Generations

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Review of What We Have Learned

By John Day, MD, PhD

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

The Swamp of Ignorance. What oftentimes is the starting place for people getting involved in ataxia is what I refer to as the *swamp of ignorance*. You start in this quagmire where you and you alone, or if you are parents watching your child, have a sense that something is wrong but you really don't know what. You don't know where to go but you go to a physician and you may or may not get answers. Often, early on, you are told something like this; "There is nothing wrong, everybody is a little bit clumsy and so go away and come back if there are any new problems." So you endure this lack of progress for a while until you finally reach someone who makes a diagnosis and you now have a name you can put on this. But then you are left in, what I have referred to as, a *desolation desert*.

The Desolation Desert. You have a name but you don't really know what it means. You don't know where it is going. You certainly don't know what you are going to do about it and you often feel that you are the only person in the world who is enduring this kind of thing.

Every year when I come to NAF's annual meeting, I ask first-time attendees whether or not they have ever met another person with ataxia; oftentimes they haven't. I think that is a tremendous burden and it is one of the main reasons that this organization was founded so that you find other people who you can talk to who have this disease. That way we can marshal our resources to work together to

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You Could Be Published!

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

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combat these diseases.

I want to point out that in addition to what this is like for you as a patient, there is a comparable situation for the physician who is taking care of you. So when a person walks into a physician's office and says that they have certain symptoms or something is not working quite right, the physician is also somewhat ignorant and unaware of what is going on. At the outset it is very unclear. The physician can start doing a gazillion tests or try to wait and see what happens so that somehow what is going on can be deciphered without a lot of hoopla. But it is often very hard. And then, once you do get a diagnosis, the physician as well, reaches this point of not really knowing what that means. Not knowing what the rate of progression is going to be, and not knowing exactly what symptoms you might endure because ataxia does a lot of different things and affects people differently. So there are comparable elements of ignorance and despair that comes up from the clinician as well as the patient.

The Treatment Ridge. But eventually you work your way through the *desolation desert* and you find out that, yes, you do have this named disease. You do have an understanding now of where it's going to go and how you are going to manage it. But what you really want to know is whether or not you are going to be able to effectively treat it. So by this time, you are scouring the web, coming to annual meetings, trying to find out what the latest in research is and whether there is a treatment that is really effective. It is at that point that the clinicians and patients together and families reach, what I refer to as a *treatment ridge*. You now see before you this daunting ridge, this daunting mountain that you know you are going to have to scale as you've come to understand not only the name of your disease, but what's going on underneath it and that there are really complex issues that are going to have to be dealt with. It is rather a challenge for all of us.

The Trail to Research. With the *Blazing a Trail in Research* theme of this meeting, I will now go through the various talks that have been made to encapsulate some of the ideas so we can see where we are going in this field of ataxia.

I will start with the overview talks that Drs. Ranum, Fahey, and Orr gave. Dr. Ranum brought you up-to-date on genetics. She helped you understand not only the basic genetics but she went way beyond Mendel to help you understand where genetics is today and how that is leading with these neurological diseases. *(Editor's note: Gregor Johann Mendel has been often called the father of genetics for his study of the inheritance of traits.)* Dr. Fahey, regarding the Australian experience, and Dr. Orr, regarding the experience within the ataxia community overall, discussed where things are in terms of understanding, management and treatment of these diseases. What they have done is shown you that there already is a "trail that has been blazed." We have a trail that has been blazed for Friedreich's; it has been blazed for SCA 1; it has been blazed for a number of different ataxias. We know how to name it, we know what it is going to do at the cellular level and in terms of the affects on the brain. Hopefully now we can begin to see how the research is scaling that *treatment ridge* to get to the edge of being able to treat these diseases.

It is very exciting but the pathway is not much more than a footpath. We don't have a lot of traffic on it yet. There are investigators at every point of the way, there are patients eager to get to the top of the *treatment ridge*. So we step back to the *swamp of ignorance* and realize that it always starts with a single patient and an insightful clinician who sees that patient and realizes that there is something going on here that they need to try to understand. He or she will work with

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the patient and try to come up with a name and maybe even identify a new disease. Then it often takes a group of people trying to move forward faster. So what happens is the clinicians will pair up with basic scientists and in that combination is a small group of investigators who will identify genetic causes of diseases and now be able to put a name on it. That was exemplified by several speakers at this meeting.

Dr. Alaedini talked about the affects of the immune system on the central nervous system and how there can be an immune-mediated form of ataxia. Dr. Subramony went through a long list of various things that can be responsible for the sporadic ataxias. There are a lot of people with sporadic ataxia and so there is a lot of work to do to help them get to the point where they have a name for their disease that is more than just sporadic ataxia. And then Dr. Zoghbi with SCA1, Dr. Puccio with Friedreich's, and Dr. Wood with the brand new finding of what's going on in SCA11, has shown us how this process really works. The clinician, making an observation of a form of ataxia, will work with the basic scientist to come up with the genetic cause that allows us to begin the process, at least get on the *trail to research*.

> **"We've got the ability to put things together and to understand it."**

Things are easier now. We have the methods. We've got the ability to put things together and to understand it. This footpath is now getting to be a dirt road or maybe even a paved road so that we can do this much more quickly. At our investigators meeting, Dr. Singleton showed us a new way for helping to identify genetic causes of disease that may make that process even faster. Dr. Burmeister also spoke with us about this. There are a number of people who are trying to get this research to increase so that we have more people who are being diagnosed more quickly.

As we move on into the *desolation desert* though, we really need a bigger team. It takes more to really understand what is going on in these various forms of ataxia. We can't do that with a single clinician and a single basic scientist. We need a team of basic scientists working together to understand, how the molecular changes, the genetic changes end up causing the nerve cell death and degeneration that underlies the ataxias. This is a much, much bigger enterprise. To begin to really understand it is an essential feature towards identifying targets that can be treated. This element of the trail that has been blazed was exemplified by several speakers. Dr. Schmahmann and Dr. Gomez illustrated several of the new methods that are available to help understand and evaluate patients. Those methods include the exquisitely fancy MRI scans that Dr. Schmahmann showed or some of the new protein discoveries that Dr. Gomez is able to identify in patients while they are alive. This is the kind of research that is leading us to having a better understanding of this disease to tell us how we can manipulate and treat it.

Dr. Koeppen has shown you a number of ways that autopsy specimens can also give us more insight into these diseases. I encourage those of you who are willing, it is obviously a personal choice, but when you are done using your brain, if you want to contribute it, I strongly encourage you to do so. It is an awkward subject to bring up and I know that it is not right for everyone and you have to make your own decision but there is no other way to identify some of the abnormalities than with autopsy review. The NAF and Dr. Koeppen can help in facilitating that for people who are willing to donate autopsy specimens. Dr. Wilmot showed how the NAF is working with the investigators to ▸▸

coordinate this. Because we need this bigger team to work with the patients and the investigators at different stages, at different institutions, in different countries then we need to have that infrastructure in place. That is what a registry is all about and we are trying to come up with ways of simplifying it so we can get the information as easily as possible. That has led us to having a somewhat easier way and it is going to get even easier for us to begin to understand not only what the name of your disease is but what its cellular features are so that we can start identifying those treatments.

This is what you are all wanting. This is what we all want as investigators. This is about developing treatments, being able to slow down the progression, stop the progression, hopefully at some point to actually reverse the disorders. The investigators have been able to show in numerous ways how complex that is and how we really need to have a much larger enterprise to attack these conditions. We need to move into the 21st century. We need the engineering to get up and over that mountain, the *treatment ridge*. This will not be done in just one or two labs. This will take the basic scientists working with the medicinal chemists working with the various high throughput screen drug discovery people working with pharmaceutical industries coming up with the methods so that we can take this knowledge base that we have now to identify the treatments. It is not going to be easy but it is there. The little winding footpath that we now have going up the mountain has shown us the way. We know that it can be done, now we have to start ramping it up so we have more treatments for more diseases that are more effective. I am confident that that is happening, although it is not happening fast enough. I am confident that over time there will be treatments and that is what the last speakers were talking about.

Dr. John Day

Dr. Schut did a tremendous job of showing us that you can get part way up this slope with drugs that are already available. *(Editor's note: See Dr. Schut's reprinted presentation on page 9.)* Some of the symptoms, some of the problems that accompany having ataxia are already treatable or at least amenable to some kind of symptomatic management so that we can begin to control them. I hope that you took heart from the talks by Drs. Keats and Zoghbi and Perlman about all of the efforts that are going on. This is not just a single trial now, this is not a single drug or a single approach. There are multiple things that are being developed for multiple diseases. The whole RNAi approach has tremendous potential. Dr. Zoghbi illustrated to you, not only that something as simple as lithium might be able to affect the course of SCA1, but that she and Dr. Orr are working together to identify numerous other targets that they can approach in various ways. They understand the biology well enough so they can actually start focusing on ways of manipulating it. Dr. Perlman detailed the numerous studies that are now underway for Friedreich's ataxia but also the other ataxias so that we are moving into the therapeutic era and you will begin to see that this way up the hill is being constructed. We are not there yet for all diseases, we are closer for some than for others, but we can begin to see that there is a potential of our getting over the hill and down to the *healthy valley* on the other side.

Blazing a Trail is almost accomplished. We've blazed a trail, we've got the foot trail, we have the means to increase the traffic on that trail. The upshot of this meeting is quite hopeful. There's a lot to do, but there's more reason than ever for

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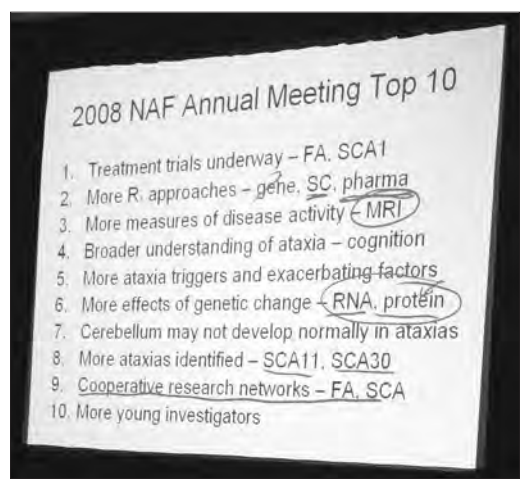
us to put our shoulder to the wheel and get things done.

I will go over the **"Top Ten List"** of what I pulled out of the important scientific lessons from this meeting:

Number Ten. We have more young investigators involved and you can be hopeful in that. NAF's new Young Investigator Research Award brings people in each year to increase the number of young investigators working on ataxia. At our investigators meeting we had 120 investigators of which one-third were young investigators. That's tremendous. Forty young investigators are working on ataxia and we are very optimistic that we can encourage them and help support them so they can move into fruitful careers to attack these many diseases.



The "Top Ten List"

Number Nine. The cooperative research networks are forming. You have heard from Dr. Wilmot about the registry. You have heard from Dr. Perlman about the number of registries and data bases that are being developed. Drs. Subramony and Ashizawa, are very integrally involved in this. We are doing this internationally so that we are connecting up with the European efforts and tying in the various countries around the world so that we can have the number of patients we need to do these studies appropriately. We can be very excited and I hope to report back to you of the further increases as we move along.

Number Eight. More ataxias are being identified. More patients are coming out of that swamp of ignorance so that we can actually put a name to their disease. I know that is not the be-all and end-all, but at least it gives you a target. We have identified at least two new forms of ataxia, each one of which helps us chip away at not only that pool of people who go undiagnosed but in helping us understand what goes on in these diseases in general.

Number Seven. The cerebellum may not develop normally in ataxias. This did not come up in this meeting much but it was a theme during our investigator's meeting. We often ask what the age of onset was for a disease. Sometimes you can give a specific age, but often times it is a bit fuzzier than that, the onset might have gone back much earlier. You may remember that you never really were agile or something similar. One of the things that a number of us are interested in is trying to understand whether something goes on very early in the development of the brain that sets the ground work for the some of the later onset degeneration. That is a key element that we need to investigate more and the investigators meeting had several key research labs represented here that allowed us to begin to attack that. I think it is a very important thing for the future.

