Generations

The Official Publication of the National Ataxia Foundation
Volume 34, Number 4
Winter 2006-07

THE NATIONAL ATAXIA FOUNDATION
50th Annual Membership Meeting
"The Bridge to Hope"
Memphis, Tennessee — March 22-25, 2007

The National Ataxia Foundation Board of Directors and the National Ataxia Foundation Mississippi Chapter would like to welcome you to the 50th Annual NAF Membership Meeting. Please join us in celebrating the 50th anniversary of the National Ataxia Foundation. This 50th anniversary presents us with an opportunity to celebrate the incredible contributions that the National Ataxia Foundation has made and continues to provide to the ataxia community.

Since the founding of the National Ataxia Foundation, NAF has contributed immeasurably to the research progress, education and awareness of ataxia. For the last 50 years NAF has played a vital role in ensuring that our doors are truly open to all those affected by ataxia and their loved ones as a "Bridge to Hope."

This anniversary is also a celebration of the "Bridge Builders," the countless volunteers, NAF members, NAF supporters, NAF staff, members of the NAF Board of Directors, NAF Medical Research Advisory Board members, ataxia researchers, NAF Chapter and Support Group Leaders, NAF Ambassadors and the founders of NAF that have built the bridges and made the connections. Thanks to you we are building awareness, making connections to more people then ever and most of all finding out more information about ataxia through vigorous research efforts to help end ataxia.

As tradition for the past 50 years, the NAF Annual Membership Meetings have brought together NAF members and their families to meet and learn from the world leading ataxia researchers and neurologist but also to build new friendships and to catch up with old friends. Whether this is your first meeting or your 50th, this years Annual Membership Meeting will be filled with education, celebration, sharing and caring!

Program Overview

Thursday, March 22

Adult Early Arrival Outing – Join us for the early arrival outing Thursday March 22. We will be going to the Memphis Grizzlies vs. Los Angeles Lakers basketball game at the FedEx Forum. Transportation will not be provided to the FedEx Forum by NAF. The FedEx Forum is located on Beale Street, two blocks from the

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Generations is published by the National Ataxia Foundation, Inc., Minneapolis, MN.

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Beale street trolley stop or a short taxi ride away from the Memphis Downtown Marriott. You may make reservations for your game tickets or find out more information on ticket prices by calling Lori at the National Ataxia Foundation at (763) 553-0020 or e-mailing *lori@ataxia.org*. Game tickets are limited. Reservations are required by **January 31, 2007**.

Teen Early Arrival Group Outing – Attention all teens! NAF is very excited to be able to take you out to see the Memphis Grizzlies basketball team take on the Los Angeles Lakers at the FedEx Forum. Join your friends for some great sporting fun! Transportation will be provided at approximately 6:00 p.m. to the game and at approximately 9:30 p.m. back to the hotel. Tickets are limited and registration is required by **January 31, 2007**. Game tickets and transportation are free to the teens only, ages 13-19. To register or for more information, please contact Bridget at the NAF office by calling (763) 553-0020 or e-mailing *bridget@ataxia.org*.

Leadership Meeting – Current Chapter Presidents, Support Group Leaders and Ambassadors are encouraged to attend the Leadership Meeting. This meeting will address questions and concerns that are unique to those in this appreciated position as well as offer the opportunity to meet one another and learn some tips from both peers and professionals. This meeting will run from 1:00 to 5:00 p.m. in the Nashville room. If you are not currently a group leader, but are interested in becoming one, please inquire ahead of time by contacting Lori at *lori@ataxia.org*.

Internet Group – This is your opportunity to meet some of those internet friends that you have met on the NAF chat room, NAF Bulletin Board, Internaf, Tricks of the Trade, Ataxia Forum, Ataxia Chat 2002, and FAPG. Join us in the Nashville room starting at 7 p.m.

Friday, March 23

Teen Program and Activities – The teens, ages 13-19, are invited to meet in the Beale room. This room is reserved for the teens to get to know each other, play games, watch movies and relax. In addition there will be scheduled group activities and guest speakers. Please make sure to mark "TEEN" on your registration form so we can plan accordingly. A full schedule will be available in the meeting program. Don't forget, teens are also welcome to attend the regular meeting program.

Breakout Sessions – Friday morning 45-minute sessions will be available on various topics. Topics will include Coping Early On-Set, Coping Late On-Set, Rehabilitation, Treatments & Medications, Nutrition, Service Dogs, Speech & Swallowing and Dance. For a complete schedule refer to the meeting agenda.

Birds of a Feather – In response to comments from last year's meeting we are going to continue to schedule Birds of a Feather on Friday afternoon. Groups will be sectioned off in individual or divided rooms based on your type of ataxia, caregivers, parents, etc. This is a tremendous opportunity for you to meet others with your type of ataxia or who share in a similar situation, and make friends that will last a lifetime. Medical professionals will also be on hand, circulating between groups, in case you have any questions.

Friday Night Reception – Please join us for a reception in the Memphis Cook Convention Center Ballroom A&B for a wonderful NAF 50th Anniversary Celebration. All registered meeting attendees are welcome to attend and entrance to this event is included with your registration. Make plans to come and celebrate 50 years of NAF! There will be '50s music and food. All NAF conference attendees are encouraged to wear their '50s attire but it's not required.

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Saturday, March 24

General Sessions – Saturday morning and afternoon will feature General Sessions in the Memphis Cook Convention Center Ballroom A&B. General Sessions are large group presentations, typically with a medical or research focus. Many of the world's leading ataxia researchers and clinicians, along with other ataxia experts, will be presenting the latest research and additional information. The meeting agenda outlines who will be speaking on Saturday. A half-hour Question and Answer session will follow the morning and afternoon General Sessions with a panel of doctors and researchers.

Church Services – Both Catholic and non-denominational church services will be held on Saturday at 6:00 p.m. in the Jackson and Chattanooga rooms respectively.

Silent Auction – As is tradition at our annual gathering, the silent auction will be held on Saturday afternoon and conclude at 7:30 p.m. We hope you get a winning bid and bring an auction item with you to the meeting. Auction items range from something that represents your state or country, such as a painting, spices, statues, and sports memorabilia, to a basket of knickknacks, hotels stays and weekend getaways.

Saturday Evening Banquet – The Saturday Evening Banquet will begin at 7:00 p.m. in the Memphis Cook Convention Center Ballroom A & B. Please stop by the St. Louis room to get your tickets, which are included in your registration fee, ahead of time. You must reserve seating for the banquet in advance. The banquet will include a plated dinner and surprising entertainment.

Sunday, March 25

General Sessions – Sunday morning wraps up the 2007 NAF Annual Membership Meeting with the final round of General Sessions starting at 8:30 a.m. in the Memphis Cook Convention Center Ballroom A&B followed by a Question and Answer Session. Our meeting agenda outlines who will be speaking on Sunday.

Additional Information

Conference Registration – Please complete and return the registration forms in this issue of *Generations* to NAF by **February 15, 2007**. Please fill out the registration forms completely, as we need all information to finalize plans. If you are bringing an attendant, please register together on the same page. Each person planning on attending the daily sessions, reception, or banquet will need to register. Event entry will not be allowed without the proper registered name tags.

Photo Waiver - By attending the 2007 NAF Annual Membership Meeting you give permission for images of you, captured during the conference through video, photo, and digital camera, to be used by the National Ataxia Foundation in promotional materials, publications, and web site and waive any and all rights including, but not limited to, compensation or ownership.

Hotel Registration and Room Rates – The hotel is located at the Memphis Downtown Marriott, 250 North Main Street, Memphis, TN 38103. To reserve a room online please go to *http://marriott.com/property/propertypage/memdt?groupCode=ataataa&app=resvlink* or call toll-free at (800) 228-9290. To receive the special standard room rate of $126 per night, please let the reservationist know that you are with the National Ataxia Foundation when making your reservation by phone. All rates are subject to sales tax. The group rate is based on adult double occupancy. More then two adults per room will result in a higher room rate. Reservations MUST be made by **February 27, 2007** to receive this special rate. There were a limited number of accessible rooms ⏩

available on a first-come, first-serve basis, but these rooms are full at this time. NAF will have a limited number of shower chairs, toilet frames, and tub bars available on a first-come, first-serve basis at the Memphis Marriott Downtown hotel front desk.

Attendant Care – Please note that NAF is unable to provide attendant care services. Due to liabilities and health concerns, NAF and hotel employees are not able to provide this service. Please do not attend without an assistant if you are need of one.

Transportation and Getting There

NAF is not responsible for transportation to and from the hotel. The following may be used as a helpful guide for your convenience.

Driving for Area Airports – Memphis (MEM)

- 1-901-527-7300
- Hotel Direction: 12 mi NW
- Driving Directions: I-240 North to I-40 West. Exit 1A at 2nd Street. Hotel is on left.

Paratransit/Additional Accessible Travel – MATA plus is a service designed to meet the transportation needs of people with disabilities in the Memphis area. In order to utilize the benefits of MATA plus, riders must have a disability that prevents them from riding the MATA fixed route bus system. In order to utilize MATA plus service, you need to fill out an application. To request your application or to get more information about MATA plus, please call (901) 722-7140 from 8 a.m. to 4 p.m., Monday through Friday.

Arrow Transportation provides wheelchair accessible transportation to and from the Memphis Airport & Memphis Marriot. Tours to local attractions and Tunica, MS are also available. Reservations must be made in advance by **March 1, 2007** and can be made by calling (901) 523-2002 and asking for the National Ataxia Foundation group rate of $35 per one-way trip to and from the airport.

Wheelchairs Express is a service for anyone needing wheelchair accessible transportation to/from the airport. Please make your reservations directly with them in advance. The telephone number for Wheelchairs Express is (901) 353-3500.

Taxi Service To and From Area Airports (One-Way)

- From MEM Airport estimated taxi fare: $27-35.

Other Transportation - The Memphis Area Transit Authority (MATA) offers public bus service from the lower outer drive near Terminal C. The airport route, 32 East Parkway Airport, services the airport hourly. To contact MATA direct, you may call (901) 274-MATA. The Downtown Memphis Marriott is not located directly on the MATA bus line.

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GoodSearch = Great Donations

There is a new and easy way to raise money for the National Ataxia Foundation just by searching the internet with *www.GoodSearch.com*.

It's simple. You use GoodSearch like any other search engine – the site is powered by Yahoo! – but each time you do, money is raised for the National Ataxia Foundation.

Last year search engines generated close to $6 billion in revenue from advertisers. With GoodSearch, part of this advertising revenue will now be directed to the National Ataxia Foundation.

Make a difference and search the internet. Here's how it works. Log on to *www.GoodSearch.com* and type "NAF" in the "I'm supporting" box. Each time you search the internet using GoodSearch a donation will be made to the National Ataxia Foundation. It's that easy!

We hope that you will not only use GoodSearch as your main search engine, but also pass this message on to your family, friends, and co-workers. Thank you.

From the Desk of the Executive Director

There is much excitement at the National Ataxia Foundation. As of this writing, the Foundation is reviewing 28 important ataxia research studies from around the world. Through your support of the 2006 NAF Annual Ataxia Research Drive, the most promising of these studies will be funded in late December 2006 for fiscal year 2007. Because of you, scientists around the world are learning more about ataxia each and every day.

