Presbyterian Homes of Roseville at 1910 West County Road D, Roseville, MN 55112. For more information contact Lenore Schultz at *lschultz@bitstream.net*. *www.ataxia.org/chapters/TwinCities/default.aspx*

### *Saturday, August 22, 2009*

**Greater Atlanta Ataxia Support Group Meeting**

At Emory Center for Rehabilitation Medicine, 1441 Clifton Rd., NE Room 101, Atlanta, GA. For more information please contact Greg Rooks at (404) 822-7451 or *atlantaataxia@gmail.com*. *www.ataxia.org/chapters/Atlanta/default.aspx*

### *Wednesday, September 9, 2009*

**Willamette Valley Ataxia Support Group Meeting**

11:30 a.m. – 1 p.m. at Albany General Hospital, 1046 Sixth Ave. SW, Albany, OR. For more information contact Malinda Moore, CCC-SLP at (541) 821-4162 or *malindam@samhealth.org*. *www.ataxia.org/chapters/Willamette/default.aspx*

### *Thursday, September 10, 2009*

**Ironman for Ataxia**

140.6-mile Triathlon in Madison, WI Sept. 10-13. Joe Golminas will be a participant and fundraiser for this event. Funds raised by Joe Golimas are in support of the National Ataxia Foundation. *https://www.kintera.org/faf/donorReg/donorPledge.asp?ievent=296288&supid=249510606*

**Tri-State Ataxia Support Group Meeting**

6:30 p.m. at Phillips Ambulatory Care Center (PACC), 10 Union Square E. New York, NY. To RSVP or for more information Contact Jeannie Soto-Valencia at (212) 844-8711. *www.ataxia.org/chapters/Tri-State/default.aspx*

### *Saturday, September 12, 2009*

**Denver Area Ataxia Support Group Meeting**

1 – 4 p.m. at the Swedish Hospital and Medical Conference Center (Spruce A&B), 501 East

*Continued on page 46*

*Calendar of Events*
*Continued from page 45*

Hampden Ave., Englewood, CO. For more information contact Tom Sathre at *tom_sathre@amc.org* or (303) 794-6851. *www.ataxia.org/chapters/Denver/default.aspx*

**Kansas City Area Ataxia Support Group**
2 – 4 p.m. at the Northeast Library, 65 Wilson Ave., Kansas City, MO. For more information contact Lois Goodman (816) 257-2428 or Jim Clark at *clarckstone9348@sbcglobal.net*. *www.ataxia.org/chapters/KansasCity/default.aspx*

**Los Angeles Area Ataxia Support Group Meeting**
We meet every other month on the second Saturday at the Westside Center for Independent Living at 12901 Venice Blvd., Venice Beach, CA. Contact Sid Luther for more information at *harryluther@sbcglobal.net*. *www.ataxia.org/chapters/LosAngeles/default.aspx*

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**SE Pennsylvania Ataxia Support Group Meeting**
You must RSVP to the meetings. To RSVP to this meeting or for more information please contact Liz Nussear at (610) 272-1502 or *lizout@aol.com*. *www.ataxia.org/chapters/SEPennsylvania/default.aspx*

**West Central FL Ataxia Support Group Meeting**
1 – 3 p.m. at Feathersound Comunity Church, 13880 Feathersound Dr., Clearwater, FL. Contact Crystal Frohna at (813) 453-1084 or *flataxia@yahoo.com* for more information. *www.ataxia.org/chapters/TampaBay/default.aspx*

### *Tuesday, September 15, 2009*

**Orange County Ataxia Support Group Meeting**
1:30 – 4 p.m. at the Orange Coast Memorial Medical Center (in the basement, next to the cafeteria), 9920 Talbert Ave., Fountain Valley, CA. For more information contact Daniel Navar at *dnavar@ucla.edu*. *www.ataxia.org/chapters/OrangeCounty/default.aspx*

**Twin Cities Ataxia Support Group Meeting**
7 p.m. at the Presbyterian Homes of Roseville at 1910 West County Road D, Roseville, MN 55112. For more information contact Lenore Schultz at *lschultz@bitstream.net*. *www.ataxia.org/chapters/TwinCities/default.aspx*

### *Sunday, September 20, 2009*

**Chicago Area Ataxia Support Group Meeting**
1 p.m. at the Good Samaritan Hospital – White Oak Room, 3815 Highland Ave., Downers Grove IL. For more information contact Craig Lisack at (847) 496-7544 or *caasg2@aol.com*. *www.ataxia.org/chapters/Chicago/default.aspx*

### *Saturday, September 26, 2009*

**Central TX 1st Annual Joe Thell IAAD Walk n' Roll**
Beginning at 10 a.m. at San Gabriel Park at the Gazebo. Please join us at the 2009 Central Texas IAAD to participate in the 1st Annual Walk n' Roll to benefit the National Ataxia Foundation. Following the Walk n' Roll there will be live music, potluck goodies, a raffle, and a candle lighting ceremony. This event is in loving memory of Joe Thell. For more information please contact Linda Crawley at (254) 793-9409 or *linda@joethell.com*. *www.joethell.com/walk_n_roll.aspx*.