Number Six. We are beginning to understand the increase in spectrum of the effects of these genetic changes so that while many of the diseases are polyglutamine diseases, not all of them are, and not all of the polyglutamine diseases necessarily work in the same way. This came up in Dr. Ranum's talk and also Dr. Perlman's talk and others. There are multiple ways that these genetic changes are causing disease, so that sometimes the skeleton inside the cells are abnormal and we are developing a new group of diseases, as Dr. Orr mentioned, the cytoskeletal disorders that might have a completely different approach towards treatment. The RNAi disorders, it might be that there is an abnormality of RNA processing that needs to be directly ▸▸

confronted or attacked if we are going to control those diseases. Maybe that is going to demand a different form of treatment. Just understanding these things is going to be very useful as we move forward.

Number Five. We are understanding more about triggers and exacerbating factors that lead to ataxia and this came up in the talk about immune system that can affect the disease. There were a number of investigators at the investigators meeting who noted the fact that the immune system also can affect ataxia and the nervous system. Maybe that is going to be another means of treating.

Number Four. Dr. Schmahmann's increasing evidence that cerebellar disease does not limit itself to abnormalities of movement. There are also abnormalities of thinking, abnormalities of emotion in some forms. There is a lot more to discover but there is a lot that can be addressed now. That played out in Dr. Schut's talk where he spoke about different treatments that are available right now and that some of these cognitive affects, some of these emotional affects can be addressed immediately.

Number Three. There are more measures of disease activity. I refer you to the talks by Dr. Gomez and Dr. Schmahmann, showing these very fancy MRI studies. They are not going to be useful in a broad multi-center study but they will be useful in terms of understanding diseases better.

Number Two. We have more treatment approaches that are being developed. We had a talk on another kind of RNA interference being developed for clinical trial in ALS that is supposed to start this year. It should be something if it works that it might give us another means of attacking some of the ataxic disorders. We did not talk much about stem cells but they have not gone away, there is still interest in that approach and some new ideas about exactly how to do that. We have talked fairly extensively about the drugs being developed.

Number One. Lastly, the number one take home message is that some of these treatment trials are now underway. For FRDA there are several that are on-going around the world, and this SCA trial with lithium is through the RIB, the regulatory agency at NIH, and will be launched in a matter of weeks.

We can be hopeful, we are not there yet, but we have the ability to identify what diseases are, to figure out what's going on with them and to begin to scale that *treatment ridge*, that currently prevents us from being able to treat them, so that hopefully, hopefully we will have meaningful treatments. Thank you. ❖

Research Subjects Needed

Research subjects are currently being sought for a questionnaire study of changes in memory, thinking and decision making skills in patients with SCA.

The study is being conducted by Dr.'s S.H. Subramony and Vicki Soukup at the University of Texas Medical Branch, Department of Neurology, 301 University Blvd., Galveston, TX, 77555-0539.

The research involves filling out questionnaires by both the patient and a close family member or caregiver.

Those willing to participate must have a diagnosis by gene test of one of the following: SCA 1, 2, 3 (Machado-Joseph disease), 6, 7, 8, 10, 12, 13, 14, and 17. Patients who are diagnosed as such without a gene test but based on a diagnosis of other family members will also be considered.

The questionnaires may take about an hour to complete.

If interested, please contact Dr. Subramony at the above address or by phone at (409) 772-2646 for more information.

From the Desk of the Executive Director

Summer is finally here in Minnesota. In rural Minnesota, the planting has been completed and the crops are beginning to grow for a Fall harvest. The National Ataxia Foundation has also planted a number of research seeds through its research "seed monies" awards in early Winter and those studies are beginning to bear fruit in a better understanding of ataxia.

Summer is also the time for the NAF Annual Membership Drive. The National Ataxia Foundation is a membership supported nonprofit organization and the 2008 Annual Membership Drive, which began in early June 2008, helps support important programs and services for ataxia families.

Michael Parent

NAF membership support helps bring scientists and clinicians together through the Ataxia Investigators Meetings. Earlier this year the Foundation hosted the 2nd International Ataxia Investigators Meeting. More than 120 world-leading ataxia scientists, clinicians, and young investigators from around the world attended this four-day meeting. This meeting enabled researchers to share information, encouraged cooperation and collaboration, and ultimately to help accelerate world-wide ataxia research.

Membership dues also help in producing various important ataxia publications, including the 48-page quarterly news publication, *Generations*. In addition, membership allows the Foundation to provide current and accurate information on its web site, *www.ataxia.org*, and to provide information on ataxia to all those who request information on ataxia.

It is through membership that NAF is able to provide ataxia chat rooms, bulletin boards, NAF Pen Pal Program, and medical referrals through the neurological resource lists. Membership support also helps bring ataxia families together to share and learn through ataxia support groups and chapters and also through the annual membership meetings.

Being a member of the National Ataxia Foundation will also benefit you personally. Members receive a discounted registration fee to attend the Annual Membership Meeting that will take place in March 2009 in Seattle. By renewing your membership or becoming a new member now, you will be assured the reduced rate when you register for the annual meeting. Members are also assured of uninterrupted receipt of the *Generations* newsletter providing readers with the most current information on research and medical advances in all the types of ataxias.

Your membership dollars work hard in giving help, hope, and understanding and unites each of us as partners in the fight against ataxia. If your membership is expiring or you are not yet a member, please become an NAF member today. Please use the back page of *Generations* to become a member, or you may go on-line to become a member at *www.ataxia.org*.

Your membership support truly does make a difference. Thank you. ❖

TISSUE DONATION

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

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Medication Considerations in Ataxia

By Lawrence J. Schut, MD

Lawrence J. Schut, MD, graduated from the University of Minnesota Medical School in 1962 and began ataxia research in 1958, one year after the National Ataxia Foundation was founded. He completed his residency in neurology and a fellowship in Neurochemistry in 1967. Dr. Schut became NAF's Medical Director in 1971. He has been involved in the clinical support teams in the discovery of SCA1, SCA5, and SCA8 mutations. Dr. Schut is currently practicing part-time in St. Cloud, Minnesota with CentraCare Clinic, a multispecialty group. He primarily cares for patients with ataxia. He is a member of the NAF Board of Directors and the NAF Medical Research Advisory Board.

The following is an edited presentation from the General Session that Dr. Schut gave at the 2008 NAF Annual Membership Meeting in Las Vegas, NV. The hand-out that was distributed at the meeting can be found on NAF's website www.ataxia.org under Events, 2008 Annual Meeting, 2008 AMM Presentations.

There are a number of symptoms that may accompany ataxia. They include incoordination, falls, dizziness, muscle fatigue and cramps. This talk is about medication. I think medication can provide relief if you can't live with your symptoms. I don't encourage my patients to "just live" with what they have. I encourage them to tell me what their other problems are besides the ataxia, what symptoms they have and how they are living with them and how the ataxia impacts their lives. I would encourage you to pay attention to these symptoms and not be afraid to discuss them with your doctor.

"All medications have potential for side effects."

However, there are some general principles to consider regarding medication intervention:

1. The cause of ataxia should be ascertained at the very beginning to make sure that you don't have a treatable ataxia, that is, ataxia due to low thyroid, deficiency of B12 or vitamin E, that you don't have some sort of toxic process going on due to inappropriate or appropriate medications. For instance, taking Dilantin for many years can cause a cerebellar syndrome which is similar to the pure cerebellar ataxias.

2. We don't have medications that significantly ameliorate the main symptom which is ataxia. Some benefit has been seen with the drugs, amantadine and buspirone. I have had a couple of people who have been helped a little by these drugs but nothing consistently.

3. The main reason for using any medications is to help manage bothersome symptoms and to intervene in life threatening complications.

4. The symptom to be treated should have significant negative impact on the patient before the medication should be used. The risk benefit ratio should always be assessed. Too often the patient goes on a drug not knowing what the risks are.

5. All medications have potential for side effects.

6. Multiple medications should not be started simultaneously. The only time it is appropriate to start more than one new drug at a time is when a patient is in the hospital.

7. Any drug that has potential for side effects of lightheadedness, drowsiness or increased risk for falls should all start at a very low dose and increase only as tolerated.

8. Once started on a medication, one must be especially careful to prevent falls when getting up at night. This is one of the concerns that I have when I start someone on any drug of any type;

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will it make your falling worse?

9. Always tell your doctor the exact name and dosage of any prescribed medication and/or supplements you are taking. In fact, it is best to make a list and take it with you to your doctor's appointment. Do not expect a doctor to recognize all your medications just because you have a handful of them in your possession.

10. Finally, a general principle. Dr. C. Everett Koop said, "Drugs don't work on people who don't use them." Take your medications as they are prescribed and only hold back if they are giving you some side effects or if you have been given some leeway on how you may take them, that is on a PRN basis. *(Editor's note: PRN is an abbreviation for "pro re nata," which means "as needed.")*

Now we will look at some of the symptoms that are bothersome.

The ataxia itself. Symptom management of ataxia is one of the most challenging things because a person who has ataxia has a symptom that is very difficult to treat. The slurred speech, the incoordination, the imbalance are all due to degeneration of the cerebellum and its connecting fibers. As you all know, you can't treat the ataxia with any reliable drug. Some people have tried amantadine and buspirone but they have very limited usefulness and are rarely of benefit. However, physical activity, aqua-therapy and, in certain sporadic ataxias, a gluten-free diet can be helpful. I observed Dr. Thomas Clouse, "Dancing with Ataxia," showing people how they can walk better with their ataxia. Now that is an intervention that I agree with. It provides exercise, more sense of balance and ability to keep on one's feet.

The symptom of fatigue is not as common in ataxia as in multiple sclerosis, but it can cause a lot of hassle at the end of the day when you are trying to get your work done, have dinner or stay up with the kids. It can be caused by sleep deprivation, more than anything else or shift work. There are too many ataxians who do shift work. I have one who works from 2:00 in the afternoon to 11:00 at night. I have another man who works in truck repair from 11:00 at night until 7:00 in the morning. He is tired all the time; he is always fatigued. Sometimes the fatigue can be due to depression, sometimes to insufficient exercise. When sudden worsening of fatigue occurs, make sure that you are evaluated for an infection, particularly of a urinary type or skin infection or pneumonia. These can be treated with antibiotics. How do you keep yourself adequately rested? Get those eight hours of sleep each night and a nap during the afternoon, if necessary. Exercise. There is a drug for shift work fatigue called Provigil (modafinil). It is a very expensive drug. If you use it off-label just for fatigue or depression or tiredness, it is okay in some instances, but definitely have your doctor carefully consider the appropriateness of its use.

Anxiety and depression are normal responses for a person who has multiple losses and increasing disability. Bipolar illness is also found in people who have ataxia. Social loss and stress in relationships and financial concerns are all causes of depression and anxiety. I will often recommend counseling and psychiatric care even before antidepressants. Sometimes, however, we go directly to antidepressants. If there is a financial concern and you are disabled, apply for Social Security as soon as possible. Traveling as much and as long as possible is a good outlet. Increase your telephone communications. Volunteer and increase your social contacts. Medications that I would recommend include SSRIs (selective serotonin reuptake inhibitors). I am not going to recommend one particular drug over another. This is for you to work out with your doctor to find which medication is best for you.

Restless legs syndrome is another untoward symptom. It is surprisingly common in ⏩

people with ataxia but it may not be due to the ataxia itself. It is an urge to move one's legs and is sometimes a creepy, crawly sensation. It is usually worse late in the evening and is improved by resting. Sometimes you will find that there is low iron in the blood. I recommend that people have their blood levels checked for total iron, ironbinding capacity, hemoglobin and ferritin. If low, then iron supplements may relieve the symptoms. If not, try Mirapex and Requip. (You have seen the television commercials extolling these drugs.) Rarely we use the Parkinson's drug, carbidopa-levodopa with some success. They are all quite expensive but often helpful.

Muscle cramps are not the same as restless legs syndrome; these are the cramps you get in your little foot muscles or calf muscles, sometimes elsewhere. Pregnant women often have them. One can quickly get out of bed to straighten the leg to make the cramp go away. Sometimes you can successfully press your foot against the footboard. Cramps may occur rarely with low potassium or magnesium. I would recommend that potassium and magnesium levels be checked in those people with frequent cramps. I do not recommend potassium supplementation without a doctor's input. Magnesium is available over the counter. Calcium may help (about 1-2 grams per day) and is also available over the counter. Quinine was used successfully for years but is now only approved for malaria and the FDA has advised against its use for leg cramps. Drugs which may be especially helpful include gabapentin and verapamil.