Currently, the Foundation is working on Phase II of our web site, *www.ataxia.org*. The Foundation made significant changes to the web site in Phase I this past summer and we are looking forward to providing you with more information and easier navigational accessibility in Phase II and Phase III. The launch date for Phase II is scheduled to begin in the first quarter of 2007.

I am pleased to report that memberships are significantly up this year. Late this past summer the Foundation began its first NAF Annual Membership Drive. We are truly thankful for those who became NAF members for the first time. It is because of you and the entire membership which allows the Foundation to publish *Generations*, upgrade the web site, develop ataxia publications, and offer help and assistance to ataxia families.

Michael Parent

In this issue of *Generations* you will find a registration form to attend the 2007 NAF Annual Membership Meeting, "Bridge To Hope." This conference is the Foundation's 50th annual membership meeting. The meeting is being hosted by the NAF Mississippi Chapter and is being held in Memphis, Tennessee on March 22-25, 2007 at the Downtown Memphis Marriot.

The conference will offer presentations from many of the world's leading ataxia scientists and clinicians who will provide the latest information on ataxia research and updates on potential therapies. There will be breakout sessions that will provide you with valuable information on nutrition, coping, exercise, genetics, and much more. "Birds of a Feather" will be offered again, allowing people who share the same concerns or same type of ataxia to meet as a group to discuss their particular needs and issues.

The annual membership meetings offer each of us the opportunity to learn the latest information on ataxia research and to develop a better understanding about ataxia. I encourage all of you to attend this landmark meeting to learn, share, network, meet new friends, and have fun. You are in store for an impressive slate of presenters, a great time, and because it is the 50th, a few surprises. I look forward to seeing you at the 50th.

NAF started through a commitment of one man, Dr. John W. Schut, the founder of the Foundation. His vision and dedication has made an everlasting and profound impact on the ataxia community. Through Dr. Schut's initial research efforts, his encouragement of others to join in this important cause, and in pursuing other researchers to become involved with ataxia research, his journey formed the foundation in which this organization is built upon … helping ataxia families.

Today I see many people who share the same vision and commitment. Board members, NAF Medical and Research Advisory Board members, NAF Chapter Presidents and officers, support group leaders, NAF Ambassadors, staff, researchers, volunteers, donors, fund raiser organizers, and others who give so much so others can have a better life. I applaud all your efforts in sharing Dr. Schut's goal in helping ataxia families.

November 24, 2006

Update on Clinical Trials in Friedreich's Ataxia

by Susan L. Perlman, M.D.

With the close of 2006, we can look back with satisfaction and forward with excitement.

Discovery and Preclinical Testing of Drugs for Friedreich's Ataxia

The genetic mutation that results in frataxin deficiency, the cause of Friedreich's Ataxia, was discovered 10 years ago.[1] Since then, basic scientists have continued to refine our understanding of the role of frataxin in normal nerve and cardiac muscle cells (carrying iron to iron-sulfur clusters in mitochondria, needed to prevent buildup of free iron, iron-related free radicals, and free radical-related damage, and to ensure the efficient production of energy to avoid an "internal energy crisis").[2]

Basic scientists have also discovered how the GAA expansion mutation in the frataxin gene actually acts to prevent frataxin production – the elongated piece of DNA in the gene causes the DNA to become "sticky" and fold back on itself, preventing the transcription of the messenger RNA needed to make the frataxin protein. The gene is effectively "silenced."[3]

And finally, the basic scientists have developed cellular (researchers in the U.S., France, and Australia) and animal models of Friedreich's ataxia.[4-6] They have developed microarray technology to study related changes in other genes and proteins in the cell affected by frataxin deficiency.[7] These systems will allow the above mechanisms to be studied in depth, will assist in the rapid development of ideas for treatment, and will aid in monitoring promising treatments that could be brought to human trials.

Candidate drugs, that arise from the collaborative efforts of basic scientists and clinical researchers working to understand the causes of FA and the types of interventions that could cure it, can take up to six years to get through testing that shows their potential to work and their safety in animals. These "pre-drug" studies can cost $25,000-80,000 per year for the discovery phase and $100,000 per year for the animal studies, funded by government, private research organizations, and pharmaceutical companies.

Pre-drug studies in FA have yielded a list of over a dozen candidate drugs targeting the above mechanisms and some have had small pilot studies done to assess possible effectiveness:

1) Prevent buildup of free iron—three forms of mitochondrial-permeable iron chelators;[8-9]

2) Prevent buildup of iron-related free radicals and free radical-related damage – coenzyme Q10,[10] idebenone,[11-12] mitoquinone,[13] Edison Pharmaceuticals compounds derived from coenzyme Q10;

3) Ensure the efficient production of energy – CoQ10, Idebenone, MitoQ, Edison compounds, pioglitazone;

4) Increase frataxin production or at least the amount of frataxin in the mitochondria – polyamides[14] and histone deacetylase

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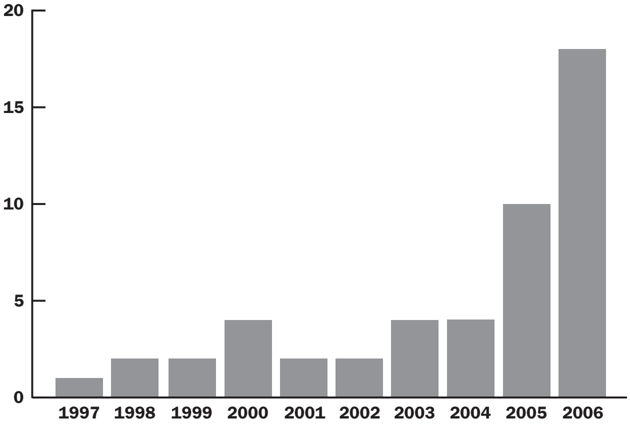
inhibitors[15] to “unsilence” the gene, transport more frataxin in from outside mitochondria,[16] reduce breakdown of frataxin in the mitochondria, gene therapy,[17-18] and erythropoietin[19] that increases frataxin levels by unknown mechanisms.

Research in FA is increasing at an exponential pace (see Graph 1).

Graph 1: Number of U.S. Studies Funded by FARA, MDA, NAF, and NIH for FA

(does not include multiple smaller grants from multiple smaller agencies)



Phase I, II, and III Clinical Trials (see Tables 1 & 2)

Before one can begin the formal clinical trial process, there has to be a way to reliably measure improvement in a patient’s exam and quality of life (clinical outcome measures, including a valid rating scale). FA researchers in the US have developed a reliable rating scale (Friedreich’s Ataxia Rating Scale or FARS[20-23]). Other researchers are looking at blood[24] or urine[25] tests and brain imaging studies[26-27] that could show improvement. There also has to be a patient registry and a network of clinical trial centers.

Only two drugs have so far moved into the formal clinical trial process. Both Idebenone and Mitoquinone have completed Phase I studies of 20-80 normal volunteers or patients, using increasing doses of the drug to determine side effects, safety, and best dosing. Idebenone was found to be absorbed best when taken with a fat-containing meal, at doses up to 60 mg per kilogram body weight per day. Mitoquinone was found to be absorbed better in the morning on an empty stomach at a total dose of around 80 mg per day. Both could cause nausea. While both did a good job of decreasing free radical oxidative stress, idebenone was felt to stimulate energy production better and mitoquinone was felt to get into the mitochondria better to tackle the free radicals. It was not clear which mechanism would be the most important for FA.

Phase I studies can take up to two years to complete. Phase II studies of 20-300 patients, divided into treatment and placebo groups, may also take up to 2-3 years to complete, to assess the potential for beneficial effects and to fully explore the safety and side effect profile of the drug. Phase I and II studies may cost $500,000-700,000 per year for about four years.

It can take up to $2-4 million to get to this point with a new drug.

Idebenone has completed its Phase II study. This was a joint effort of the NIH and Santhera Pharmaceuticals and was run by Dr. Nicholas Di Prospero at the NIH. Forty-eight patients between the ages of nine and 17 years old were enrolled in a double-blind, placebo-controlled, six-month study of placebo vs. Idebenone at three doses (4-8mg/kg, 10-20mg/kg, and 30-50mg/kg; 12 patients were in each of the four possibilities). On the International Cooperative Ataxia Rating Scale (ICARS – an older European rating scale for ataxia), there was a suggestion of improved ataxia scores and activities of daily living for those on the medium and high doses. The urine test of oxidative stress did not change on Idebenone (perhaps it is not a sensitive enough test). The cardiac testing has not yet been analyzed (although the heart has benefited in prior smaller trials at lower doses).

Mitoquinone will be starting its Phase II »

Table 1: Types of Clinical Trials

Type	# of Subjects	Length	Aim of Study
N of 1	1	Ongoing	Do I get better or stop getting worse on this drug?
Pilot	Up to 20 All get drug	Weeks to months	Is a larger study worth doing, will there be problems?
Phase I	20-80 normal or patient in groups of 3	2 years	Escalating doses to learn side effects, safety, best dose.
Phase II	20-300 Control and drug groups	2 years	To assess potential for good effects, as well as side effects. Also designed as "futility" study – to show a drug doesn't not work (fewer subjects, less cost).
Phase III	300-3,000 Control and drug groups	3-5 years	To prove efficacy. May include crossover design or open extension trial.
Phase IV	100s-1,000s Open drug use	Ongoing	To find out more about the effects of an approved drug.

study in 2007, pending approval by the FDA of the protocol (the start of the study will be announced on the NAF and FARA websites). Antipodean Pharmaceuticals is planning to enroll 130 ambulatory patients from age 12 and up, at four centers in the U.S. (Los Angeles, San Francisco, Galveston, Atlanta) and two centers in Australia/New Zealand. Half of the patients will be on placebo and the other half on the drug. The study will last one year and will be using the FARS to measure improvement in ataxia.

Idebenone will be ready to move on to its Phase III study also in 2007. Phase III studies are the final step before submission for FDA approval for a new drug. They involve 300 or more patients, usually spread out at multiple centers, and also use a double-blind, placebo-controlled protocol. The primary purpose of a Phase III study is to show that the drug really works. Phase III studies can cost up to $4-5 million ($10,000 per patient) and are a major commitment by any pharmaceutical company. Because of this, the pharmaceutical company has the final say (along with the FDA) about how a study will be run. Placebo controls (a group of patients who do not receive the drug, but are given a "fake drug" instead) must be used to prove that it is the drug, not other factors, causing the improvement. Often the study must limit the type of patient accepted into the trial, for instance only patients who can walk (are ambulatory), to assure that they can get the best possible results with the fewest patients (100s not 1,000s) in the shortest period of time (months not years).

From discovery to FDA approval can take upwards of 15 years and cost $500-700 million for a promising new drug.

The genetic mutation that results in frataxin deficiency, the cause of Friedreich's Ataxia, was discovered 10 years ago. We still do not have a cure. There still remain many hurdles (regulatory, financial, and scientific) between us and a cure. It is easy for scientists and pharmaceutical companies to become impatient and consider turning their efforts aside to less difficult or more profitable lines of research. However, if patients and families have been able to stay the course for these 10 years, then certainly scientists and pharmaceutical companies can muster the resolve to continue

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the public-private partnership that the patients and families have fought so hard to establish.