**Detroit MI 1st Annual IAAD Walk n' Roll**
10 a.m. registration, 11 a.m. start at Detroit's Tri-Centennial State Park, 1900 Atwater St. (between Orleans and St. Aubin). Parking on St. Aubin in lot. Picnic immediately following walk. No registration fee – donations only. Opportunity drawing with all proceeds to benefit the National Ataxia Foundation. To volunteer and for more information please contact Tanya Tunstull at (313) 736-2827 or *tinyt48221@yahoo.com*. *www.ataxia.org/chapters/ Detroit/default.aspx*

**San Diego 3rd Annual**
**Charley McLaughlin IAAD Walk n' Roll**
8:00 a.m. at Tuna Harbor Park in downtown San Diego. No registration fee – donations only. All proceeds benefit the National Ataxia Foundation. To volunteer and for more information contact Earl McLaughlin at (619) 447-3753 or *sdasg@cox.net*. *www.ataxia.org/chapters/SanDiego/default.aspx*

**Orange County and Los Angeles Support Groups 1st Annual Walk n' Roll**
8 a.m. at the city of Long Beach's Shoreline Aquatic Park area. In memory of Kay Bell. Please call (323) 788-7751 for the latest information. ❖

# 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 March 2009 through April 2009. 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.

John Aalberts
Susan Alexander
Paul Anderberg
Badr Awad
Donald Banta
Catherine Baumgartner
Jane Brewer
Jaime Brooks
Nancy Brophy-Brooks
Kyle Bryant
Peggy Burttram
Marion Clark
Deborah Corney
Janet Coyne
Allan Crawford
Karen Crawford
Judy Crawford-Weidick
Marcia Cyganowski
John Daigle
Anita Dillaha
Ernest Di Monte
Sherry Dombrowski
Denise Dudley
Rev. William Dugal, III
Diane Dusbiber
Katie Ernzen
William Evens Sr.
Kathleen Foster
Julie Frenz
Bonna George
Heather Gregson
Paschal Guercio
Craig Haarsma
Jane Haley
David Henry Jr.
Greg Hess
Jeffrey Hinch
Virginia Horel
Krista Humes
Scottie Johnson
Abby Johnston
Eileen Jubina
Fred Kaffke Jr.
Dr. David Kalamas
Robert Keithly
Regina Kelly
Thomas Kennedy
Hakim Khan
Salim Khan
Maj. (Ret) Young Kim
Brian Kohl
Jordan Kohl
Jamie Kosieracki
Catherine Koukl
Denise L'Abbe
Hrysoula Lane
Soula Lane
Rodger Larsen
Gabriel Law
Linda Lee
John Lehto
Milly Lewendon
Tony Lewendon
Phyllis Lindberg
Jana Lintz
Julie Lipari
Alex Lomick
Mendall Long
Stephanie Lovelock
David Lowsley
Ralph Luciani
Carly Magnuson
Deborah Markham
Zona Markus
Andy Matala
JoAnn McKee-O'Hern
Earl McLaughlin Sr.
Earl McLaughlin Jr.
Linda Mitchel-May
Minnie Molini
Holly Montgomery-Deane
Patrick Moore
Dolores Morello
Thomas Musilli
Bruce Nanninga
Rhonda Page
Mildred Palese
Cathy Peets
Angelo Pepe
Ikue Pollak
David Price
James Riley
Janet Riley
Don Roemke
Jenney Roemke
Robert Runyan
Greg Russell
James Russell
Patricia Rust
Jeff Scheffler
Josephina Schembre-McCabe
Derek Semler
Collin Shannon
Cynthia Shannon
Kevin Shannon
Sherry Sharp
Steven Shears
Charles Snow Jr.
Hilbert Spector
Joseph Stamler
Darrell Stenseth
Heidi Suggs
David Summers
Larry Swier
Neil Thompson
Dorothy VanDoren
James Van Vleet
William Walus
Anna Widing
Carrie Williams
Jill Wright
Linda Yeager
Debbie Young
Rona Zelniker

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## Remembering NAF in Your Will

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

Most of the time the Foundation is unaware of the kind acts of these champions until after they are gone, but each time we are deeply touched and honored by their selfless commitment in helping others.

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

We are truly thankful for their humanitarian and compassionate acts and we will be eternally grateful for the impact they have made in helping ataxia families. Their legacy lives on in the hope they have given ataxia families.

Perhaps this is the time to consider adding the National Ataxia Foundation in your will.

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

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

## GIFT – HONOR – MEMORIAL

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

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

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

My contribution is:

☐ In Memory ☐ In Honor ☐ Gift Membership

Name ____________________
Occasion ____________________

Send Acknowledgment Card to:
Name ____________________
Address ____________________
City/State/Zip ____________________

From:
Name ____________________
Address ____________________
City/State/Zip ____________________

## MEMBERSHIP

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 ____________________
City/State/Zip ____________________
E-Mail ____________________

## 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 # ____________________
Exp. Date ____________________
Signature ____________________
Phone Number ____________________