Dr. Lawrence Schut

Spasticity is a frequent problem in certain types of ataxias. This is increased muscle tone or tight muscles. It is associated with involuntary muscle spasms in which the legs draw upward or extend. They are stimulated sometimes by tight clothing or by painful stimulation of the lower limb(s). I recommend that people decrease their skin irritation, remove tight clothing or treat an underlying bladder infection that may sometimes aggravate spasms. Muscle stretching and physical therapy are very helpful and the medications that are recommended are generally quite good. I particularly like to use baclofen, diazepam or tizanidine. The latter is more expensive. Dantrium has some possibilities for liver toxicity and so I am quite loathe to use it as a general rule. Botulinum toxin (Botox) can be useful for selected muscles.

Tremor may be a part of ataxia and that is a problem where I would recommend that you have a clear cut diagnosis as to the type of tremor that you have. I will mention them briefly. There is what we call a physiologic tremor. This is the tremor that you have as a normal part of living. The other types of tremors are resting tremor, benign essential tremor, postural tremor and a kinetic tremor. There are various types of medications that are used for each. Beta-blockers and primidone are the mainstays.

Jittery eyes is a symptom that some people have. It is a symptom associated with SCA6 and other kinds of ataxia. I have several patients who claim that they cannot read because the pages are jumping so badly. Recently, Memantine, an MNDA receptor antagonist, used to treat Alzheimer's disease was found to be somewhat useful for jittery eyes. So you can talk to your doctor about using an Alzheimer's drug for your jittery eyes.

Sexual dysfunction is found in a relatively small number of ataxia patients and maybe as one is getting older it comes along as a problem due to aging. It is more commonly seen in the

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Medication Considerations in Ataxia
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sporadic ataxias particularly multiple system atrophy. It occurs in conjunction with bladder and bowel dysfunction. Interventions for sexual dysfunction include hormonal testing and urologic evaluation. Look for psychogenic causes which often are at the root of sexual dysfunction. Look for other signs of autonomic failure, such as low blood pressure upon standing. The treatments for sexual dysfunction or erectile dysfunction are well-known. They are advertised on television all the time, Viagra, Cialis and Levitra. There's something called Muse which is inserted in the opening of the penis or injected into the penis but is not much used now.

Orthostatic hypotension is low blood pressure caused by standing up suddenly often associated with a faint feeling upon standing. It is a complication of multi-system atrophy or a complication from anti-hypertensive drugs or autonomic neuropathy due to diabetes. Have a thorough evaluation if you have this particular symptom of being lightheaded when you're standing after sitting. Interventions can be to quickly lie down to get the blood back into your head. Check your anti-hypertensive medications with your doctor to make sure you are not taking too much. If you are able, wear elastic stockings. This is helpful especially for those who cannot get any control of their low blood pressure. Elevate the head of the bed at night time. This brings some control of autonomic dysfunction. The medications |that we recommend are either Florinef or Pro-Amatine. The first is not too expensive, the |latter is quite expensive.

Bladder control problems are seen somewhat in the ataxias and in people who don't have ataxia. There can be urgency or frequency, incontinence, retention, failure to empty fully because of a flaccid, soft, flabby bladder or failure to store because of a spastic bladder. Causes can be male prostate problems, female incontinence, poor bladder support or neurogenic bladder due to a central nervous system or autonomic pathway damage. Interventions: see your family doctor first and get an ultrasound pre- and post-voiding, have a prostate check, get a gynecological examination where appropriate, check for urinary infection. I advise urodynamics which is done by a urologist checking the flow of urine and how the bladder contracts. Tapping above the bladder, just above the symphysis pubis, will stimulate bladder contractions at times. Medications are many for spastic, overactive bladder, for urinary retention, for painful urination, enlarged prostate, and to relax the pelvic floor.

> **"Neck, back and hip pain are the most common symptoms for people with ataxia."**

Bowel problems can also be seen in ataxia, mostly constipation or, to some extent, fecal incontinence. The cause of constipation is often too little fluid intake, too much junk food, low fiber in your diet, inactivity or autonomic failure as seen in MSA. Intervention is to drink enough fluids, increase your fiber intake, eat your fruits and vegetables and add ground flaxseed on top of your oatmeal. Medications for constipation are many and for diarrhea: Imodium or Lomotil. Diarrhea is not too much of a problem for those with ataxia.

Neck, back and hip pain are the most common symptoms for people with ataxia. One of the problems is that ataxia people do not have enough activity, the bones soften, the calcium depletes, and they fall frequently and break bones. See your doctor about your bone density on a yearly basis. Check your vitamin D levels if there is a problem with osteopenia or osteoporosis. After you fall and hurt yourself do not hesitate to go in and get x-rayed. Keep as active

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Medication Considerations in Ataxia
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as possible. Water exercise (aquatics) is particularly good. Keep your diet up with adequate calcium and Vitamin D. See your doctor and ask how much calcium and vitamin D you should be taking. There are drugs that help the bone density including, Didronel, Actonel, Fosamax. These are all prescribed by your doctor and given once a week.

Regarding lithium, I am reluctant as a representative of the National Ataxia Foundation to say, "Go ahead and ask your doctor to prescribe lithium." It is not FDA approved for ataxia. We don't know how it will affect an ataxian. There are toxicities that can include tremor, cardiovascular arrhythmias, hypotension, vertigo or restlessness. You have to have your blood tested frequently to make sure that the lithium level is not going too high. Keep watching your Internet and keep reading *Generations*. We will be keeping up on this issue. But I think taking it before we really are ready to recommend it might well be a mistake. ❖

Preparing the Legal Component

Planning For the Financial Future of A Person With A Disability

By Arnie Gruetzmacher

This is the third part of a five-part series of articles regarding the Life Plan. Arnie has spent the last 27 years working with families of persons with a disability assisting them in preparing a Comprehensive Life Plan. If you have any questions regarding financial/estate planning, please e-mail or address the Editor and Arnie will reply in our next issue or contact you directly.

In the last issue of *Generations*, I discussed the Life Plan for the benefit of the family member with a disability and the importance of having the plan in written form. Now I will explain the legal component.

One of the first challenges facing families who begin the legal component is to locate an attorney who has the necessary skills and experience in working with families who have a person with a special need. Interview the attorney and ask, "How many families of persons with a disability have you worked with in the past year?" If the reply is less than 12, find a different attorney. Because this is a team process, your attorney should be willing to work closely with you, your financial advisers and various social services agencies.

Developing the legal component of the comprehensive life plan will include the following basic documents:

Will – A will distributes your property according to your final instructions, as written in the will. A court, usually called a Probate Court, ensures this is done. Additional provisions can be provided such as naming a guardian for all minor children, a minor's testamentary trust for the benefit of minor children and if you have a large estate, estate tax saving trusts can be used.

Durable Power of Attorney for Financial – A Power of Attorney is a legal instrument that is used to delegate legal authority to another. The person who signs (executes) a Power of Attorney is called the Principal. The power of Attorney gives legal authority to another person (called an Agent or Attorney-in-Fact) to make property, financial and other legal decisions for the Principal.

A Principal can give an Agent broad legal

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Preparing the Legal Component
Continued from page 13

authority, or very limited authority. The Power of Attorney is frequently used to help in the event of a Principal's illness or disability or in legal transactions where the principal cannot be present to sign necessary legal documents.

Medical Power of Attorney – A Medical Power of Attorney gives someone you trust the legal authority to act on your behalf regarding health care decisions if you ever become incapacitated or unable to communicate

Living Will – This written, legal document spells out the types of medical treatments and life-sustaining measures you do and don't want, such as mechanical breathing (respiration and ventilation), tube feeding and/or resuscitation. In some states the living will may be known by a different name, such as a health care declaration or health care directive.

Supplemental Needs Trust – The function of the Supplemental Needs Trust (SNT) is to take on the role of a loving parent, family member or other provider in funding supplementary needs. These are needs that go beyond what is provided by government benefits. The SNT can provide funding to buy materials for a hobby, tickets to a movie, a trip, videos, or a television set. The SNT, properly drafted, tells the trustee (the person who steps into the shoes of the parents) how to use proceeds provided by the parents for the family member's unique needs. These proceeds may come from the parents' Will, Living Trust, their life insurance, or other source. Legally, the Supplemental Needs Trust is the owner of these assets, not the person with a disability. This is critical to assuring continued eligibility for key government benefits, including Medicaid.

The Supplemental Needs Trust will not work properly if you have not established the customary Last Will and Testament. The will should say something like, "I hereby leave 50 percent of my estate to the Jane Doe Supplemental Needs Trust."

Supplemental Needs Trusts generally end after the death of the person with a disability and any remaining assets will be distributed according to the terms of the trust, usually to relatives and donations to a favorite nonprofit. The trustee provides for the final arrangements and other expenses. The trustee also has the discretion to end the trust if the laws change and it is formally challenged by government.

Again, use caution in selecting your attorney; it is imperative that he or she has the necessary experience.

In the next issue I will be discussing the financial component of the Comprehensive Life Plan and helping you answer the questions of "How much money is enough?" and "Where will it come from?" ❖

New Product Supports NAF

Laura Masserant of Enhance Your Lash has dedicated her work towards creating a false eye lash kit that is easy to use and will give women the salon look and feel they desire at a fraction of the cost.

Laura's experience with ataxia is one that is very personal. For the past 15 years her husband has struggled with the disease, as have several of his family members.

A portion of the proceeds from the purchase of an Enhance Your Lash Kit will go to the National Ataxia Foundation to support ataxia research.

To learn more about or to purchase your kit and support the Foundation's important work, please call toll-free 1-877-LASH101 or visit *www.enhanceyourlash.com*.

Featured Board Member of the NAF: Craig Lisack

Craig Lisack was born and raised in Chicago with seven other siblings. He studied at Loyola University, majoring in marketing, and currently resides in Chicago where he works in sales for a company which provides various marketing lines.

Craig Lisack

Over the past 30 years, Craig has worked primarily in the fluid power industry with several large components manufacturers and distributors. His territories often covered a large geographically area and as a result, his travels kept him on the go. "I get my partiality to teamwork-based solutions to challenges from my education and upbringing," stated Craig.

Then, about 10 years ago, Craig began to experience symptoms of incoordination. It took about four years after onset to be diagnosed with Sporadic ataxia. "Everything changed big time after being diagnosed. There was no history of ataxia in my family and I was very concerned and needed more information about ataxia," Craig stated.

Craig continued, "It was through my research in finding out more about ataxia that I became aware of the National Ataxia Foundation. Through the Foundation, I began attending the local ataxia support group meetings and met many wonderful people who shared many of the same issues and concerns I had. The support group truly made a difference in my life and I now am honored to serve as the local support group leader."

Craig was elected to the Foundation's Board of Directors in 2008. Although newly elected, Craig brings with him a first-hand understanding of ataxia, a strong marketing background, a passion to provide meaningful programs to ataxia families, and an eagerness to support research for all forms of ataxias. "What we learn through research for one form of ataxia can many times help other forms of ataxia." Craig stated.

Craig concluded, "Yes, ataxia has changed my life, but I am thankful for the great people I have met as a result and I relish the opportunity to try and help others similarly afflicted in some small way."

The National Ataxia Foundation welcomes Craig Lisack to the Board of Directors and looks forward to working with him as we continue our important journey in supporting promising ataxia research and providing meaningful programs and services to ataxia families. ❖

Raising Ataxia Awareness

Lawrence Schut, MD, a member of the National Ataxia Foundation Board of Directors and NAF Research and Advisory Board, wrote an article titled "Ataxia: A complex group of diseases" that will be published in the May 2008 *Minnesota Health Care News*. This publication is dedicated to consumer advocacy with a mission of educating, engaging and empowering the reader.

A transcript of the General Session presentation entitled "Medication Considerations in Ataxia" that Dr. Schut gave at the March 2008 Annual Membership Meeting in Las Vegas, NV can be found on page 9 of this issue of *Generations*.

The NAF Board of Directors along with the Seattle Ataxia Support Group and the Ataxia Society of Vancouver, Canada would like to invite you to attend the

National Ataxia Foundation
52nd Annual Membership Meeting

March 20-22, 2009
(Leadership Meeting March 19)

Join us in Seattle for the Annual Membership Meeting!

The **Doubletree Hotel – Seattle Airport** is pleased to provide the facilities for the 2009 National Ataxia Foundation Annual Membership Meeting.