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Table 2: Funding a Public-Private Partnership

Discovery – clinicians and scientists working out the cause of the disease, the "dominos" that fall over, and a group of targeted candidate drugs.
- $25-80,000 per year over many years
- Government, private research foundations

Preclinical testing – test tube and animal studies.
- $100,000 per year for at least 2 years
- Government, private research foundations, pharmaceutical companies

Phase I and Phase II –
- $500-700,000 per year for 4 years
- Government, private research foundations, pharmaceutical companies

$2-4 million to get to this point

Phase III –
- $4-5 million ($10K/subject)
- Pharmaceutical companies, with help of private research foundations

FDA Approval

Post-marketing studies – for long-term side-effects and good effects and possible other uses of the drug.

Forming a NAF Support Group

Why start an ataxia support group? Giving people who share the same issues and concerns a way to meet and learn together is an important part of a support group. Where isolation is replaced by inclusion and fellowship. Where misinformation is replaced by understanding and being informed. Support groups allow for learning, sharing, caring, friendship, and networking.

Support groups also serve as a local voice about ataxia issues, from hosting an International Ataxia Awareness Day (IAAD) event, to speaking to a local civic group, or contacting a local newspaper about your support group and ataxia. Support groups have a lot of fun through various social outings such as a group picnics or going as a group to a sporting event. NAF Ataxia Support Groups bring local ataxia families together to help one another and to let the local community know about ataxia.

Many support groups invite a variety of speakers to attend the support group meetings. Local neurologists, geneticists, physical therapies, nutritionists, government agencies, and others attend to discuss various issues and topic that are of concern to the group.

Many NAF Ataxia Support Groups conduct fund raisers to raise awareness and to raise funds to support the important work of the National Ataxia Foundation. The Foundation provides a fund raising kit that will give you suggestions in ways to raise funds to help you in your fund raising efforts or you may want to try something unique for your local area.

Getting Started

The first thing to do is to complete an NAF Ambassador form. You must first become an NAF Ambassador before you can start a support group. There are various criterions to look at in determining the eligibility of an NAF Ambassador's application, including that the applicant must be an NAF paid member.

Once you become an Ambassador, the Foundation will help you locate ataxia families in your area to determine if there is interest in establishing a support group. The Foundation will provide mailings to local ataxia families in your area and list you in the NAF Ambassador section in each issue of the publication *Generations*.

Once it is determined there are sufficient number of people interested in starting a support group, the Ambassador will need to complete a NAF Support Group application. Once approved, NAF will assist you with technical support in giving suggestions for meeting places, speakers, awareness programs, fund raising, and much more.

Make a Difference

NAF Support Groups make a difference in the lives of local ataxia families. If you would like to learn more about starting a support group, please call the NAF office at (763) 553-0020 or e-mail Lori Shogren at *lori@ataxia.org*. Thank you.

Editor's note: A special thank you to Bill Lee for his input into this article and for his important work in helping support groups.

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Caregiver's Corner

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

Loss, Grief, and Loneliness

Allowing Time for Healing

Grief is a normal, natural response to losing someone you love, and expressing the emotions you feel when you lose a loved one is very important. Emotions that are not expressed can make you depressed or cause other psychological or physical problems.

The stages and experiences of grief are similar for everyone – but the time it takes to pass through them varies. Most people start to feel less sad and lonely in about a year. This includes spending the holidays without the person who died. The grieving process can take longer than a year for some people, but may never go away entirely because someone you love can never be completely forgotten.

When you lose someone, you may experience such intense and conflicting emotions that you feel like you are going crazy. This happens to many people. However, by recognizing the common stages of grief, you can learn to handle feelings that might otherwise be alarming. Remember, the grieving process is natural and, ultimately, will restore balance to your life. Your life has changed, but you can find a way to get things back to normal again by allowing yourself to feel and express your emotions.

The Common Stages of Grief

Although most people go through nine stages of grief, some may not experience all of these stages and they may go through them in random order before reaching acceptance. These stages include:

1. **Shock and numbness**: Can last from a few days to several months.
2. **Denial**: Refusing to acknowledge and accept the loss.
3. **Emotional release**: Overwhelming sadness and bouts of crying, often at unexpected times.
4. **Guilt**: Feeling that you could have done more to help.
5. **Disorganization & anxiety**: Confusion, inability to concentrate, causing feelings of panic.
6. **Memory flashbacks**: Suddenly remembering both the good and bad times.
7. **Loneliness & depression**: A long period of sadness and loss of interest in things that used to be fun.
8. **Anger and resentment**: Being angry at doctors, family, friends, God, and even the one who died.
9. **Recovery & acceptance**: Returning to a more normal life. This doesn't mean you forget the person you loved, but you do not think about them all the time and feel sad.

Grief Support Groups

Your grieving process will be easier if you meet with others who have had a similar experience. Grief support groups often meet at churches, synagogues, county mental health offices, and hospitals. Many hospice organizations sponsor support groups. Ask your doctor or other health care professional to recommend a group. Eventually, you will find a way to make peace with the pain of loss and move on with your life.

Serious Warning Signs

If your feelings seem like they are out of control or otherwise unmanageable, make an appointment with a professional counselor or other mental health professional. Your doctor can give you a referral. Also, if you know someone else who seems like they might need help because they are struggling with strong ⏩

Turn Stock Gains into Help and Hope

The Dow is hitting record highs and both the NASDAQ and S&P 500 continue to show strong gains. Perhaps it is time to look at your stock portfolio and reinvest some of your gains into a proven performer.

Directly donating appreciated securities, such as stock, to the National Ataxia Foundation significantly helps your overall tax strategy and appreciably helps the important work of the Foundation. By directly donating appreciated stock, donors have no capital gains tax liabilities and are also able to deduct the full market value of the stock.

There have been a number of families and individuals who have seen the advantages of directly donating appreciated stock to the NAF. A number of these donors have specifically designated the securities for ataxia research. Because of the generosity of these donors, the Foundation has been able to support promising ataxia research and provide meaningful programs for ataxia families.

Please consider investing in the NAF through a donation of appreciated stock. Your investment will provide help and hope to ataxia families and give you a significant tax advantage.

Before you make a gift of directly donating appreciated stock, please consult your tax advisor or financial planner to make sure you receive all the tax advantages available to you.

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emotions; offer to help them find a counselor – for example, if you or someone you know:

1. Feels strong hostility
2. Loses all emotional feeling
3. Begins using alcohol or drugs
4. Feels happy when it would be more appropriate to be sad
5. Withdraws from friendships and activities
6. Seems profoundly depressed

Denial and Loss of the Dream

When a person gets sick and then dies, caregivers and family members experience the loss of their loved one, but they also experience the loss of the dreams they shared with them. Disease might prevent their loved one from sharing in daily activities and making long-term plans. Living with chronic illness can take the fun out of life. This is a wound that must be acknowledged and dealt with. Being in denial for a long period of time can also cause stress. Expressing your feelings, allowing time for healing, and the support of compassionate friends is the best way to get through the grieving process. Each time we experience a loss and ignore it, things can only get worse. Grief must be recognized and experienced. There's no avoiding it.

Sometimes you might feel like you are on a strange, new path, lost in a wilderness that is totally unfamiliar. You may feel angry and frustrated that things have not turned out the way you planned. There may be times when you are not finished grieving for one loss, when another loss occurs. The grieving process can be very difficult, but it can also be the light at the end of the tunnel. Loss, grief, and loneliness create new challenges, but they also allow us to experience our feelings and put them behind us.

Source: Caregiver's Journey, Bonnie G. Danowski, Family Caregiver and Healthcare Advocate.

Taking Care of Yourself – Forgiveness

Part of the normal grieving process is forgiving the person who died for any real or imagined faults. You might even need to forgive them for dying. You also need to forgive yourself for anything you think you might have done wrong, or something you should have done, but didn't. The inability to forgive creates stress, which can lead to physical, mental, and emotional problems. If you are having trouble with forgiveness, find someone to talk to about it, either a professional counselor or a compassionate support group. ❖

SCA6: A Tail About a Tail

The following is a research summary of a grant funded by NAF.

If searching for the cause of a disease, such as hereditary ataxia, is a bit a like trying to find the criminal after he has left the crime scene, then the search for the cause of spinocerebellar ataxia type 6 (SCA6) has just uncovered a new *suspect*.

When SCA6 was first discovered in 1997 by Huda Zoghbi's group at Baylor College of Medicine, their findings were viewed with extreme interest and curiosity. The mutation they discovered was a familiar type – a trinucleotide repeat, sort of a genetic stutter – which researchers were accustomed to seeing in genes causing other forms of ataxia or other neurological diseases. However, the mutation in SCA6 occurred in a gene that makes an equally familiar protein, a calcium channel protein, which had never been associated with spinocerebellar ataxia. The repeated gene section in SCA6 provided another example of the expanded tracts of glutamine residues within a protein chain of amino acids. This tract, however, was found in the tail portion of a calcium channel called the P/Q-type voltage-gated calcium channel. Larger versions of these polyglutamine tracts had been found in several other disease-causing mutations including those responsible for Huntington disease, SCA 1, 2, and 3. They are believed to cause disease by mis-folding and accumulating inside the cell, interfering with normal cellular metabolism. Finding a mutation in a calcium channel was surprising. Ion channels serve as gated portals that open and shut intermittently, allowing specific ions (sodium, calcium, potassium) to pass from one part of a cell to another at the right time for a nerve cell to function properly. Mutations in these channel proteins do cause diseases, such as epilepsy and muscle diseases, but they frequently cause episodic disorders, presumably because channel proteins function intermittently.

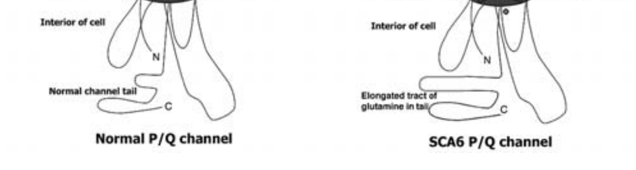

Figure 1. Spinocerebellar ataxia 6: suspect 1. SCA6 could cause ataxia by making leaky calcium channels. A) Drawing of part of normal P/Q channel with calcium entry controlled. B) P/Q channel bearing an SCA6 mutation (red), depicting how channels may become leaky.

In our initial study of SCA6, we reasoned that the slightly elongated polyglutamine tract found in the tail of calcium channel in patients with SCA6 might disturb channel function. Too much or too little calcium in cerebellar nerve cells might be a problem. Together with Dr. Pierre Charnet's group in Montpellier, France, we tested this theory by attaching the elongated glutamine tracts from SCA6 patients to the tails of calcium channels that we injected into cells used for measuring calcium currents. We found that, in fact, the calcium channels containing the patients' elongated glutamine tracts tended to open easier and remain open longer when given the usual opening triggers. Therefore, we felt we had our first *suspect*, "leaky" calcium channels (Figure 1). We initially hoped that this finding would be confirmed by others and the concept of cerebellar Purkinje cells being damaged by excessive calcium in SCA6 would lead to drug therapy strategies aimed at "tightening up" the gate of the leaky calcium channels.

When other laboratories tried to reproduce our study, however, the problem proved not to be so simple. It turns out that the calcium ⏩

channels made from this same gene can have several different variations in their structure with different behaviors, yet still carry the mutation. As a result, when other laboratories studied different calcium channel variations bearing the SCA6 mutations they had conflicting results. Sometimes the SCA6 mutation caused calcium channels to open too easily and other times to open less easily or to misbehave in other ways. With this finding, it was difficult to envision how to design of treatments. Should the goal be to develop a drug to make SCA6 calcium channels close more tightly as we found, or to open more easily as others found? Did we have the *right suspect*?