Rooms are available for the **special group rate** of $139 per night. Please be sure to make your reservations by **February 16, 2009** 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 are a very limited number of ADA rooms available on a first-come, first-serve basis. To reserve an ADA room, you must contact NAF at **(763) 553-0020**. NAF will have a limited number of shower chairs, toilet frames and tub bars available on a first-come, first-serve basis.

To book your stay online, go to *http://doubletree.hilton.com/en/dt/groups/personalized/CTAC-DT-NAF-20090316/index.jhtml*, or if you would prefer to make your reservations by phone, please call toll-free **1-800-222-TREE** and ask for the National Ataxia Foundation conference special rate (Group Code: NAF).

Watch for the 2009 AMM Registration Form in the Winter 2008-09 issue of *Generations*.

We look forward to seeing you in Seattle!

Tools for SCA1 Therapeutic Development

By Kerri Carlson, PhD
University of Minnesota, Minneapolis, MN

This grant was funded by the National Ataxia Foundation in December 2005. The research was completed December 2007.

Spinocerebellar ataxia type 1 (SCA1) is a neurodegenerative, genetic disorder caused by a mutation in the SCA1 gene. SCA1 codes for the protein ataxin-1. Recent studies using mouse models of SCA1 have suggested that therapies aimed at reducing the level of the ataxin-1 protein in cells may be effective for treating SCA1. One important regulator of mutant protein levels in the cell is the phosphorylation of ataxin-1 at serine 776. We believe that strategies focused on preventing this phosphorylation event may be lead candidates for SCA1 treatments. The aim of our NAF funded research was to further study the modulation of ataxin-1 phosphorylation with the long-term goal of identifying novel therapeutic targets for SCA1.

To begin, we used a cell-culture based assay to screen a library of 2000 compounds (either FDA approved drugs or natural occurring compounds) to identify inhibitors of ataxin-1 phosphorylation with the idea that such a compound might be a novel therapy for SCA1. The therapeutic value of any given compound will depend on a number of factors including the necessary dose of the compound to generate the desired effect and the toxicity of the compound to the cell. From our library screen we identified nine compounds that reduced the phosphorylation of ataxin-1 by greater than 50% at a reasonable dose without any observed toxicity to the cells that were treated. In the future, we plan to test the effectiveness of these compounds in an animal model.

To further study the regulation of ataxin-1 phosphorylation, we compared this process in cos-1 tissue culture cells (an artificial system) and the cerebellar Purkinje cells (a primary site of SCA1 neurodegeneration). In the Purkinje cells of transgenic mice overexpressing a form of mutant ataxin-1 that does not enter the nucleus of the cell, we do not detect phosphorylated ataxin-1. In contrast, in cos-1 cells that express the same form of mutant ataxin-1, we are able to detect phosphorylated ataxin-1. These data suggest that the pathways regulating S776 phosphorylation are not the same in tissue culture cells and Purkinje cells implying that further studies of this phosphorylation event should be conducted in a model system that more closely resembles the Purkinje cell.

Because of these findings, we turned our attention to looking at the zebrafish as a novel model organism for studying ataxin-1 phosphorylation. Like humans and mice, the zebrafish is a vertebrate with a cerebellum that has Purkinje cells. Technologies have been developed to rapidly knockdown genes of interest in the developing zebrafish. This technology would allow us to explore different candidate genes and monitor the effect of their knockdown on ataxin-1 phosphorylation. Finally, zebrafish are emerging as a new, rapid technology for studying the bioactivity and toxicity of candidate drugs before testing these drugs in larger animal models. A zebrafish system would serve as a

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useful intermediate for verifying the activity of our candidate drugs from the original drug screen before testing them in our SCA1 mouse models.

With these ideas in mind, we identified and characterized the zebrafish ATXN1 genes. Unlike humans, zebrafish have two ATXN1 genes, atxn1a and atxn1b. Like human ataxin-1, the zebrafish ataxin-1 proteins are expressed in the adult cerebellar Purkinje cells and more importantly are phosphorylated at S776 in the adult brain. Our findings suggest that the zebrafish will be a useful model for future studies looking at the regulation of ataxin-1 S776 phosphorylation and for identifying and characterizing drugs that inhibit this phosphorylation event.

We thank the National Ataxia Foundation very much for their generous support throughout the previous year. We hope that our research on ataxin-1 phosphorylation will be a stepping-stone for developing an effective SCA1 treatment in the future. ❖

September 25, 2008

International Ataxia Awareness Day

International Ataxia Awareness Day (IAAD) is celebrated around the world every year on September 25th to spread the word about ataxia and to raise awareness about the effects of ataxia. There are many ways you can participate in IAAD. The National Ataxia Foundation's 2008 IAAD kit is filled with many ideas on ways you can get involved. It can be found on NAF's website at *http://www.ataxia.org/events/international-ataxia-awareness-day.aspx*.

You can help raise ataxia awareness by telling others about ataxia, telling your story to your local media about how ataxia has affected you, or requesting that your state, county or city officials sign a proclamation naming September 25 as International Ataxia Awareness Day in that locality. Also support and attend IAAD events that are planned by your local ataxia support group.

International Ataxia Awareness Day events not only raise ataxia awareness but 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, including organizing a bake sale, garage sale, or a "walk n' roll" in your area. Ataxia awareness products are available for purchase on page 37 of this issue of *Generations* that you may want to order now.

Earl McLaughlin (center) accepts a plaque of appreciation from Arnie Gruetzmacher during the 2008 NAF Annual Membership Meeting

Last year the NAF San Diego Ataxia Support Group held the first ever NAF Walk n' Roll in honor of Charlie McLaughlin to celebrate IAAD. This was a highly successful event for which the San Diego Support Group was recognized at the 2008 NAF annual membership meeting in Las Vegas in March. Earl McLaughlin, the San Diego Ataxia Support Group Leader, accepted a plaque of appreciation from NAF on behalf of the San Diego support group for their spirited efforts in organizing this event. ❖

7th Annual All California Ataxia Research Meeting (ACARM)

The 7th Annual All California Ataxia Research Meeting (ACARM) will be on Sunday, September 14, 2008 at the Doubletree Hotel – San Jose Airport.

These meetings are organized to provide hope for ataxians throughout California, the West Coast and the world. All of the doctors are from California and donate their time. Occasionally there may be a guest speaker.

We encourage attendees to stay overnight at the hotel, although it is not required. Room rates are $119 per night for double occupancy and $10 for each additional person staying in the room. There are a limited number of ADA rooms. The hotel is one-half mile from the airport and offers complimentary ADA shuttles equipped with wheelchair lifts. You may call the hotel at (408) 453-4000. Mention the National Ataxia Group to receive the discounted hotel rate. The hotel's website is *http://doubletree1.hilton.com/en_US/dt/hotel/JOSE-DT-Doubletree-Hotel-San-Jose-California/index.do*.

To attend the meeting, please complete the Registration Form below and include your non-refundable meeting payment of $50 (USD) per person by check or money order **no later** than Friday, September 5. We are unable to accept credit cards. This fee covers lunch, coffee and meeting costs. After that date registrations will be taken at the door for $40 and will **not** include lunch. Any profits from this event will be donated to NAF.

You are invited to the "Get Acquainted" dinner on Saturday, September 13, at the hotel's Coffee Garden Restaurant which has a casual "al fresco" atmosphere. Please arrive at the restaurant between 5:30 to 6:30 p.m. for a $10-15 per plate at-your-cost dinner.

The meeting begins on Sunday at 8:30 a.m. with registration, coffee and a "mix and mingle" time. The first speaker is scheduled to begin at 9:30 a.m. The meeting will end at 4:10 p.m. after an hour-long "Q and A" session with the doctors. Come and enjoy a day of research into the ataxias. For more information see *http://home.comcast.net/~fernandesml/ACARM7/ACARM7.mht*.

ALL CALIFORNIA ATAXIA RESEARCH MEETING (ACARM)

REGISTRATION FORM

Sunday, September 14, 2008 • Doubletree Hotel – San Jose Airport

Attendees' Names (please print):

_____

_____

_____

_____

Non-Refundable Payment Enclosed:

Lunch & Program
($50 x number attending): $ _____

Voluntary Donation to NAF: $ _____

Check Total: **$** _____

Please indicate number of lunches: _____ Grilled Veggie Wrap _____ Chicken Caesar Salad

Please indicate the number of hotel rooms you have reserved: _____

Please mail this completed form and check made payable to "ACARM" to:

ACARM7, c/o Ikue Pollack, 12285 Saratoga Creek Dr., Saratoga, CA 95070 • Telephone: (925) 516-6906

My Journey for Knowledge

By Pinalben "Pinky" Patel

I was diagnosed with Friedreich's ataxia (FRDA) at about age 11. I describe myself as a quadriplegic without balance. I also have a pacemaker and insulin-dependent diabetes. My FRDA has progressed more quickly than in others who I know with the same disease.

Because of the severity of my disability, I need a fair amount of help in bathing and dressing. Hence going to college after I graduated from high school in 2003 seemed like an impossible hurdle. I learned that Vocational Rehabilitation* (VR) may help with funding for personal care attendants and some of the tuition, fees and books for college. My parents concerns were that my needs would be difficult for a stranger to meet and I wouldn't be taken care of properly. My concerns were that I wanted to focus on my studies rather than training someone to handle my needs.

Pinalben "Pinky" Patel

But even with my parents and my concerns, I applied to Western Kentucky Community and Technical College (WKCTC) to finish the general requirements for a bachelor's degree. I took classes on campus and on the Internet. After placing a "help wanted" ad in the newspaper and interviewing applicants, I chose two women because I felt that one person alone would not be sufficient to help me in the restroom. It has always taken both of my parents to help me.

I had arranged a taxi for transportation. My parents wanted an attendant to commute with me so one met me at the campus while the other met me at home. They took turns sitting with me in class to take notes. The college provided extended time and a scribe when I needed to take a test.

Everything seemed to be running smoothly until four weeks into the semester when both aides had to quit because of health problems. Luckily, I met a student who knew how to work with people with disabilities. She became my regular aide for the whole year for which VR helped pay. The best part was that she could assist me in the restroom by herself. She never missed a day of work without ample notice. Since some of her classes were at the same time as mine, the school provided a note taker for me. I began tutoring students during my second semester at WKCTC. I joined Phi Theta Kappa and became secretary for that group. My first year ended peacefully.

In my second year I had to find a new aide because the previous one changed colleges. This time I posted "help wanted" fliers across campus because I didn't want to spend money for a newspaper advertisement. A female nursing student saw the flier and agreed to be my aide. She was excited to work with me because she would be able to attend her classes while I tutored. Everything was set for the next semester. Then in the middle of the summer when I called her, she told me she wouldn't be taking the job because she had to care for her daughter.

It was time to start panicking since I didn't have any other respondents from the flier. But through a friend I did find someone to hire, although her personality was completely different from mine. I tolerated it because I didn't want to spend time searching for another aide and because she was able to help me in the restroom by herself. I did all the extra-curricular activities and took as ▸▸

many classes as I had the previous year. However, this aide wasn't very reliable. She would call in sick a minute before she was to be at my house. On those days I attended classes only and returned home in time to use the restroom. I dealt with it and when the year ended I graduated with High Distinction with an Associate of Arts degree.

However, I wanted to finish my bachelor's degree and I knew I could do that at Murray State University, about an hour away from where I lived. Vocational Rehabilitation paid for a wheelchair lift to be installed in our van so I could commute with my aide driving. I predicted some attendant unreliability so I scheduled fewer classes and did not participate in extra activities. I thought I had it all planned, but I could not have been any more wrong.

This is when I realized that I had taken for granted the ease of having an attendant when I was in high school. Now I was having a difficult time finding reliable people. Some aides did not show up. Often they did not give me a hint of their farewell. They would have a smiling, gracious face until the time when they just wouldn't come. I was lucky that my parents and friends were able to help me in their absence. Matter of fact, I gave up trying to find any reliable people to work with me during my last two semesters at MSU. I changed my major so that I could take most of the classes on the Internet.

After four years, I received my Bachelor's of Integrated Studies in Print Communications with Honors at age 25. Factors that contributed to my success were: my will to study, my living in a big town where accessibility is available, and my parents, who supported me by getting me ready and providing transportation to college when I needed it. Vocational Rehabilitation played a vital role in financing my studies. They helped in getting computers, software, and any other adaptive equipment I needed for college. I am grateful for VR's financial help; without it I might never have completed my degree. However, I have a suggestion that I believe can improve VR's services for people in situations like mine. VR provides funding to pay the wages of personal care attendants for persons with a disability to attend college. I believe that instead of funding the person with the disability, VR should give the money directly to the college for the salaries of the aides who will assist that person in being successful at school. My experience demonstrated that finding a reliable aide on my own was difficult. And finding a substitute when the aides did not show up or wanted a vacation was a nightmare, too.

I think an educational institution would be better able to find reliable people to assist those with disabilities attending college. It would be nice to know that when you arrive at your school that someone will be there to assist you. That was the security I had in high school, but I did not realize how valuable it was until I started college.

★*Editor's note: Vocational Rehabilitation, as the author discusses, is administered by the Rehabilitation Services Administration (RSA), which oversees grant programs that help individuals with physical or mental disabilities to obtain employment and live more independently through the provision of such supports as counseling, medical and psychological services, job training and other individualized services. RSA's major Title I formula grant program provides funds to state vocational rehabilitation (VR) agencies to provide employment-related services for individuals with disabilities, giving priority to individuals who are significantly disabled. For more information see www.ed.gov/about/offices/list/osers/rsa/index.html.* ❖

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 Foundation.

In Pursuit of Dreams

By Traci Powell

In this story I will discuss my experiences with academia and how I pursued my dreams while facing Friedreich's ataxia. I want to demonstrate how a person can be creative in confronting the various challenges of academia with success.

I'm an African-American female who was born and raised in San Diego, CA. There was always a strong emphasis in education in my family. I was encouraged to press on beyond my circumstances. Little did I know what physical challenges I would face. In my early years, disability was a foreign concept to me. I ran and played freely. But step by step, the winds howled and the clouds darkened the skies. Before I knew it, a full blown storm was apparent.

Traci Powell

I began to notice certain physical anomalies. My handwriting, which had been praised during my elementary years, was becoming sloppy. This seemed to occur out of nowhere. But people have a way of mixing denial with encouragement by giving it a positive slant; "You have the handwriting of a doctor." As time went on, it worsened along with my balance problem. In spite of that, it was clear that I should pursue academic excellence.

I started at University of California-San Diego (UCSD). The Office for Students with Disabilities was very supportive. Disabled student services offices vary in how helpful they are, but I have some suggestions: ask many questions and get to know the people in this office. I encourage you to explore your campus and become a part of various organizations that interest you. Find out every resource that might be available at school and throughout the community; attend as many of the new student events as you can. The dedication of those who work with disabled students makes a huge difference, and I was fortunate. These people brought laughter, fun and insightful ideas to what could have been a very difficult situation for me. I learned that with the proper adaptive equipment, time management and a positive attitude I would be able to achieve my goals and move forward. When I saw myself as being highly valuable and able to make a significant contribution to the world, there was nothing that could stop me.

During my senior year I applied to medical school in pursuit of my childhood dream of becoming a doctor. I already had the handwriting for it. But things did not work out. Most of the medical schools had a stipulation that a person needed a certain level of physical abilities to be considered. This seemed like an obstacle that I had no way of getting around. But I was determined to try.

I graduated from UCSD with a BS in Biology. I took a research position in a genetics lab at the Salk Institute. I decided to reapply to medical school, choosing schools that seemed more lenient with their physical requirements. While I was doing this, I became more interested in genetics and made the decision to apply to graduate school rather than medical school. Although the attitudes of those in the upper echelons of academia seemed unwilling to give me the opportunity to contribute to science, there were

Continued on page 30

Registration room

Below: Silent Auction

DeNiece Roach and Lori Shogren

Information and banquet sign-up table

Ride Ataxia II presentation

Ride Ataxia II arrival

THE NATIONAL AT

51st Annual Mem

"Blazing a Tra

Las Vegas, Nevada —

Getting some Las Vegas sun

Camille Daglio and

Thank you to everyone who submitted photos for this issue of Generations!

More smiling at the banquet

Below: The Wolfsons at the banquet

Below: Mary Vida and Mary Lisa Orth

Saturday evening banquet attendees enjoy a fabulous meal

Bart and Pat Beck

K

TAXIA FOUNDATION

nbership Meeting

il in Research"

– March 28-30, 2008

l Monty Sims

Earl McLaughlin, Robin Viland and Pip

Below: Mary Fuchs, Rita Garcia, the Fidlers

Having a great time at the banquet

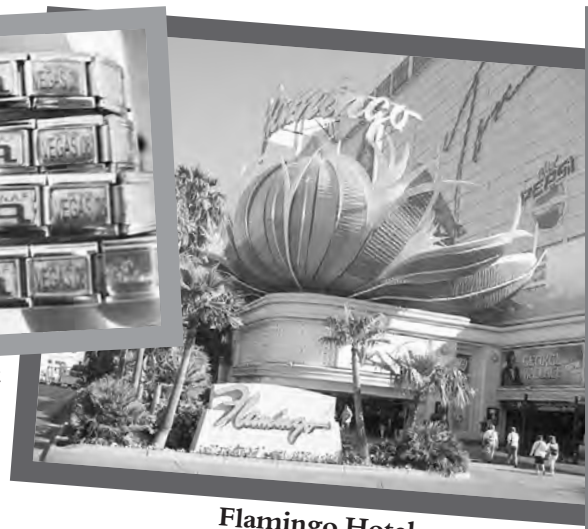
Smiling banquet attendees

Kim and Brian Beck

Kyle Bryant and the Johnsons

The Zilles family

Four types of Ataxlet



Flamingo Hotel

Dr. & Mrs. Schut receive Lifetime Recognition Award

Coffey family recognition

Below: Gerry Mahler and Arnie Gruetzmacher

Mike Parent presents a plaque to Dr. Susan Perlman

Milly Lewendon and Brenda Dixon announce 2009 AMM

Doctors George "Chip" Wilmot, Michael Fahey, S.H. Subramony, Laura Ranum, Robert Wilson and Harry Orr at the Q&A session

Caregiver's Corner

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

Safe Transfers: Easy Does It!

Back strain and back problems are common complaints among family and professional caregivers. Using the wrong technique when moving a person is one of the chief causes of this complaint.

Moving a Person

When you have to move someone – either in bed or out of bed – remember these tips:

- Plan the move and know what you can and cannot do.
- Let the person do as much work as he is capable of.
- Avoid letting the person put his arms around your neck or grab you.
- Use a transfer belt to balance and support the person.
- Place transfer surfaces (wheelchair and bed) close together.
- Check wheelchair position, **brakes locked**, armrests and footrests swung out of the way.
- Let the person look to the place where he is being transferred.
- If the person is able, place his hands on the bed or chair so he can assist in the movement. If the person has had a stroke or is afraid, have him clasp his hands close to his chest.
- Ask the person to *push* rather than *pull* on the bed rails, the chair, or you.
- Work at the person's level and speed and check for pain.
- Avoid sudden jerking motions.
- Never pull on the person's arms or shoulders.
- Have the person wear shoes with good treads or sturdy slippers.

Helpful Advice for Moving a Person

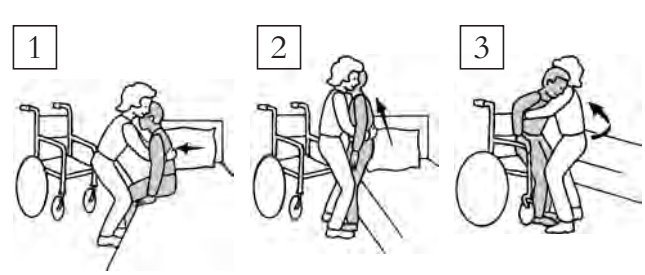
These pointers are for the *caregiver only*.

1 • Tell the person what you are going to do.
• Before starting a move, count with the person, "1-2-3."

2 • To feel in control, get close to the person you are lifting.
• While lifting, keep your back in a neutral position (arched normally, not stiff), knees bent, weight balanced on both feet. Tighten your stomach and back muscles to maintain a correct support position.
• Use your arms to support the person.
• Let your legs do the lifting.

3 • Pivot (turn on one foot) instead of twisting your body.
• Breathe deeply.
• Keep your shoulders relaxed.

When a lot of assistance is needed with transfers, tie a strong belt or a transfer belt around the person's waist and hold it as you complete the transfer.

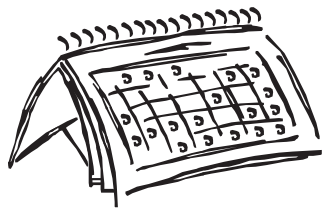


Encourage Independence

Let the person assist as he is able. It's okay for the person to stand up partly and sit back down.

Continued on page 29

My First Year



By Tracey Gallant Balis, Dedham, MA

I have titled this story "My First Year" because it contains a story similar to the stories in baby books that are kept after a baby is born that shows the goals and milestones that they achieved during their first year of life. Although my story is quite different than one in a children's milestone book, I will share what has occurred during this first year of being diagnosed with SCA2.

Although I was officially diagnosed in February of 2007, I have lived with symptoms of the disease for years. During those years I have tried to do the best that I can for my children. I want to show them by my example. If I am sad and frustrated most of the time they will see that. The last thing I would want to do is to show fear and sadness and how truly difficult it is to live with this disease.

Tracey Gallant Balis

Once the initial shock of being diagnosed wore off a little bit, I began the journey of living with ataxia. My first step was to get a cane to help balance my walking ability. After only a short time, just two months, I began using a walker. It was hard but I knew it was necessary for my safety. The walker worked well for a few months, and then I got a new walker, the type with brakes. Day by day my coordination, balance and strength deteriorated at a rate far quicker than I thought was possible.

I never got used to using one thing before it was time for the next. And next was a manual wheelchair. Although this was good for safety, not having to worry about falling, the downside was that my arms were as weak as my legs. So using the manual wheelchair was far too difficult. Once again the tides were changing and it was time for new equipment. Now I have a power wheelchair and my world has changed dramatically in many ways.

Here is a funny story: The first time I tried the power wheelchair and went from one room to another, I actually got dizzy. I asked my occupational therapist about this and we chuckled. That was the fastest that I had moved in almost a year.

Now I can do things independently, which the cane and walkers were not allowing me to do. Although I still need much help with almost everything, at least with the power wheelchair I do feel that little bit of freedom. It is a struggle to get in and out of but I keep trying and managing. I can now go from one room to the other. If I would like a snack in the kitchen, I am able to get one and that feels good.

My first year has been a tough one, physically and mentally. I still feel like I am in a whirlwind, a spinning tornado. I hope to hit a plateau soon and level off a bit, but for now, the wheels keep spinning and everyday is just a little tougher than the day before. My speech is now beginning to suffer, the words in my head are not as easily spoken as they once were, but I go on. I go on because of my three children. They need to see me set an example so if the day comes when unfortunately one, two or all three of them are diagnosed with SCA2, they will have seen my example and know what they have in store.

My first year has also opened my eyes and other senses wider than they have ever been in my life. I do not look at a flower the same way I used to. I look at it now more in depth, for a longer period of time. I enjoy its scent and all the ▸▸

beauty that flowers have to offer. I do this with a number of things. Things I may have overlooked before, I now take a second look at and savor in the wonder of them.

My animals have played a strong part in their ability to comfort me. I believe animals have quite a sense; they know when there is something wrong and they are there for me. They, as well as my support system and my family are always there to pick me up. Animals are wonderful and I recommend them highly to anyone suffering with such a disease.

Although I am 40 years old, I feel as though I am a child all over again. I am having to relearn how to feed myself. I now need to be taught all over to do things that I have done for 40 years. So it feels somewhat as though I am a child again and that is a very strange feeling.

To sum up my first year, it has been quite a year of changes and I am sure that my second year will hold as many, or even more.

I would like to add that the National Ataxia Foundation has made an impact on my life and actually played a key role when I was just a pre-teen girl, even before I was diagnosed with SCA2. When my father was diagnosed, it helped immensely that he became a part of the foundation through his own work in writing for *Generations*. This helped me to know that if the day possibly came when I may be faced with this debilitating disease, standing in place would be a wonderful organization that could help and guide me with any questions, feelings and thoughts that I had. I do not feel alone knowing that the National Ataxia Foundation is there by my side. I know there is someone I can talk to, someone who will listen and someone who will hear me. The National Ataxia Foundation has been one of the strongest forces, a joyful force, that has helped me in everything that I have had to deal with over the past year. I look forward to continuing to work with them in the future, as we all should. It is a wonderful organization whose sole purpose is to truly help those of us that are afflicted with all of the different types of ataxias.