With this quandary in mind, Holly Kordasiewicz and Randall Thompson in my laboratory started a new project a few years ago. We were interested in finally putting to rest the idea that the polyglutamine tract in the tail of the channel could ever behave on its own like something similar to the other polyglutamine degenerative diseases. That is, while we and others were struggling with the concept of abnormal channel behavior as the prime *suspect* in SCA6, others were drawing a picture of how other polyglutamine expansion disorders caused neurological disease by sending the mutant protein, or a fragment of the protein, with its expanded polyglutamine tract, into the nucleus of the nerve cells to cause damage. The expanded polyglutamine tracts seem to enter the nucleus, the genetic control center of each cell, and alter the normal molecular machinery that affects nerve-cell viability. We and others had previously traced the distribution of the P/Q calcium channel in brain tissue and cerebellar nerve cells using labeled antibody probes and found that it is predominantly localized in the usual places calcium channels are found, the membrane (surface) of the nerve cell body and small branches called axons and dendrites, that is, outside the nucleus.

In our recent study, however, we developed a new pair of antibody probes, one for the extreme tail of the protein, and one that bound to the main body of the channel protein. When we tested the binding of these antibodies in cells induced to artificially produce the channel protein, we found, to our surprise, that one antibody probe detected the main portion of protein in the membrane of the cell – where it was supposed to be forming an ion channel – while the tail probe detected the tail portion of the protein both on the membrane and *within the nucleus* of the cell. We then used this new tail probe antibody on human and mouse brain tissue and found that it also detected the tail of the protein *in the nucleus*.

More detailed studies told us two things. First, the gene that made this protein did not just make a single calcium channel protein molecule, because we found a separate fragment that was cleaved off the channel protein and resided in the cell. Second, that fragment was transported to the nucleus by a natural system that proteins use to enter the nucleus to deliver important messages or instructions for cell functioning. Two additional facts emphasize the importance of this observation for finding the cause of SCA6. First, the cell type that has the highest quantity of this calcium channel protein and in which the tail fragment goes to the nucleus is the *Purkinje cell* of the cerebellum, the very nerve cell that dies in SCA6. Second, the tail fragment that is cleaved from the calcium channel protein and is transported to the nucleus contains the polyglutamine tract that is expanded or mutated in SCA6. Therefore, in the quest to understand the cause of SCA6 a *new suspect* and new scenario was at hand. In this scenario, the probable perpetrator in the death of the Purkinje cells was not an abnormally functioning channel with a leaky gate, but a fragment of the channel protein that is naturally cleaved off

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SCA6: A Tale About a Tail
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this channel and sent to the nucleus. The mutant fragment with the expanded tract of glutamine residues is transported to the nerve cell nucleus to perform a normal signaling function, but because it contains the expanded tract it somehow harms the cell (Figure 2).

When we tested this idea by inducing cells to express just the tail of the protein, we found that the tails were transported right to the nuclei of nerve cells and that tails that contain the expanded tract are excessively toxic to both cultured cells and nerve cells. Finally, when we blocked transport of the tail, toxicity was prevented.

If this second *suspect* turns out to be the culprit and cause for SCA6, then SCA6 as a disease process will become more closely aligned to the polyglutamine-mediated degenerative neurological disorders. While the details of how the transported toxic tail harms the Purkinje cell nucleus still need to be worked out, the basic process may more closely resemble what occurs in Huntington Disease as well as spinocerebellar ataxia types: SCA1, SCA3, SCA17, spinobulbar muscular atrophy, SCA17 and dentatorubropallidoluysian atrophy. Each of these disorders also involves the transport of a whole or fragment of protein that has a mutant, expanded polyglutamine tract. Learning why these proteins are toxic and developing ways to prevent it should lead to better treatments of each of the ataxias.

By borrowing insights from each other we have all helped this field move more rapidly.

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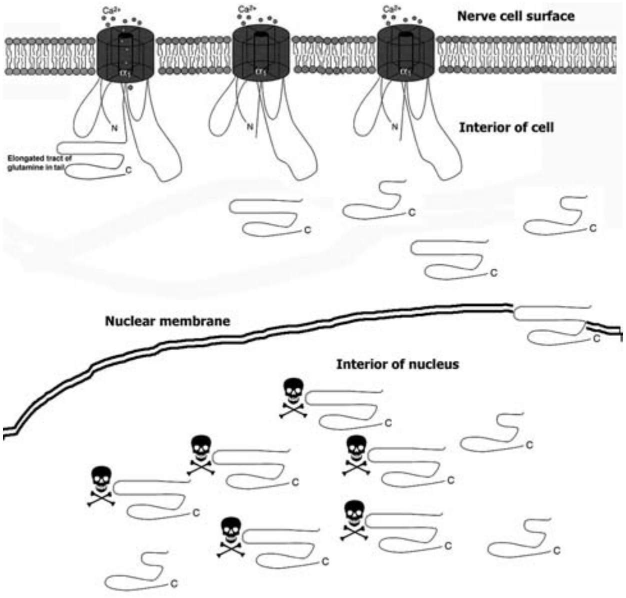

Figure 2. Spinocerebellar ataxia 6, suspect 2. SCA6 could cause ataxia by cleavage and translocation of the tail of the channel protein to the nucleus, where it has a toxic effect.

International Ataxia Awareness Day

Orange County California Ataxia Support Group

Submitted by Peggy Hyatt

International Ataxia Awareness Day was celebrated at Marie Callender's in Fountain Valley, CA. It was our first fundraiser. We passed out flyers for one week and on the 25th we ate lunch/dinner or both, at Marie Callender's and had great fellowship and excellent food.

Our goal as a group is to submit information packets with meeting locations to all the neurologists and physical therapist in Orange County in hope of being in touch with more people with ataxia and increasing general awareness.

San Diego Ataxia Support Group

Submitted by Earl McLaughlin

For the second year in a row, the San Diego Ataxia Support Group held a fundraiser to celebrate International Ataxia Awareness Day. Nearly $800 was raised that day, plus other donations were sent directly to the NAF. The fundraiser was held at a local restaurant, which donated 20% of its sales to diners who presented a flier distributed by the group. The manager of the restaurant said it was the largest turnout they'd had in some time. Estimates are that their Monday night business was tripled. Plans are being made for next year, including expanding to a second location.

The Greater Atlanta Ataxia Support Group

Submitted by Dave Zilles

The Greater Atlanta Ataxia Support Group held an International Ataxia Awareness Day Proclamation signing with Georgia Governor Sonny Perdue on September 20 at the Capitol in Atlanta.

This was our fifth annual signing and we had another great turnout. The event was followed by the Annual IAAD Picnic held at Lake Lanier on Sunday, September 24. We had hot dogs and hamburgers cooked on the grill and everyone brought side dishes and drinks. We

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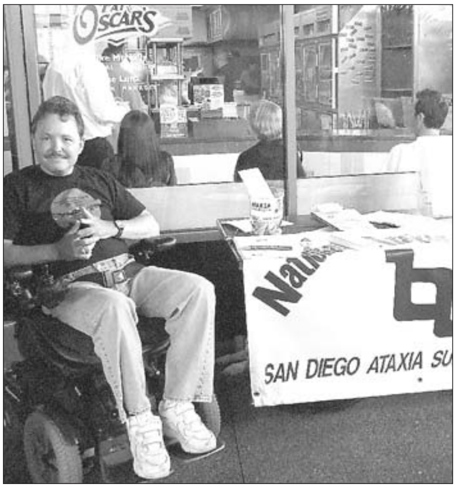

Earl McLaughlin next to the San Diego Ataxia S.G. IAAD fundraiser booth at a local restaurant.

2006 IAAD Proclamation Signing: The Greater Atlanta Ataxia Support Group held their Fifth Annual Proclaimation Signing to raise awareness for ataxia.

International Ataxia Awareness Day

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had about 25 people attend.

On September 30, the group met at Stone Mountain, just outside Atlanta, to watch the famous laser show against the world's largest relief sculpture, the Confederate Memorial Carving.

The entire carved surface measures three acres, larger than a football field. The carving of the three men – Stonewall Jackson, Robert E. Lee and Jefferson Davis – towers 400 feet above the ground, measures 90 by 190 feet, and is recessed 42 feet into the mountain. The deepest point of the carving is at Lee's elbow, which is 12 feet to the mountain's surface.

N.E. Florida Ataxia Support Group

Submitted by June McGrane

The N.E. Florida Ataxia Support Group met on September 23 at the Homestead restaurant in Jacksonville. We celebrated National Ataxia Awareness Day at the restaurant with a special cake decorated for the occasion.

We distributed NAF IAAD pins, ataxia window clings and bumper sticks to all the members. The ataxia quilt square we created was on display for all to see.

This special cake was enjoyed by members of the N.E. Florida Ataxia Support Group in honor of International Ataxia Awarness Day.

How I Celebrated IAAD

Submitted by Mary Jane Damiano

I have served as Coordinator of International Ataxia Awareness Day for the Village of North Syracuse since 2000. The awareness of ataxia was greater then ever this year. We distributed IAAD bookmarks at 34 libraries throughout Syracuse and Onondaga County. We received IAAD Proclamation from the Village of North Syracuse, the City of Syracuse, and the County of Onondaga.

John Heindorf, Mayor of the Village of North Syracuse served as Master of Ceremonies at our IAAD Ceremony on September 21, 2006 at North Syracuse Community Center. The event paid tribute to those ataxia patients that were present. Diane Browning, Deputy Mayor of the Village of North Syracuse, conducted a candlelight ceremony representing hope and unity by all those who suffer from the disease and those who care for them. State Senator David J. Valesky spoke about New York State's efforts to fund ataxia research. Jeff Paston, National Ataxia Foundation volunteer, spoke about ataxia in President Abraham Lincoln's family. Refreshments donated by Wegmans Food Markets were served. Fergerson Funeral Home donated a fresh flower centerpiece for the head table.

Jack Parker and I appeared in a front page article about the community's efforts to increase the awareness of ataxia in the September 27 edition of the North Syracuse *Star-News*.

Submitted by Bill Lee

Frederick Mayor Holtzinger presented, in person, a Proclamation for IAAD on Tuesday, September 26 at City Hall. The County Commissioners were not able to do a personal presentation this year; instead, they sent their proclamation to me, with regrets.

▸▸

I would just like to remind everyone how easy it is to line up an IAAD proclamation. All it takes is a phone call!

Submitted by Deborah Omictin

On Sunday, September 24, I celebrated International Ataxia Awareness Day at Mount Eden Presbyterian Church, where Pastor Zondra Newsome performed a candle lighting ceremony with the children. She explained to them and the entire Congregation that I, Elder Deborah Omictin, have a rare progressive disorder of the nervous system affecting balance and coordination called ataxia and explained why we lighted a candle for Hope and Unity.

At the Northern California Ataxia Support Group's September 16 meeting, we supplied attendees with IAAD pins and bookmarks.

On September 25, my husband King wore his IAAD t-shirt and my nine-year-old niece Sophia wore an IAAD pin.

Submitted by Shawn Hagler

An article was published in *The Times Picayune* on Sunday, September 10 featuring Carla Hagler, Louisiana Chapter Leader. The article entitled “Displaced by Katrina, Slidell Women Restarts Support Group,” can be found in the “Slidell Picayune” section of the newspaper.