(Editor's note: This is the second article submitted by Tracey, who like her father, John Gallant, during the 1980's, writes for Generations on the challenges of living with ataxia.) ❖

Caregiver's Corner
Continued from page 27

Be Safe

As the caregiver, you should seek training from a physical therapist to provide this type of care in order to reduce the risk of injury to yourself or the person in your care.

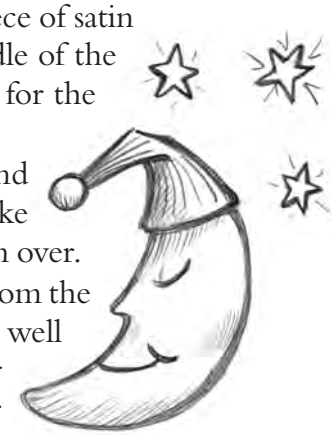
A therapist will help correct mistakes you make and can take into account special problems. To determine the best procedure for you to use, the therapist will consider the physical condition of the person you care for and the furniture and room arrangements in the home.

Bedroom Comfort and Safety

It is common for the elderly or a person with a disability to have trouble turning over or getting in and out of bed. These tips may help:

• Talk to the health care provider to see if medication may have to be adjusted.

• A satin sheet or piece of satin tucked across the middle of the bed can make it easier for the person to turn over.



• Flannel sheets and heavy blankets can make it more difficult to turn over.

Make sure the path from the bed to the bathroom is well lit. Use a nightlight or leave open a closet door with the light left on. Keep the bedroom floor clear of things that could cause a fall – don't leave shoes, books, or magazines on the floor. ❖

In Pursuit of Dreams
Continued from page 22

a couple of schools that were willing to give me a chance. I chose Stanford.

I spent seven years working on my PhD in genetics at Stanford University. It took every strategy that I could think of to get through this time. There were major stumbling blocks at every turn. But it wasn't like this just for me: all of the students were feeling the pressure.

After graduating and six months of post-doctoral research, I left Stanford in pursuit of my career goals of becoming a professor at the college level. I left with a promise of a post-doctoral research position. We had communicated by e-mail, but when we had the face-to-face interview, things changed. I was disappointed and discouraged, but not ready to give up. I was a tutor and a biology lab instructor at the local community college. Maybe a lab instructor was in some way seen as an experiment; could the unknown professor in the wheelchair be able to properly teach a biology laboratory class?

That summer I was able to do an internship at the National Academy of Sciences in Washington, D.C. I met someone who put me in touch with the director of a unique teaching/research post-doctoral program in biology at The University of North Carolina at Chapel Hill. Before I left for North Carolina, I was able to find a wheelchair-accessible apartment, get a roommate/care-giver and obtain the various equipment that I needed: a van with a lift, a hospital bed and other public transportation all by using the Internet.

The SPIRE post-doctoral program would allow me to spend two years doing human genetic disease research and one year of teaching genetics at one of the Historically Black Colleges and Universities (HBCUs). I also had opportunities to be a guest lecturer at many of the other HBCUs in North Carolina. It was not always smooth sailing, but I was able to follow my dreams. I would not have had this rich and fulfilling experience along with my new sense of independence without going to the southeastern part of the country.

Unfortunately, I also learned that regardless of my education, my speech and disability would be a continuous battle. This became clearer once my post-doctoral program ended. I was again teaching a regular biology class at a local community college. After negative reactions from students and negative scores from one of the faculty members, I suggested that I teach online courses. The chairperson immediately took to this idea suggesting a course in heredity that she wanted turned into an online class. So I am going through the training and I wait to see what future opportunities will come to me with this type of teaching.

> **"If you are able to attend an annual NAF member meeting, I encourage you to do so."**

Based on my experience, I have some advice for those who want to pursue academics and life in general: network as much as possible, get to know your professors, accept your limitations and go beyond them, adapt to your circumstances, never quit, and remember the serenity prayer: God grant me the serenity to accept the things I cannot change, courage to change the things I can; and wisdom to know the difference.

I have also found that getting involved in NAF's support group meetings is one way of keeping yourself informed. I have learned so much from *Generations* about what is happening in the ataxia world. If you are able to attend an annual NAF membership meeting, I encourage you to do so. Being surrounded by so many people with various kinds of ataxias is helpful. It gives you the opportunity to share information with and learn from people who are confronting the same issues. ❖

Chapter and Support Group News from Around the Country

Central New York Ataxia Support Group

By Linda Johnson

The Central New York Ataxia Support Group met Saturday, April 5th. Andy and Linda Johnson provided the group with an overview of the NAF Annual Meeting held in Las Vegas. The group also enjoyed hearing about the adventures of Andy and Linda in Ride Ataxia II. The next meeting is tentatively scheduled for June.

India Ataxia Support Group (SAMAG)

By Chandu George

I wish to share with everyone about the ataxia awareness program I conducted with my sister in the last week of April. We are both "FA'ers." The program was covered by Indian Media and was later telecast on TV across India. The message my sister and I conveyed was to raise awareness on ataxia, which is not heard about or known much in India. We conveyed the message, "There is life with ataxia."

My sister's message drew lots of attention, praise and admiration for her holistic approach and for saying, "First we should accept ourselves, then others will accept you." Later we discussed the importance of society coming forward, providing encouragement and working for the welfare of ataxians. We discussed the current research on ataxia being funded by NAF and, finally, the program ended on a happy note as the media emphatically said, "LIFE IS BEAUTIFUL."

Chandu George being filmed by a TV crew

The program was well received and appreciated by many patients, their parents, caregivers, and the Indian public who immediately queried TV channels which telecast the program about us. To top it all off, an Indian movie star and politicians came forward and pledged their support to work for the cause of ataxia.

Since our idea was to pass on the message to people in remote corners in India, the program was spoken in the Indian local language, Telugu. To make this program available to viewers everywhere, I have posted the video in two parts on YouTube. To view it online please visit the following links: Part 1 - *www.youtube.com/watch?v=wIBJDrVktxA* and Part 2 - *www.youtube.com/watch?v=P_q7Nsod_FI.*

Greater Atlanta Ataxia Support Group

By David Zilles

On May 16, the Greater Atlanta Ataxia Support Group participated in their first Braves 50/50 Raffle. This is a program conducted by the Atlanta Braves Baseball Team to allow charities to sell 50/50 raffle tickets for a couple of hours before the game and up until the end of the second inning. The tickets sell for one for $3,

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Chapter and Support Group News
Continued from page 31

two for $5, and five for $10. The money is collected and at the end of the sixth inning a winner is drawn and they receive 50% of the total pot. The other 50% is split between the Braves and the charity (our group, in this case). Thursday night was a little slow but the total pot was $2,300 and we received $575, plus we got tickets to see the rest of the game. This was a very easy and fun way to raise funds for the support group. We suggest that if your local support group has a major league team, you check it out.

The Greater Atlanta Ataxia Support Group at the Braves game

On Saturday, May 17, we held our support group meeting at Emory. We had Rebecca Ramage-Tuttle, the Executive Director for Disability Link, one of the Georgia Centers of Independent Living in Atlanta, who spoke to the group about the State Independent Living Council and what the centers can do to help people with disabilities. She talked about moving people out of nursing homes, employment placement, training for independent living skills, peer support and information referral. The information was very interesting to the group.

We also talked about several fund raisers that had been held in April for Friedreich's ataxia by the Van Schoick and Zilles families, as well as the Walk for Wishes4Me, a foundation helping to supply housing for individuals on ICWP.

Our next meeting is August 23rd.

Los Angeles Ataxia Support Group

By Sid Luther

On May 10 the Los Angeles support group met at the Westside Center for Independent Living (WCIL). Ten attendees heard a wonderful presentation by speech and swallowing expert Anne Lefton, who detailed the processes of speech and swallowing and gave us great tips on how to improve those functions. She also answered many questions from the group.

President Sid Luther put out a call for volunteers to staff the NAF booth at the Abilities Expo in Anaheim on May 30-June 1. Also on the events calendar is a concert in the park during the month of June as well as a trip to the Hollywood Bowl in August. Plans are already in the making for our December Christmas Lights boat cruise and dinner.

And, of course, President Sid is still looking for someone to join him with the skydiving experience, planned through the Casa Colina Outdoor Adventures program. Any takers?

Our next meeting on July 12th will be the annual barbecue, always a well-attended event. This year's roast will be at the home of Thom Fritz at 2228 Penmar Avenue, located near the WCIL, our usual meeting place.

Call Sid Luther for details at (818) 246-5758 or e-mail *harry luther@sbcglobal.net*. We'll see you there!

Metro Area Chicago Ataxia Support Group

By Christopher Marsh

April 19th was the first meeting of the Metro Area Chicago Ataxia Support Group. The turnout was outstanding, and fun was had by all. It was the first meeting, so I didn't make ▸▸

it very structured. No speakers were scheduled, however Dr. Chris Gomez was in attendance. I wanted us to just hang out and get to know one another better. We went around the room and introduced ourselves, we gave our diagnoses and we briefly shared our stories. Then we all had cake and conversation. It couldn't have been better!

The Metro Area Chicago Ataxia Support Group

Northeast Florida Support Group

By June McGrane

The Northeast Florida Support Group held a meeting on May 3rd at the Baptist South Hospital in Jacksonville. Mac Kelso, one of our members, showed his film on our group's trip to the NAF Annual Membership Meeting in March in Las Vegas. It was very informative, detailing research and seminars and various sites around Las Vegas. We had a discussion period and social hour. Afterwards our group had dinner at a nearby restaurant.

The Northeast Florida Support Group

Our group will meet again August 9th at Baptist South Hospital at 1 p.m. We are very pleased to have as our guest speaker, Dr. Tom Clause, who will demonstrate walking and "Dancing with Ataxia."

The last meeting of 2008 will be on November 8th at 1 p.m. It will be held again at Baptist South Hospital.

Northern California Ataxia Support Group

By Rebecca Douglass

The Northern California Ataxia Support Group held its April meeting at Our Savior's Lutheran Church in Lafayette on April 12, 2008. Attendance was very small and the scheduled speaker was unable to attend.

Some of the attendees had just returned from the NAF Annual Membership Meeting in Las Vegas and an interesting and informative round-table discussion was held involving some of the speakers and treatments featured there.

Topics included the use and cost of Coenzyme Q10 and Idebenone, which are being used by many of us. They are not covered by insurance unless specifically noted to be of use for a particular ataxia and they are very expensive. Jim Torres has the website of Swanson's Catalog, which has the best price for these products and he will send it on to anyone interested.

Other topics discussed were featured speakers such as Dr. Schmahmann of Harvard Medical School and his presentation on the role of the

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Chapter and Support Group News
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cerebellum in issues other than just motor control. Studies are now being conducted to learn the coordinating role in behavior, cognition, psyche and emotions, to name a few areas. This subject is especially important for families and caregivers of ataxians in order to better understand some of the least understood problems they may be facing. We discussed foot care for someone who was not there today.

Another event around the Las Vegas meeting was the cycle ride of Kyle Bryant and the Ride Ataxia II team, which made a 600-mile trip from Sacramento to Las Vegas to increase awareness of ataxia and raise funds for research. This was quite a production involving many volunteers. Sean, one of the participants, was selected to carry the Olympic torch in San Francisco. Our group designated $100 of our annual donation to NAF in honor of this event.

Dr. Rich Ivry of UC Berkeley will be with us for the July meeting. His studies also involve the ability of the cerebellum to coordinate and make changes in memory, attention and problem solving, which are things that we have not typically associated with ataxia before. He has a flyer which is available at our meetings. It describes his work which is not a clinical trial and does not include medication of any type.

We expect a large turnout for Dr. Ivry's presentation. The date is July 12, 2008 in Lafayette, as above. To attend or join the group, please go to page 38 of this magazine for the Northern California Ataxia Support Group listing and contact information for Group Leader Deborah Omictin. There are also websites listed there to access information.

SE Pennsylvania Support Group

By Liz Nussear

As we approach our 13th year as the only Pennsylvania support group, we have evolved into a very caring group that meets the second Saturday of each month at Mercy Suburban Hospital in Norristown, PA. Newcomers are always welcome. We meet in the Gerber Room on the second floor. Please note that we do not meet in July or August.