Submitted by Sister Mary E. Baker

I am a retired teacher of the University of Saint Mary in Leavenworth, KS. I have sporadic ataxia and am a resident of a nursing home facility. I have a motor scooter, however, so I am able to go to other buildings on campus, one of which is the University of Saint Mary. When I noticed the press release for International Ataxia Awareness Day I did the following:

1. Placed the poster and press release on a bulletin board in the nursing home for all the nurses and aides to read.
2. Sent the press release to all faculty, staff, and students at the University of Saint Mary as well as friends and relatives.
3. Placed the poster and press release on a bulletin board for beginning students in the RN/BSN program at the university to read.
4. Volunteered to be a “real patient” in the USM Nursing Therapeutic Interventions Class so a therapist could demonstrate the proper techniques used when making transfers from bed to wheelchair. After her demonstration, I showed the students the many assistive devices I use to maintain my independence and explained how I live with ataxia.
5. Explained to the nursing students what I have difficulty doing now and encouraged them to be aware of what actions we take for granted.
6. Sent e-mail, including the press release, to all the members of our religious community, the Sisters of Charity of Leavenworth, and posted the information on our Sisters of Charity of Leavenworth web page.
7. Wore my “Ataxia is not a foreign cab” t-shirt as a conversation starter to get people to read the press release. ❖

IAAD Proclamation: The Town of Westport, MA gave a certificate proclaiming September 25 at International Ataxia Awareness day, the fourth time the town has had a proclamation signed. Shown above are Board of Selectman Chairman Steve Ouellette (right), Janet Coyne (seated) and Stacy Leger.

They Won't Come Around to See You Complain

By Harvey Nevis

In days of old, when I was bold
And disability wasn't invented

I'd run along the streets all day
And strive to be contented

I dreamt of great things I knew I could be
And of things I would love most to do

Alas, reality caught up with me
And I saw what was really true

No feats of greatness
No mountains to climb
It somehow fell apart

For how can you
Make your dreams come true
With an empty heart

Would you please tell me the meaning of life!
What is it all about?

At times an outsider still looking in
A silly clown with a past on grin

How lonely life looks and yet I see
Lives abounding in people like me

What is their secret?
How did they get that way?
Will I ever get a chance to play?

Don't dare show others
how much you're in pain

For they won't come around
to see you complain

CFC Giving

If you are a federal employee and give through your local Combined Federal Campaign (CFC), please consider giving to the National Ataxia Foundation. The Foundation's CFC number is 1028.

Please encourage your co-workers to also give to the Foundation.

Shopping on the Web

Didn't get that special gift you were expecting from Santa? There is a place to find that special item: *www.iGive.com*.

No matter whether you are looking for the latest fashions, office supplies, books, jewelry, or more, you have found the right place at *www.iGive.com*. The site offers hundreds of stores to choose from and brand names you know and trust.

Best of all, every time you make a purchase on *www.iGive.com*, the National Ataxia Foundation receives a donation! What could be better? Help yourself to great shopping and help the Foundation at the same time.

IAAD Follow-up

If you participated in International Ataxia Awareness Day and it was not mentioned in this issue of *Generations* please let us know and it will appear in the spring issue.

Please send materials to *Generations* Staff, 2600 Fernbrook Lane, Suite 119, Minneapolis, MN 55447 or send e-mail to *naf@ataxia.org*.

The Phantom

By Lara Carbajal, Albuquerque, NM

Dedicated to my son Donnie (1962-1993), to my son Richard and to all the parents who have lost, or are losing, a child with a degenerative disease.

A Phantom is your enemy,
A silent killer you cannot see.
More devastating day by day,
As capabilities fade away.

Your courage is beyond belief,
As though you try to soothe the grief,
Of friends and family, Dad and I,
Who feel so helpless standing by.

At times I feel my heart will break,
But hide the tears for others' sake.
I ask God for the strength to let you go,
He surely must know that I love you so!

Is there no miracle cure in sight?
I say to my loved one, "Fight, Son. Fight!"
And fight you do, to no avail;
It seems your enemy will prevail.

I can hardly bear that you're slipping away.
I'm desperate to know what do or say.
What will I do when you are gone?
The void in my life will go on and on.

To accept "what is", I search my soul;
Protecting her children is a mother's role!
"What more can be done?" in anguish I cry,
As I sob in my pillow and ask, "Why, God why?"
I need the courage that you have shown,
This challenge is the greatest one I've known.

I try to celebrate each day,
That I can smile and touch and say,
"I love you, Son, with all my heart."
I pray for guidance and do what I must.
I now rely on faith and trust.

The only thing that comforts me,
Is my belief in eternity.
We'll each close the door on this earthly life,
And enter a place where there is no strife.

How wonderful that place will be!
Where those we've loved, again we'll see.
What joy to be with you once again!
Free of disability and pain.

Oh, my dear son, as I kiss your face,
I see you *running* in that beautiful place.
I see you whole and happy and free!
No longer is the Phantom your enemy.

When the time comes and you decide to go,
Through all my tears, despair and woe,
I'll thank God for the time we had,
The love we shared and I'll be glad
That you're with God, and safe…at peace
The hardships are over;
Your struggles have ceased.

The memories of you will linger forever,
And I know once again we'll be together.
We'll have weathered the storm
and when it is done,
I'll love you forever for being my son.

The Board of Directors of the National Ataxia Foundation
Cordially Invites You to the 2007 Annual Membership Meeting

"The Bridge to Hope"

Dates: March 22-25, 2007

Location: Memphis Downtown Marriott
250 North Main Street
Memphis, Tennessee 38103
(866) 449-7387 or (800) 228-9390

Advance Registration Fee for NAF members or Spouse/Caregiver:

A low per person registration fee of $50 gains you complete access to all Break Outs and General Sessions, as well as participation in teen sessions, exhibits, breaks, the Friday Night Reception, and the Saturday Evening Banquet. *Sign up early to get this low advance rate!*

Advance Registration Family Rate:

(This rate is applied to NAF members, their spouse/caregiver and children under 18 only!)
$50 per person with a maximum fee of $200.

Non-Member Advance Rates:

If you are not a current paid member of NAF, the advance registration rate is $100 per person with a $400 maximum for families.

Late Registration or Registration at Door (NOT RECOMMENDED):

The fee for registrations postmarked after February 15, 2007 is $75 per person for NAF Members ($300 maximum for families) and $125 for non-members ($500 for families).

PLEASE NOTE: The Registration Fees DO NOT include any Adult Early Arrival Outings or transportation fees.

Instructions for Registration:

1. Complete the enclosed registration form and mail, with your payment, to NAF headquarters. **Please fill out the form completely.** We will need all of the requested information to complete preparations for the meeting. (Registration fees do not include hotel reservations. Please see next item.)
2. **Registration Fees.** If you plan to attend either just the conference or just the banquet, the **full** per person fee will still be charged. If you are bringing your children to the meeting, the following fees will be charged: children two years and under are free; children three years and over will be charged the full conference fee.
3. Childcare services will not be provided by NAF or its local volunteers
4. Complete and return both pages of the Registration form by February 15, 2007. Please fill out the name portion of the registration exactly as you would like it to appear on your name badge.

Registration Deadline is February 15, 2007

Please complete both pages of this registration form and return to the following address:

National Ataxia Foundation, 2600 Fernbrook Lane, Suite 119, Minneapolis, MN 55447-4752
(763) 553-0020 Fax: (763) 553-0167 E-mail: *naf@ataxia.org*

2007 NAF Annual Membership Meeting Agenda

Please Note: Due to circumstances beyond our control, this meeting agenda is subject to change.

WEDNESDAY, March 21

Event	*Location*	*Time*
NAF Registration	Natchez	6:00 - 9:00 p.m.

THURSDAY, March 22

Event	*Location*	*Time*
NAF Registration	Natchez	8:00 a.m. - 9:00 p.m.
Early Teen Outing	Grizzlies vs. Lakers, FedEx Forum	6:30 - 10:00 p.m.
Early Adult Outing	Grizzlies vs. Lakers, FedEx Forum	7:00 - 10:00 p.m.
Leadership Meeting	Nashville	1:00 - 5:00 p.m.
Internet Group	Nashville	7:00 - 9:00 p.m.

FRIDAY, March 23

Event	*Location*	*Time*
NAF Registration	Natchez	7:30 a.m. - 6:30 p.m.
Breakout Sessions	Various Meeting Rooms	8:00 a.m. - noon
Lunch	*On Your Own*	12:00 noon
Birds of a Feather (see below)	Various Meeting Rooms	2:00 - 5:00 p.m.
Reception	MCCC Ballroom A&B	7:00 - 10:00 p.m.

BREAKOUT SESSION SCHEDULE

Time	Heritage 1	Heritage 2	Heritage 3	Heritage 4	Heritage 5	Heritage 6
8:00 a.m.	Speech & Swallowing	Coping Late On-Set	Caregiver Coping	Rehabilitation	Dance	Treatments & Medications
9:00 a.m.	Genetics	Coping Early On-Set	Service Dogs	Nutrition	Depression	Adult Siblings
10:00 a.m.	Speech & Swallowing	Coping Late On-Set	Caregiver Coping	Rehabilitation	Dance	Treatments & Medications
11:00 a.m.	Genetics	Coping Early On-Set	Service Dogs	Nutrition	Depression	Adult Siblings

BIRDS OF A FEATHER — 2:00 - 5:00 p.m.

Birds of a Feather Informal Groups will meet from 2:00 - 5:00 p.m. in scattered areas throughout the Heritage Ballroom and other meeting rooms. Please check the hall signs for your specific group's location.

PARENTS BIRDS OF A FEATHER — 2:00 - 5:00 p.m. in the Nashville Room

This Birds of a Feather group time will be used to listen and share experiences. This will be a powerful time for each of us. The session will begin with identifying some expectations of the group members and addressing their issues/concerns.

CAREGIVERS AND SPOUSES BIRDS OF A FEATHER — 2:00 - 5:00 p.m. in the Knoxville Room

This Birds of a Feather will be used by caregivers to share with other caregivers their experiences and concerns in this most appreciated role.

2007 NAF Annual Membership Meeting Agenda

Please Note: Due to circumstances beyond our control, this meeting agenda is subject to change.

SATURDAY, March 24

Event	*Location*	*Time*
NAF Registration	Natchez	7:30 a.m. - 5:30 p.m.
General Sessions	MCCC Ballroom A&B	8:00 a.m. - noon
Lunch	*On Your Own*	12:00 noon
General Sessions	MCCC Ballroom A&B	2:00 - 5:00 p.m.
Silent Auction	TBA	3:30 - 7:30 p.m.
Catholic Service	Jackson	6:00 - 6:45 p.m.
Non-denominational Service	Chattanooga	6:00 - 6:45 p.m.
NAF Banquet	MCCC Ballroom A&B	7:00 p.m.