We have been fortunate to have a physical therapist share her knowledge of strengthening exercises and ways to maintain balance and endurance. Her next visit will include information on therapeutic yoga, which all of us anticipate will help with relaxation and stretching our bodies.

We have been fortunate to have a lawyer who specializes in disability claims attend our meeting and offer us suggestions and guidelines for applying for SSDI.

In addition, we have been blessed to have a neuropsychologist from the Hospital of the University of PA, who has in her time with us, made us feel very positive about who we are. She has been faithfully visiting our group for the last 10 years. She has offered suggestions on spouses who care for their loved one. She has also been so enthusiastic about what she has learned from us. She has asked us questions to get us thinking positively about our own circumstances and how we may be able to improve a situation at hand.

Being close to Philadelphia gives us many specialists in the area but the most important aspect of our monthly meetings is the time we share and care with one another. We have all learned a great deal from one another and have become an ataxia support "family."

I dedicate this article to the memory of Chip "Crash" Niles, who demonstrated determination to live his life to the fullest. Chip never complained about having a degenerative disease, cerebellar ataxia, and never asked "Why me?" He continued to live his life with a passion for loving a beautiful wife and was very fortunate to have four loving children who cared for his needs in a very special manner. Nothing stopped "Crash" from doing what he needed to do ⏩

to enjoy his life. His smile brightened each Saturday that he and his wife Kitty spent with the group. During support group meetings his smile never ceased, and he was always very caring and honest in his comments.

Chip "Crash" and Kitty Niles

Chip received his nickname "Crash" when during a support group meeting, as he was joyously smiling that smile, he shared the story of his visit to a local medical supply store to investigate scooters. When he entered the store, the 12 or so employees sitting behind cubicles paid no mind to Chip or his wife Kitty. They did not offer a "Hello" or "May I help you?" So Chip got on one of the scooters, put it in high gear and plowed into the display shelves. Many of us laughed at the story, as several of us had been to that store and experienced the same lack of attention. Needless to say, Chip and Kitty had to return to the store at a later date, and noticed that all of the batteries were removed from all of the scooters.

He attended his Hot Rod car shows, gaining assistance from very caring friends with his wheelchair and then his electric scooter. "Crash" demonstrated to all of us, the "Positive People in PA" (as the SE Pennsylvania Support Group members calls themselves) what is important: live your life to the fullest despite bodily limitations. Those limitations don't define you as a person ... your heart does, and Chip's heart shown through his everlasting smile.

May "Crash" be in "Hot Rod Heaven." Although he suffered with having ataxia, it never stopped him from sharing and caring and simply having a good time. Thank you, Kitty, for the generous monetary memorial gift in memory of "Crash" for our group to help defray the cost of the meetings.

Tampa Bay Ataxia Support Group

By Crystal Frohna

On May 10th we met at Feathersound Community Church in Clearwater. A sub sandwich lunch was served and we all enjoyed double chocolate brownies baked by one of our member's wives.

One of our guest speakers was Paul Scaglione, MSO, a Licensed Occupational Therapist who has been practicing for over 14 years. Paul's presentation ran the gamut from visual acuity problems to fine motor skills. He took questions from group members and showed us some equipment that might be useful to us, including several pens designed for people with difficulty writing, a button hook and a material that holds

The Tampa Bay Ataxia Support Group

whatever is set on it without disturbing the surface beneath. For example you can put a pad of paper on it and the paper will stay put while you are trying to write (a big help). It can also be used as a placemat to keep your plate and utensils in place. There are dozens of uses for this

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amazing material and the best part is it is inexpensive. You can buy a huge roll at Wal-Mart for about $20. He also showed us a pen that is shaped like a butterfly which I am going to try. It is sold at Walgreen's.

Next we had the privilege of having Tom Clouse, MD, working one-on-one with us and presenting his "Dancing with Ataxia" philosophy. He was able to help several members improve their walking in just a few minutes and left each of us with five CD's of his personal thoughts on strengthening muscles and how to "retrain" ourselves to walk once again. We thank him for joining us and driving all the way from Naples just to attend our meeting. We look forward to having him back soon!

Tri-State Ataxia Support Group

By Denise Mitchell

Our second meeting added about six new people so we have a diverse group of approximately 30 members. Most importantly we discussed raising awareness of the disease and that should be a goal for the group. As we are still getting to know one another, a lot of time was spent sharing feelings. Many expressed an interest in having a speaker who can educate us all concerning the many different forms of ataxia. I look forward to our meeting on June 11th.

Twin Cities Area Ataxia Support Group

By Lenore Schultz

The Twin Cities Ataxia Support Group has been meeting every third Tuesday of the month. Some months we just do something fun like watch a movie. But we have also had a woman teach us some Tai Chi movements that can be done in a chair. This winter we had the nurse from the University of Minnesota ataxia clinic come and speak to us and answer questions. She was very humorous and wants to be able to provide whatever help she can to those affected by ataxia to make their lives a little better. This month, the woman who coordinates ataxia research at the U of M is coming to talk to us and lead us in a discussion of how we can become involved in ataxia research.

I write a summary for everyone on our support group list which I send out each month. In addition there is one member who has become our webmaster and puts the summary of our meeting on the web page which is linked from the NAF home page. He also lists what is planned for our next support group meeting in the following month. Check it out at *www.ataxia.org*. ❖

NAF Merchandise

BOOKS

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 NEW!

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

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
Offers demonstrations of how effective dialog can help move patients and doctors to productive relationships. Paperback. $10

Friedreich's Ataxia Research Cookbook
Julie Karjalahti of Savage, Minnesota has published this cookbook to raise money for FA research. Includes recipes from around the U.S. $12

Recipes and Recollections *by Kathryn Hoefer Smith*
Full of delicious recipes and recollections, this book is perfect for fund raisers. 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-minute in-depth look at ataxia and ataxia research. VHS $20 or DVD $25

SHIRTS / MISCELLANEOUS

2008 Annual Membership Meeting T-Shirt
Dark blue with "Blazing a Trail in Research" logo. Various sizes. $10 NEW!

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

NAF Denim Shirt
Denim with white embroidered NAF logo. $27.50

"Ataxia is not a foreign cab" T-Shirt
White. New design. Sizes small to XXX-large. $10

"Ataxia is not a foreign cab" Sweatshirt
Ash colored. Sizes small to XXX-large. $20

NAF Baseball Caps
White w/ blue embroidered NAF logo or blue w/ white embroidered logo. Velcro strap for sizing. $10

Window Cling or Bumper Sticker
$1 each or 6 for $5

NAF Ataxia Awareness Band
Blue. One size fits all. $2

NAF Ataxia Awareness Ribbon Magnet
Blue with white lettering/logo. $4

To order, call (763) 553-0020, fax (763) 553-0167 or mail this completed form to
National Ataxia Foundation, 2600 Fernbrook Lane, Suite 119, Minneapolis, MN 55447

Description	*Qty.*	*Size*	*Each*	*Total*

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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.

Chapters

Chesapeake Chapter

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Adamstown, MD 21710-9666
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Web: www.geocities.com/HotSprings/Oasis/4988/
www.ataxia.org/chapters/Chesapeake/default.aspx

Louisiana Chapter

Carla Hagler, President
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Web: www.angelfire.com/la/ataxiachapter
www.ataxia.org/chapters/Louisiana/default.aspx

Mississippi Chapter

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E-mail: daglio1@bellsouth.net
www.ataxia.org/chapters/Mississippi/default.aspx

Support Groups

Alabama

BIRMINGHAM S.G.
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www.ataxia.org/chapters/Birmingham/default.aspx

Arizona

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

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

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Connecticut

See Tri-State Ataxia S.G. under New York

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

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

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

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Mount Prospect, IL 60056
(847) 253-2920
E-mail: caasg@comcast.net
www.ataxia.org/chapters/Chicago/default.aspx

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http://health.groups.yahoo.com/group/u-r-notalone/
www.ataxia.org/chapters/ChrisMarsh/default.aspx

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Huntingburg, IN 47542
(812) 630-4783
E-mail: monicasfaith@insightbb.com
www.ataxia.org/chapters/Louisville/default.aspx

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KANSAS CITY S.G.
Lois Goodman
17700 East 17th Terrace Court S #102
Independence, MO 64057
(816) 257-2428
www.ataxia.org/chapters/KansasCity/default.aspx

Louisiana

See Louisiana Chapter

Maine

MAINE SUPPORT GROUP
Kelley Rollins
P.O. Box 113
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E-mail: rollins@gwi.net

Monique Godbout
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Lisbon, ME 04250
E-mail: mrgodbout@excite.com
Web: www.ataxiaME.com
www.ataxia.org/chapters/Maine/default.aspx

Maryland

HOWARD COUNTY S.G.
Tim Daly
(410) 715-1241
Web: www.geocities.com/hcasg/
www.ataxia.org/chapters/HowardCounty/default.aspx

Continued on page 40

Chapters, Support Groups and Ambassadors
Continued from page 39

Massachusetts

NEW ENGLAND S.G.
Donna & Richard Gorzela
45 Juliette St.
Andover, MA 01810
(978) 475-8072
www.ataxia.org/chapters/NewEngland/default.aspx

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DETROIT AREA ATAXIA S. G.
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Mississippi

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Missouri

KANSAS CITY S.G.
Jim Clark
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Gladstone, MO 64118
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E-mail: clarkstone9348@sbcglobal.net
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MID-MISSOURI ATAXIA S.G.
Roger Cooley
1609 Cocoa Court
Columbia, MO 65202
(573) 474-7232 before noon
www.ataxia.org/chapters/RogerCooley/default.aspx

New Jersey

See Tri-State Ataxia S.G. under New York

New York

CENTRAL NEW YORK ATAXIA S.G.
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2849 Bingley Rd.
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North Carolina

See South/North Carolina

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Chapters, Support Groups and Ambassadors
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Mobile: 0091-0-9466355238
E-mail: abhinav_kedia_2000@yahoo.com
www.ataxia.org/chapters/AbhinavKedia/default.aspx ❖

Stay in Touch!

News and photos covering your group's activities and updates about happenings in your area regarding education, support or awareness is important to our readers.

Send stories, events and reports by e-mail to *naf@ataxia.org* or by mail to the NAF office address listed on page 2. The deadline for the fall issue is August 15, 2008.

Calendar of Events

Saturday, July 12, 2008

Kansas City Area Ataxia Support Group
2-4 p.m. at the Northeast Library, 65 Wilson Ave., Kansas City, MO. Contact Lois Goodman (620) 223-1996 or Jim Clark at *clarckstone9348@sbcglobal.net*. *www.ataxia.org/chapters/KansasCity/default.aspx*.

Los Angeles Area Ataxia Support Group
2-4 p.m. at the Westside Center for Independent Living, 12901 Venice Beach, CA. Contact Sid Luther for more information (818) 246-5758. *www.ataxia.org/chapters/LosAngeles/default.aspx*.

North Texas Ataxia Support Group Meeting
10 a.m.-noon at Los Colinas Medical Center, 6800 Mac Arthur Blvd at Hwy 161, Irving, TX. Contact David Henry Jr. *www.ataxia.org/chapters/NorthTexas/default.aspx*.

Northern California Ataxia S.G. Meeting
11:30 a.m.-3:00 p.m. at Our Savior's Lutheran Church, 1035 Carol Lane, Lafayette, CA. Contact Deb with any questions at *rsisbig@aol.com*. *www.ataxia.org/chapters/NorthernCalifornia/default.aspx*.

San Diego Ataxia Support Group Meeting
1-3 p.m. at Sharp Rehabilitation Center, 2999 Health Center Dr, on the East side of Hwy. 163 between Genessee Ave and Mesa College Dr, behind Sharp Memorial Hospital. There is plenty of free parking. *www.ataxia.org/chapters/SanDiego/default.aspx.*

Southern NY Area Ataxia/HSP Support Group
1 p.m. at Our Savior Lutheran Church, 1400 Rt 52, Rooms 107 & 108, Fishkill, NY. Contact Ann Lakin at *alakin90@aol.com*. *www.ataxia.org/chapters/SouthernNY/default.aspx*.

Tampa Bay Ataxia Support Group Meeting
1-3 p.m. at Feathersound Community Church, Clearwater, FL. Contact Chris Frohna (813) 453-1084 or *chrisfrohna@yahoo.com*. *www.ataxia.org/chapters/TampaBay/default.aspx*.