Saturday General Sessions

Time	*Speaker*	*Topic*
8:00 a.m.	Arnie Gruetzmacher	Welcome and Opening Remarks
8:30 a.m.	Michael Wilensky, MD	Managing the Ataxia Patient
9:00 a.m.	Harry Orr, PhD	Ataxia Research Review
9:30 a.m.	Break	
10:00 a.m.	Laura Ranum, PhD	SCA 8 Research
10:30 a.m.	Sid Gilman, MD	Sporadic Ataxia
11:00 a.m.	Henry Paulson, MD, PhD	Update on Spinocerebellar Ataxia Type 3 / Machado-Joseph Disease
11:30 a.m.	Q&A Panel	
12:00 noon	Lunch	
2:00 p.m.	Meri Firpo, PhD	Using Stem Cells as a Model of Human Development
2:30 p.m.	S.H. Subramony, MD	Uncommon Causes of Ataxia
3:00 p.m.	Robert Wilson, MD, PhD	Experimental Therapeutics for Friedreich's Ataxia
3:30 p.m.	Khalaf Bushara, MD	Ataxia and Allergy to Wheat
4:00 p.m.	Beverly Davidson, PhD	microRNAs in SCA1
4:30 p.m.	Q&A Panel	

SUNDAY, March 25

Event	*Location*	*Time*
NAF Registration	Natchez	7:30 - 11:00 a.m.
Business Meeting	MCCC Ballroom A&B	8:00 - 8:30 a.m.
General Sessions	MCCC Ballroom A&B	8:00 a.m. - 1 p.m.

Sunday General Sessions

Time	*Speaker*	*Topic*
8:30 a.m.	Jeremy Schmahmann, MD	The Cerebellum in Behavioral Neurology and Neuropsychiatry
9:00 a.m.	Mark LeDoux, MD, PhD	Other Movement Disorders in Patients with Ataxia
9:30 a.m.	Susan Perlman, MD	Non-Experimental Issue of Diagnosis and Management for Friedreich's Ataxia
10:00 a.m.	Break	
10:30 a.m.	Sara Ying, MD	Eye Movement Abnormalities and Ataxia
11:00 a.m.	Arnulf Koeppen, MD	Why Are the Dominant Ataxias So Different from Each Other?
11:30 a.m.	John Day, MD, PhD	Review of What We Have Learned
12:00 noon	Q&A Panel	
12:30 noon	Arnie Gruetzmacher	Closing Remarks

2007 NAF Annual Membership Meeting Registration

1. Name: ______________________
Address: ______________________
City/State/Zip: ______________________
Country: ______________________
Phone: ______________________
E-mail: ______________________
InterNAF/Chat Name: ______________________
☐ Adult (18+) ☐ Teen (13-17) ☐ Child (0-12)

3. Name: ______________________
Address: ______________________
City/State/Zip: ______________________
Country: ______________________
Phone: ______________________
E-mail: ______________________
InterNAF/Chat Name: ______________________
☐ Adult (18+) ☐ Teen (13-17) ☐ Child (0-12)

5. Name: ______________________
Address: ______________________
City/State/Zip: ______________________
Country: ______________________
Phone: ______________________
E-mail: ______________________
InterNAF/Chat Name: ______________________
☐ Adult (18+) ☐ Teen (13-17) ☐ Child (0-12)

2. Name: ______________________
Address: ______________________
City/State/Zip: ______________________
Country: ______________________
Phone: ______________________
E-mail: ______________________
InterNAF/Chat Name: ______________________
☐ Adult (18+) ☐ Teen (13-17) ☐ Child (0-12)

4. Name: ______________________
Address: ______________________
City/State/Zip: ______________________
Country: ______________________
Phone: ______________________
E-mail: ______________________
InterNAF/Chat Name: ______________________
☐ Adult (18+) ☐ Teen (13-17) ☐ Child (0-12)

Assist Dog ______________________

Assist Dog ______________________

TRAVEL INFORMATION

Flying? ☐ Yes ☐ No *If no, how will you be traveling (i.e., driving, bus)?* ______________________
Air Carrier: ______________________
Flight Number: ______________________
Arrival Date/Time: ______________________
Hotel Check-in Date: ______________________
Departure Date/Time: ______________________
Hotel Check-out Date: ______________________

Please complete the following table for each person:		**#1**	**#2**	**#3**	**#4**
1. Is this your first NAF Annual Meeting?	**Y or N**				
2. Are you attending the Saturday evening banquet? (included in your registration fee)	**Y or N**				
3. If you are attending the Banquet, would you like the Vegetarian (V) or Gluten-Free (G) option?	**Blank, V or G**				
4. Will you be using a Scooter (S), Manual Wheelchair (M), Electric Wheelchair (E), or a Walker (W)?	**Blank, S, M, E or W**				
5. Will you be participating in the Teen Program?	**Y or N**				

By attending the 2007 NAF Annual Membership Meeting you give permission for images of you, captured during the conference through video, photo, and digital camera, to be used by the National Ataxia Foundation in promotional materials, publications, and web site and waive any and all rights including, but not limited to, compensation or ownership.

2007 NAF Annual Membership Meeting Registration

Payment Information for NAF MEMBERS	**Amount**	**Quantity**	**Total**
Registration Fee for INDIVIDUAL Members and Spouse/Caregiver	$50 ea.		
FAMILY RATE *(Applies to NAF members who have a **Household**, **Patron**, or **Lifetime** Membership. This includes members, their spouses and children under 18 only!)* **Maximum: $200**	$50 ea. *or maximum* $200		
Late Registration for NAF Members *(Includes all registrations postmarked after Feb. 15 and **all registrations at the door**)*	$75 ea.		
Payment Information for NON-NAF MEMBERS	**Amount**	**Quantity**	**Total**
Registration Fee for Non-NAF Members	$100 ea.		
FAMILY RATE for Non-NAF Members *(Maximum family rate for individuals, their spouses and children under 18 who are not members of NAF)* **Maximum: $400**	$100 ea. *or maximum* $400		
Late Registration for Non-NAF Members *(Includes all registrations postmarked after Feb. 15 and **all registrations at the door**)*	$125 ea.		
Teen Early Arrival Outing Thursday Evening **Free for TEENS 13-19 ONLY!*	Free*		

Take advantage of the MEMBER RATE and JOIN TODAY!	**Quantity**	**Total**
Yes, I would like to be a member of NAF! Please add an ***ADDITIONAL*** ☐ $25+ (Annual Individual) ☐ $45+ (Annual Household) ☐ $100+ (Annual Patron) ☐ $500 (Lifetime) ***You may register for the meeting as a member if you sign up today!***		
Yes, I'd like to help others attend an annual meeting in the future! Here is my sponsorship contribution! ☐ $50 (Offset of Registration) ☐ $250 (Travel Grant) ☐ Other: _____________ (Any amount is helpful!)		

TOTAL CHARGES:	

PAYMENT INFORMATION: ☐ Visa ☐ MasterCard ☐ Check enclosed

Name of Card Holder: ______________________________

Address: ______________________________

City: ____________________ State: __________ Zip: ____________ Country: ______________

Phone Number: ____________________ Signature of Card Holder: ____________________

Credit Card Number: ____________________ Expiration Date: ____________________

Registration Deadline is February 15, 2007

Please complete both pages of this registration form and return to the following address:

National Ataxia Foundation, 2600 Fernbrook Lane, Suite 119, Minneapolis, MN 55447-4752
(763) 553-0020 Fax: (763) 553-0167 E-mail: *naf@ataxia.org*

THE NAF BOARD OF DIRECTORS AND THE NAF MISSISSIPPI CHAPTER WOULD LIKE TO INVITE YOU TO ATTEND THE

National Ataxia Foundation 50th Annual Membership Meeting

March 23-25, 2007

(Leadership Meeting March 22)

Join us in Memphis for the Annual Membership Meeting!

The beautiful Downtown Memphis Marriott and Memphis Cook Convention Center is pleased to provide the facilities for the National Ataxia Foundation.

Rooms are available at the **special group rate** of $126 per night.

Please be sure to make your reservations by **February 27, 2007** 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.

To book your stay online, go to *http://marriott.com/property/propertypage/memdt?groupCode=ataataa&app=resvlink* or if you would prefer to make your reservations by phone, please **call toll free (800) 228-9290** and ask for **the National Ataxia Foundation Conference special rate**.

There were a limited number of ADA rooms available on a first-come, first-serve basis. *These rooms are full at this time.* NAF will have a limited number of shower chairs, toilet frames and tub bars available on a first-come, first-serve basis at the Memphis Marriott Downtown hotel front desk.

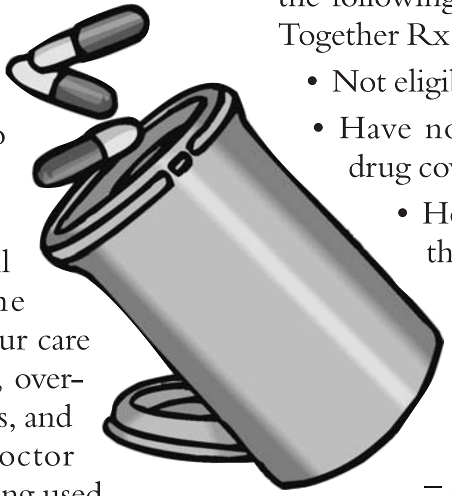
We look forward to seeing you in Memphis!

Medications and What to Ask the Doctor

Small Things Can Cause Big Trouble

NAF has permission to reprint the following excerpts.

Medications should always be taken *exactly* as prescribed. Keep an up-to-date list of them and when they should be taken. Never make any changes without talking to the doctor first. Learn to recognize changes in symptoms, because it might mean the person in your care needs to have a prescription changed. Drugs can be expensive, confusing to use, and have unwanted side effects. Patients or caregivers should be sure to ask the doctor and pharmacist how to use them correctly.



At the Doctor's Office

Give the doctor a list of all the medications (and the dosages) that the person in your care is taking, including eye drops, over-the-counter products, vitamins, and herbal remedies. Tell the doctor about any other treatments being used, because using multiple treatments can be dangerous. Tell the doctor about any allergies, including food allergies. Questions to ask:

- Which medicine relieves pain the best?
- How long does it take for the drug to work?
- Are there side effects? What should you do if you notice any?
- Will any one drug react with other drugs?
- Could changes in diet, exercise, reducing stress, or other things help the condition?
- If more than one drug is needed, ask the doctor if they can be taken at the same times each day. If a drug must be taken at a difficult time (for instance, in the middle of the night), ask about other choices.
- Can a lower dose be prescribed without bad effects?
- Is it possible to buy a one-week supply of a new medication to see if there are any serious side effects? Are free samples available to try?

Resource for You

FREE Prescription Savings Card

Individuals and families who meet all four of the following requirements are eligible for the Together Rx Access Card:

- Not eligible for Medicare
- Have no public or private prescription drug coverage
- Household income equal to or less than:
  - – $30,000 for a single person
  - – $40,000 for a family of two
  - – $50,000 for a family of three
  - – $60,000 for a family of four
  - – $70,000 for a family of five
- Legal resident of the U.S. or Puerto Rico

If you meet all of the eligibility requirements listed above, simply call 1-800-250-2839 to start savings averaging 25-40% on your prescriptions. For the most current list of medicines and products, visit: *www.TogetherRxAccess.com*.

Medication Safety Tips

1. Refill prescriptions early so you won't run out.

2. If someone will be taking several medications on his own, find a pharmacy that will do simplified packaging.

3. Check expiration dates frequently and discard any medicines that are out-of-date.

Continued on page 44

Aquatic Therapy: Exercising Has Never Been So Easy

by Earl McLaughlin

The benefits of physical exercise cannot be overstated. At the 2007 National Ataxia Foundation Annual Membership Meeting in Memphis, this will once again be the topic of a breakout session. For the first time "aquatic therapy" will be added as a session. I have found that exercising in water makes my workouts easier and it has produced results.