Tuesday, July 15, 2008

Twin Cities Ataxia Support Group
7 p.m. at Presbyterian Home in Roseville (off 35W on County Rd D). Contact Lenore H Schultz at (612) 724-3784 or *lschultz@bitstream.net*. *www.ataxia.org/chapters/TwinCities/default.aspx*.

Saturday, July 19, 2008

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. Contact Daniel Navar at *dnavar@ucla.edu*. *www.ataxia.org/chapters/OrangeCounty/default.aspx*.

Sunday, July 20, 2008

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

Saturday, August 9, 2008

Kansas City Area Ataxia Support Group
2-4 p.m. at the Northeast Library, 65 Wilson Ave., Kansas City, MO. Contact Lois Goodman (620) 223-1996 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 Los Colinas Medical Center, 6800 Mac Arthur Blvd. at Hwy 161, Irving, TX. Contact David Henry Jr. *www.ataxia.org/chapters/NorthTexas/default.aspx*.

San Diego Ataxia Support Group Barbecue
For information contact Earl McLaughlin at (619) 447-3753 or *sdasg@cox.net*. *www.ataxia.org/chapters/SanDiego/default.aspx*.

Southern NY Area Ataxia/HSP Support Group
1 p.m. at Our Savior Lutheran Church, 1400 Rt 52, Rooms 107 & 108, Fishkill, NY. Contact Ann Lakin at *alakin90@aol.com*. *www.ataxia.org/chapters/SouthernNY/default.aspx*.

Sunday, August 10, 2008

Seattle Area Ataxia S.G. Summer Fun Activity
Contact Milly Lewendon at *mmlewendon@comcast.net*. *www.ataxia.org/chapters/Seattle/default.aspx*.

Saturday, August 16, 2008

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. Contact ⏩

Daniel Navar at *dnavar@ucla.edu*. *www.ataxia.org/chapters/OrangeCounty/default.aspx*.

Chicago Metro Support Group
1-3 p.m. at the Chicago Public Library - Edgewater Branch, 1210 West Elmdale Ave., Chicago, IL. Contact Christopher Marsh at (312) 217-7737 or *cmarsh34@ameritech.net*. *www.ataxia.org/chapters/ChrisMarsh/default.aspx*.

Tuesday, August 19, 2008

Twin Cities Ataxia Support Group
7 p.m. at Presbyterian Home in Roseville (off 35W on County Rd D). Contact Lenore H Schultz at (612) 724-3784 or *lschultz@bitstream.net*. *www.ataxia.org/chapters/TwinCities/default.aspx*.

Saturday, August 23, 2008

Greater Atlanta Ataxia Support Group Meeting
1 p.m. at Emory Center for Rehabilitation Medicine, 1441 Clifton Rd., Room 101, Atlanta, GA. *www.ataxia.org/chapters/Atlanta/default.aspx*.

Saturday, September 13, 2008

Denver Area Ataxia Support Group Meeting
1-4 p.m. at the Swedish Hospital and Medical Conference Center (Room Spruce A), 501 East Hampden Ave, Englewood, CO. Contact Tom Sathre at *tom_sathre@acm.org* or (303) 794-6351. *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. Contact Lois Goodman (620) 223-1996 or Jim Clark at *clarckstone9348@sbcglobal.net*. *www.ataxia.org/chapters/Kansas City/default.aspx.*

Los Angeles Area Ataxia Support Group
2-4 p.m. at the Westside Center for Independent Living, 12901 Venice Beach, CA. Contact Sid Luther for more information (818) 246-5758. *www.ataxia.org/chapters/LosAngeles/default.aspx*.

North Texas Ataxia Support Group Meeting
10 a.m.-noon at Los Colinas Medical Center, 6800 Mac Arthur Blvd at Hwy 161, Irving, TX. Contact David Henry Jr. *www.ataxia.org/chapters/North Texas/default.aspx*.

SE Pennsylvania Ataxia S.G. Meeting
10-11:30 a.m. at Mercy Suburban Hospital, 2701 Dekalb Pike, Norristown, PA. Contact Liz Nussear at (610) 272-1502 or *lizout@aol.com*. *www.ataxia.org/chapters/SEPennsylvania/default.aspx*.

Southern NY Area Ataxia/HSP Support Group
1 p.m. at Our Savior Lutheran Church, 1400 Rt 52, Rooms 107 & 108, Fishkill, NY. Contact Ann Lakin at *alakin90@aol.com*. *www.ataxia.org/chapters/SouthernNY/default.aspx*.

Sunday, September 14, 2008

ALL California Ataxia Research Meeting (ACARM7)
See page 19 for details.

Tuesday, September 16, 2008

Twin Cities Ataxia Support Group
7 p.m. at Presbyterian Home in Roseville (off 35W on County Rd D). Contact Lenore H Schultz at (612) 724-3784 or *lschultz@bitstream.net*. *www.ataxia.org/chapters/TwinCities/default.aspx*.

Saturday, September 20, 2008

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. Contact Daniel Navar at *dnavar@ucla.edu*. *www.ataxia.org/chapters/OrangeCounty/default.aspx*.

Sunday, September 21, 2008

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

Thursday, September 25, 2008: International Ataxia Awareness Day
"International Ataxia Awareness Day" is an international effort from ataxia organizations around the world to dedicate September 25 as International Ataxia Awareness Day. Each participating country, state, or individual may have a specific plan for this event. *www.ataxia.org/events/international-ataxia-awareness-day.aspx*.

Saturday, September 27, 2008

New England Ataxia Support Group Meeting
Noon-3 p.m. potluck at the Massachusetts General Hospital. Contact Donna or Rich (978) 475-8072. www.ataxia.org/chapters/NewEngland/*default.aspx.*

Walk n' Roll For Ataxia
Tuna Harbor in San Diego, CA. For information contact Earl McLaughlin at (619) 447-3753 or *sdasg@cox.net*. *www.ataxia.org/chapters/San Diego/default.aspx*. ❖

Memorials and In Your Honor

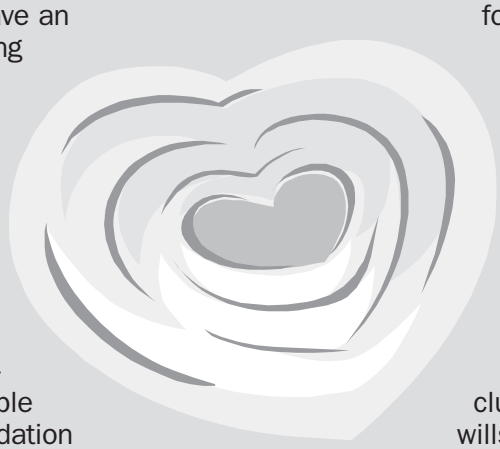
The National Ataxia Foundation is grateful to those who have made contributions in memory or in honor of their friends and families whose names are listed below. This list reflects contributions made in April 2008. We are sorry that we cannot separate the memorial contributions from those made in honor 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.

Tracey Balis
Lenda Barth
Erris Blain
Thomas Blain
Emma Brumbach
Kyle Bryant
M/M Edward Callis
Richard Carr
William Chwee
Raymond Davis
Thomas Di Pietro
Joseph Drake
Mary Fuchs
John Gallant Jr.
Lynn Gates
Steve Greenblatt
Paschal Guercio
June Hagan
David Henry
David Henry Jr.
Edward Horvath
Smile Huang
R.D. Hunt
Jamie Kosieracki
Dan Lane
Oscar Lipke
David Lowsley
Earl McLaughlin
Michael Mills
Diane Mitchel
Carl Moles
Clarence Montecino Jr.
Patrick Moore
Dolores Morello
Nancy Nelson
Chip Niles
Evelyn O'Neal
Malcolm O'Neal
Norma Payne
Greg Pettit
David Price
Jim Price
Karol Price
David Schon
Jamie Schon
Riley Schon
Dr. Larry Schut
Derek Semler
Evalyn Sizemore
Joey Staiger
Dianne Stevens
Ernest Talarico Jr.
Dennis Trietsch
Jesse Valdez
William Walus
Susan Weiler
June West
Michelin Whipple
Michael Wolfson ❖

The Ripple Effect

The simple act of dropping a small pebble in a pond is an action that creates a reaction in the water: a sound, a splash, and ripples. The sound and splash fade quickly, but the ripples endure, affecting the entire pond and beyond.

An act of human kindness is an action that can be felt by many and have an everlasting effect. Supporting the National Ataxia Foundation through deferred giving, such as wills, is one such action that can make a lasting impact.



Including the National Ataxia Foundation in your will gives hope to the entire ataxia community. Giving a gift through deferred giving creates a ripple effect that allows the Foundation to continue to support cutting-edge ataxia research and provide important programs and services for ataxia families.

Adding the Foundation to your will first takes an action. That action will touch the lives of each ataxia family now and into the future. Including the Foundation in your will also has a ripple effect on you. Long after we are gone, our gifts through deferred giving keep on working in helping ataxia families.

Over the years the Foundation has received a number of gifts through deferred giving. We are forever grateful for their kind action in making it possible through their wills to fund promising ataxia research and to help provide vital programs for ataxia families.

In fact, a number of crucial ataxia research studies would not have been funded without the support of individuals who took action and included the Foundation in their wills. What we are learning from those research studies will help other researchers in finding more answers in stopping ataxia. A true ripple effect.

Please take action today and create your own ripple effect by including the National Ataxia Foundation in your will. Thank you.

SCA7: Putting a Name to the Disorder

By Suz Pohl

Spinocerebellar Ataxia type 7 (SCA7) is a disorder we had not heard of until eight months after our 27-month old daughter Mearan passed away from what the doctors termed an undiagnosed neuromuscular disease. Through autopsy, the doctors were able to diagnose in death what hundreds of tests had failed to do while Mearan was alive. Mearan had the infantile form SCA7, a rare genetic disorder that kills the cerebellum portion of the brain.

By the time Mearan's diagnosis was found, we learned three other family members were affected with the same disease. We were finally able to put a name to the disease that was taking so much from our family.

The Pohl family in 2001

My husband Kyle's mother, Sharon, had been suffering with undiagnosed ataxia and other related symptoms for several years prior to Mearan's passing. In hindsight, we can see the resemblance of some of their symptoms, but the difference in Mearan and Sharon's ages, infant and adult, made the definite connection impossible until after Mearan's autopsy. Sharon tested positive for SCA7 and the disease continues to progress rapidly in her.

The Army activated Kyle just three months after Mearan's death. The stress caused by her passing and being activated for Operation Iraqi Freedom was more stress than Kyle's body could handle. He began to exhibit classic signs of SCA7: lack of balance and coordination, memory problems, swallowing difficulties and choking, and eye abnormalities. After returning from Iraq, Kyle was tested and confirmed positive for SCA7. Every day he struggles with the symptoms of this disease and what it is doing to his mind and body, however Kyle is living life to the fullest.

Our son, Bracken was diagnosed with SCA7 at five years old. He had been struggling with severe balance and coordination issues, visual impairments, which like his sister Mearan, eventually progressed to blindness, learning and memory problems, and swallowing and choking difficulties. Bracken lost his battle with SCA7 at the age of seven years old. Days before he passed away, Bracken told us he just wanted to go to heaven to be with Jesus and Mearan.

Looking back at my husband's grandmother and great-grandmother, it is obvious they each also had undiagnosed cases of SCA7. What was ruled as "old age" and possibly Parkinson's disease was in fact SCA7.

Kyle and I have two remaining children, Gavin (17) and Kegan (14). Gavin has been tested for SCA7. We praise and thank the Lord he is negative. Kegan has a 50% chance of having the disease; however, he has chosen not to be tested, and we stand behind his decision.

Our family has been through a great deal because of a disease we had never heard of, SCA7, and our future with it may appear bleak. But our faith in the Lord and our love for one another far outweighs anything negative SCA7 can throw our way. We live each day as if it were our last: enjoying life as we laugh and love everyone we come into contact with. We find joy in the Lord and His many glorious blessings, cherishing the knowledge that someday we will all be reunited again in heaven.

We sincerely appreciate receiving *Generations* from the National Ataxia Foundation. It keeps us updated on new medical information and research, as well as connecting us with people walking similar paths that we are walking. ❖

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 _____