Imagine exercising in an environment where your joints are cushioned, you have more range of motion, and you get the feeling of being weightless. That is exactly what you get when you exercise in water. It provides the body with buoyancy to help with balance and support that you simply can't get when exercising on land. The water temperature cools the body so that over-heating doesn't occur. Because of this, individuals can exercise longer and work harder, which in turn helps build endurance. People who can't walk without the use of a walker or use a scooter can often do so in water.

It is important to note that aquatic therapy is not swimming. While it is true that swimming and pool access has been the subject of breakout sessions at annual membership meetings in the past, structured aquatic therapy has not. Aquatic therapy is using the benefit of water to exercise various parts of the body. Since I never learned to swim, I was not interested in a session on swimming, and it took me meeting someone who benefited from water exercise (not just swimming) to convince me to try it.

In April of this year, I started exercising in a pool twice a week and I could immediately feel the benefit. I could stretch and move parts of my body that were nearly impossible to move while on land. I could do knee bends, rotate my hips and shoulders, do abdominal crunches, stretch out my arms, legs, and back. My range of motion was unbelievable. This was due primarily to the cushioning and buoyancy of the water.

My interest started when I ran into a lady with SCA at the All-California Ataxia Research Meeting (ACARM) whom I had not seen since the last NAF Meeting in San Diego. I found out that she has been enrolled in a water exercise class. I had heard of the class, but I was never into swimming and always had an excuse not to try it. I was amazed at the improvement of her physical condition, so I decided to check into this further. I contacted an aquatic therapist and developed a routine, which I have been doing in addition to my "land" exercise routine.

Since I started doing aquatic therapy, I have received quite a few compliments on my healthy appearance, and my attendants have also noticed an increase in my strength. I feel that my general heath has improved, meaning there is not only a physical benefit, but a psychological benefit as well. There is a definite improvement in my balance, muscle tone, flexibility, and strength.

Finding a place to exercise is pretty simple. There is the YMCA/YWCA, Salvation Army, schools, community centers and hospitals. Many gyms have indoor pools. Most public pools provide different types of equipment to assist those who need extra stability to walk, float or swim in the water. Many, if not all, public facilities are equipped with automatic lifts or ramps (thanks to ADA) to assist participants in and out of the water, as well as helpful lifeguards to help with transfers, move lane lines, or help with equipment.

Some people suffer from a respiratory ailment and could not take advantage of this. While I do not have a respiratory ailment, I do not like to submerge my head (partly because I can not swim, and I panic when I go underwater). Thanks to a Kiefer Inflatable Swim Collar (*www.kiefer.com*; search for "620002") that doesn't happen to me. The collar provides me with enough buoyancy that I can lay back to float and feel completely safe.

I look forward to sharing more with you in Memphis. If you have questions before then, please do not hesitate to contact me at *emclaugh@cox.net*.

Meet the NAF Board of Directors

The National Ataxia Foundations's Board of Directors are volunteers who dedicate countless hours to help ataxia families. The Board is responsible for providing direction and overseeing the operations of the Foundation. It also reviews ataxia research proposals and makes funding decision on these applications.

Over the years the Board has developed a number of committees to oversee various functions of the Foundation. Each board member chairs or co-chairs a committee.

The Board is made up of a diverse group of caring people. Each member brings with them expertise on certain issues to help the Foundation's efforts to provide important programs to ataxia families. ❖

Featured Board Member of the NAF: Dr. Laura Ranum

Laura Ranum, Ph.D. has served on the National Ataxia Foundation's Board of Directors since 1998. She also serves on the NAF Medical and Research Advisory Board. Dr. Ranum has had a long-term interest in the ataxias which goes back to her post-doctoral work on the identification of the SCA 1 gene with Dr. Harry Orr.

Dr. Ranum is a Professor of Genetics, Cell Biology and Development and a member of the Institute of Human Genetics at the University of Minnesota. Her lab continues to focus on the identification and characterization of genes that cause ataxia. Since 1998 her lab has identified the genes for SCA 5, SCA 7, SCA 8, and myotonic dystrophy type 2.


Dr. Laura Ranum

Dr. Ranum has been published in numerous scientific journals and is well known throughout the world for her work in ataxia research. Earlier this year, Dr. Ranum received national media attention due to the discovery of the SCA 5 gene, the gene in President Lincoln's family.

Dr. Ranum is well known and respected throughout the scientific community as she serves as a reviewer for numerous scientific journals and funding agencies including the Muscular Dystrophy Association and the National Institute of Health.

Her current research focus is on generating mouse models to help better understand these diseases and to improve mapping strategies that will allow for the identification of additional genes.

Many of you have met Dr. Ranum through her presentations at NAF Annual Membership Meeting general sessions, breakout sessions, and "Birds of a Feather." Her commitment and dedication in helping ataxia families is well recognized and she is a very popular and well respected speaker at the conference.

Dr. Ranum brings to the Board scientific expertise and a broad understanding of how ataxia affects each family member. She has given so much in her fight against ataxia and to the ataxia community.

We are pleased and honored to have Dr. Ranum on the Board of Directors and Medical and Research Advisory Board. We are truly thankful for her commitment. ❖


USA
DISABLED & PROUD!
NASCAR

NAF Merchandise

BOOKS

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

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

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

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

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

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

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

NEW!

VIDEO / CD

Ballads of a Family Man CD
A CD containing 10 songs in memory of Billa Ballard. $5 of the purchase price goes to support the work of the NAF. $13 (includes S&H)

"Together there is Understanding" Video
A continuation and expansion of the NAF video "Together There is Hope," this 50-minute video provides an in-depth look at ataxia and ataxia research. VHS $20 or DVD $25 (includes S&H)

SHIRTS / MISCELLANEOUS

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

NEW!

2006 Annual Meeting T-Shirt
Vintage long-sleeve with "Beacon of Light" logo. Sizes XL to XXX-large. $10

2005 Annual Meeting DVD or VHS
Set of 5 DVDs $75. Set of 4 VHS $50.

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

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

Window Clings & Bumper Stickers
$1 each or 6 for $5

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

NEW!

NAF Ataxia Awareness Ribbon Magnets
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*

ORDER TOTAL: ____________________

PLEASE ALLOW 4-6 WEEKS FOR DELIVERY

NAME: ____________________

ADDRESS: ____________________

CITY ____________ STATE: ____ ZIP: ______

PHONE: ____________________

For credit card orders, please fill out the following information (you must include phone number and signature):

CIRCLE ONE: Visa Mastercard

NAME ON CARD: ____________________

CARD #: ____________________

EXP DATE: ____________________

SIGNATURE: ____________________

THE NATIONAL ATAXIA FOUNDATION

50th Annual Membership Meeting

"The Bridge to Hope"

Question and Answer

Do you have a medical question that you would like answered?

We understand that not all of our members are able to attend the upcoming annual meeting in Memphis. We believe it is important, however, that you are still able to have your questions answered. If you would like to submit a medical-related question, please fill out the form below, as clearly as possible and send it to us at the address below.

Questions and Answers may be published in *Generations*.

DISCLAIMER: No information identifying you or the person mentioned on this form will be made public.

Your Name (Optional): ____

E-Mail (Optional): ____

Type of Ataxia (if known): ____

Question(s): ____

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PLEASE RETURN THIS FORM TO:

Becky Kowalkowski, Patient Services Director
National Ataxia Foundation, 2600 Fernbrook Lane, Suite 119, Plymouth, MN 55447
or e-mail the above information to *becky@ataxia.org*

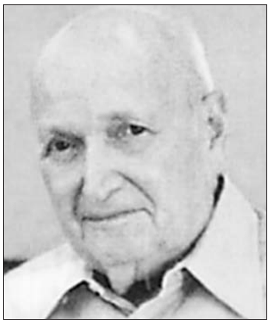
Deadline: February 15, 2007

Benjamin J. Cantor

March 25, 1910 – October 27, 2006

Benjamin J. Cantor was born in Boston, MA, and was a resident of Belmont since 1950. He was a graduate of Northeastern University School of Engineering in 1931 and Boston College Law School in 1937. He served as captain in the Signal Corp. Radar Unit attached to the Air Force in World War II.

Ben, a pioneer in the specialized field of forensic photography, founded and operated the Boston Photo Service from 1931-1978. He then founded Legal Evidence Photography Seminars. During his career Ben wrote many articles for legal and photographic journals on the role of photographs and the expert witness in court trials and he delivered many lectures. He was the co-author of *Photographs in Civil Litigation* and the author of *The Role of the Expert Witness in a Court Trial* and *Courtroom Guide for Non-Lawyers*.


Benjamin J. Cantor

He was a life member of Professional Photographers of America and National Press Photographers Association; founder and life member of Evidence Photographers International Council; and member of the American Academy of Forensic Sciences and American College of Forensic Examiners. Ben received a number of awards during his career.

When he saw a need to make a difference or help others, Ben took action. He served as president of the Kiwanis Camp Allen for Blind Girls in New Hampshire. A founder and honorary member of the Wightman Tennis Center of Weston, he was an avid tennis player for many years. Most recently he was an advocate for the construction of a senior center in Belmont.

Several years before his death Ben was diagnosed as having spinocerebellar ataxia. Learning there was no support group in the area, he and a fellow patient founded the New England Support Group of the NAF.

Ben was a devoted son, husband, father, and grandfather who loved his family unconditionally. People and relationships were of utmost importance to him. Those who were blessed to know him were impressed with his compassion, generosity, integrity, terrific sense of humor, and optimism. He was intelligent, motivated, and perceptive and he always saw the good in people. He was a man of high moral and ethical character. We are all richer because Ben Cantor touched our lives. Our finest tribute to him will be to carry on his messages to all whose lives we touch. He will be deeply missed. ❖

Employer Matching Gifts Programs

There are many companies that will match the gift you make to the National Ataxia Foundation. Ask your employer if they have a matching gifts program. If they do, your gift will double in value.

NAF receives matching gifts from companies all over the United States. Sometimes the matching gift is $5,000 or more. Please encourage your co-workers to also contribute to the Foundation. Their gifts will also double through your company's program.

Thank you to all the donors who have already given and to their companies who have so generously matched their gifts.

Each dollar contributed brings help and hope to ataxia families across the nation.

Chapter and Support Group News from Around the Country

The NAF Exhibit at the Southern California and Detroit Metro Abilities

By Earl McLaughlin

The Southern California show was held in June in Anaheim, CA, and was staffed by members of the Orange County Ataxia Support Group and Sid Luther, leader of the Los Angeles Ataxia Support Group. This was the last event lead for NAF by the late Kay Bell.

The Detroit Metro Abilities Expo was held in August in Novi, MI, and was staffed by Sherry and Randy Dombrowski from Romulus, MI, and Earl McLaughlin, NAF Board Chair of the Abilities Expo Committee, and Judy Jarina from San Diego, CA.

Left to right: Lynn Ball, Earl McLaughlin and Sherry Dombrowski at the Detroit Metro Abilities Expo.

The Abilities Expo is the largest show in the nation devoted exclusively to products and services for people with disabilities and others who need assistance, family members, and health care and rehabilitation professionals. It offers an opportunity to see, try, compare, and buy products and services that can enhance people's lives to make life easier, more productive, more independent, and more enjoyable. A show like the Abilities Expo gives the NAF an opportunity to spread the word regarding ataxia. It's a great way to increase public awareness.

The NAF usually exhibits at two Abilities Expos each year. For 2007, plans are being made to exhibit at the San Antonio show (a new city) in January and the Southern California show (for the 21st time) in June.

Chesapeake Chapter

By Carolyn Davis

The Chesapeake Chapter held its annual potluck picnic and social on Saturday September 30 at the Sumner Village Community Center in Bethesda, MD. Twenty-five people gathered for an enjoyable afternoon of eating, socializing, and sharing updates on various topics. The Chapter provided chicken and all participants brought a dish to share for a scrumptious repast.

Lois Johnson shared thoughts on the NAF Annual Membership Meeting, "Beacon of Light," held in March. She expressed the need to support the meeting itself as well as supporting one another.

Dr. Sarah Ying, Assistant Professor of Neurology at Johns Hopkins University School of Medicine, presented information on studies of cerebellar control of eye movements using the MRI. She described eye movements as "windows into your brain." Eye movement abnormalities are some of the first symptoms that can be detected on these sensitive tests. The clinical manifestation of eye movements varies among patients with different SCAs.

Continued on page 36

Chapter & Support Group News
Continued from page 35

Dr. Ying is involved in a study to pinpoint those differences.

Also joining us at the picnic was Dr. David Solomon, Assistant Professor of Neurology at Johns Hopkins School of Medicine. He answered some questions later in the day.

Carl Lauter reported on the NINDS Forum held at NIH, "Showcasing Success in Neuroscience Research." The importance of patient advocacy/support groups, no matter the size, was stressed.

Libby Labash brought attention to an NIH study of swallowing disorders. One of the purposes of the study is to determine if muscle stimulation can reduce aspiration. She also brought a report on a new tool for studying degenerative diseases. Scientists at the Linus Pauling Institute at Oregon State University have a new technique "to watch, visualize and precisely measure a key oxidant in animal cells."

Libby and Carl presented the fifth annual "Lauter Award" to Dick and Martha Sargent for their long and faithful service to the Chesapeake Chapter of NAF. Dick's sister was afflicted with ataxia, and Dick and Martha continued their involvement and service with NAF for many years even after his sister's death. Dick indicated that he can't quit if others are still working. He paid tribute to Carl, for whom this chapter award is named, as the "Joe Gibbs of CC-NAF" who has continued to serve for many years.

A few other items were then discussed prior to ending our afternoon together.

A color photo of the Chapter's quilt square was displayed. The square itself had already been sent to NAF. Carl explained that his father had been in charge of the water supply in the District of Columbia and was part of a three-state organization including Maryland, Delaware, and the District of Columbia. Carl had adapted a letterhead design from the "Chesapeake Chapter" of this water organization for the design of the quilt square. The square was completed by Mrs. Lena Zalewski, a close friend of one of our chapter members, Lois Johnson.

Reminders were given about the 2007 NAF Annual Membership Meeting in Memphis on March 22-25, 2007. The CC-NAF Annual Medical Meeting is scheduled for February 17, 2007, at Montgomery College in Rockville, MD. Carl is lining up speakers.

Contact information was given for the Maryland Health Insurance Program for uninsurable Maryland residents: Seth Edlavitch at (410) 234-3030.

Information and registration forms were made available for the Brain and Tissue Bank for Developmental Disorders funded by the National Institute of Child Health and Human Development (NIH) and located at the University of Maryland in Baltimore.

On display were Proclamations made in Frederick County, MD, concerning this year's International Ataxia Awareness Day. This is the seventh year that the County has issued this proclamation.

Although Carl had been referred to as the "Joe Gibbs of CC-NAF," he referred to Tony Blair, indicating that he will have to leave office sometime. He and Astrid will soon move into a retirement place closer to their two granddaughters.

Los Angeles Ataxia Support Group

By Sid Luther

The Los Angeles Ataxia Support Group meets Bi-monthly at Westside Independent Living Center (WCIL) on the second Saturday between 2 and 4 pm.

In July Jim Fritz hosted the annual BBQ at his home in Venice. Thanks Jim! Fifteen people attended and all had a great time fellow-shipping and pigging out. At this time we were able to get a group picture for the quilt square for the 50th Anniversary Quilt.

At our September meeting Thom Fritz led, talking about his new book, "Rollabout Australia." Thom told us about his exciting adventures in the "Land down under, OZ." ▸▸

For more Information on this exciting and humorous book contact Thom at *thomas.fritz2@verizon.net*. Sid Luther also spoke about International Ataxia Awareness Day (IAAD) and passed out blue-and-white candles.

In November we are looking forward to hearing Dr. Joanna Jen from UCLA speaking about "What's New in Ataxia Diagnosis and Treatment." Our annual Pizza Party will be held at the same time. Good information and good food; this should be a great meeting.

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Northern California Ataxia Support Group – NCASG

By Deborah Taylor Omictin

Forty-five people including a "first-timer" attended the Northern California Ataxia Support Group's last meeting of the year on September 16. Our guest speaker was Dr. Arnulf Koeppen, all the way from New York. We appreciated him for taking time out of his busy schedule to speak to our group yet again. Dr. Koeppen is also a member of the National Ataxia Foundation's Medical and Research Advisory Board, where he coordinates brain tissue donation for ataxia research. He gave presented an "Update on Friedreich's Ataxia."

Dr. Koeppen received his M.D. from the University of Goettingen Medical School in Germany, his post-graduate education in neurology from the Somerset Hospital in Somerset, New Jersey, the Montefiorne Hospital and Medical Center in New York, and Northwestern University in Chicago. He is currently Chief of Neurology Service at the VA Hospital in Albany, NY and Professor of Neurology at the Albany Medical Center. To view Dr. Koeppen's PowerPoint presentation (*Friedreich'sAtaxia-AnUpdate.pdf*) please see the NCASG Website at *http://www.geocities.com/casupport/*.

About half the group came early for a support group photo that was used to make into a quilt square (the other, a photo of the Golden Gate Bridge, was sent to NAF). Char Danielson at NAF will use them in the quilt she is making for NAF's 50th Anniversary Meeting in Memphis next year.

We had a delicious catered Mexican food lunch because we have no cook. Thanks to Mike Fernandes for coordinating. Pam Fadam volunteered to join a planning committee for NCASG to decide whether we continue lunches, as we just broke even on this lunch. Please contact me and volunteer to join the committee if you are interested.

Be sure to sign-up with Jim Flagg at *jim flagg@comcast.net* to sign the confidentiality form if you want an NCASG roster of members addresses and phone numbers mailed to your home (or let Jim know if we can save the stamp by e-mailing the roster to you). To have our meeting flyers mailed directly to your home, you must become an NAF member because NAF mails our flyers. You can sign up online or on the back of this *Generations* magazine.

The Northern California Ataxia Support Group at their September meeting.

A member of our group said of her first meeting, "I have learned a lot yesterday from all of you. I've been diagnosed of having SCA-6 in December 2005 (fairly new), but I have learned a lot from the meeting, to learn that you're not alone, to learn not to self-pity, to be as independent as you are able (of course we lost our ability in a way, but that doesn't mean we lost *the life*). All of the people in the meeting were/are full of energy! Thank you to the people that this support group *exists*!"

To subscribe to our on-line group, please

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send an e-mail to *NoCalAtaxia-subscibe @yahoogroups.com*.

Sign up to borrow VHS or DVD copy of the "Together there is Understanding" video our group purchased.

We welcome everyone to our next meeting on January 13, 2007 at Our Savior's Lutheran Church in Lafayette, CA at 11:30 a.m. For further information on the Northern California Ataxia Support Group (NCASG), please contact Deborah Taylor Omictin NCASG Leader at (510) 783-3190 or by e-mail at *Rsisbig@aol.com* or by visiting our website at *http://www.geocities.com/casupport/*.

……

Orange County California Ataxia Support Group

By Peggy Hyatt

The Orange County Ataxia Support Group mourned the loss of our friend and leader Kay Bell in August. She will be missed by all.

In September our speaker was professor and attorney Todd Litman. His lecture was on the importance of having estate planning essentials such as a living trust with a last will and testament. Todd also gave some good information regarding Medicare medical guidelines.

We finished our square for the ataxia quilt and it came out very nicely. Our photographer, Vince Beaumont, took several pictures of our group and one of our assistant group leaders had a very nice picture of Kay. We made the October 1 deadline.

The Greater Atlanta Ataxia Support Group held their Picnic Celebration and Social at the Lake Lanier West Bank Park at Buford Dam.

……

Greater Atlanta Area Support Group

Submitted by Dave Zilles

The Greater Atlanta Area support group helped support NAF by providing volunteers to man the NAF booth at The Society for Neuroscience annual meeting held at the World Congress Center in Atlanta.

Our thanks go out to Greg Rooks, James Curtis, Teri Kemper, Paul Aust, Sue Gronka and Dave Zilles. They all helped hand out literature and answered questions from attendees.

The group continues to focus on fundraising with the Carnival Cruise Raffle. The drawing will be November 4 at the regular support group meeting. At this meeting we will be discussing our meeting plans for 2007, our agreement to help the Mississippi Chapter at the NAF Annual Meeting and 2007 fund raising plans. Dr George "Chip" Wilmot will also bring the group up to date on any current ataxia research.

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Chicago Area Ataxia Support Group

By Craig Lisack

An excellent turnout of over 40 people witnessed an informative presentation on ataxia by Dr. Puneet Opal of Northwestern University at our September meeting.

Dr. Opal shed light on promising research projects presently in progress, in addition to answering our ataxia-related questions in a straightforward and understandable manner. We are sincerely grateful to Dr. Opal for his time and cooperation.

The group approved formation of a fundraising committee in order to study options for future fundraising efforts and events. Many good suggestions were offered by members as to potential fundraising ⏩

and awareness activities.

The CAASG is also exploring the possibility of group field trips for next year. Ideas include ball games, a Rehabilitation Institute visit, and a trip/meeting to The University of Chicago's Ataxia Clinic, hosted by Dr. Chris Gomez.

Our last meeting of the year on November 19 is our social event of year. We have a potluck luncheon planned (the main course is furnished by group funds) in conjunction with a silent auction of donated items. The auction proceeds are used to fund the group's following year activities.

……

Denver Area Ataxia Support Group

By Tom Sathre

The Denver Area Ataxia Support Group met September 9 at Swedish Hospital in Englewood, CO. Seventeen people were there, split 50-50 between ataxians and caregivers. We had a potluck lunch.

We had two speakers, including one who spoke about a "Hope with Every Step" footrace on September 23. Given this race's closeness to International Ataxia Awareness Day, this is what we will support. (The speaker's daughter has ataxia.) The other speaker spoke about reflexology, a discipline that helps ataxians and others.

After the second speaker there was a group discussion about the various problems that this relentless disease has brought on.

We picked up the listings of ataxia doctors and their phone numbers and the recent notes from National Ataxia Foundation.

On the "give-away" table was a list of "free or low cost" things we ataxians can do for ourselves – things such as "never get dressed in the dark." All copies of that list were gone by the end of the meeting.

The room coordinator for the hospital where we meet came into the room near the beginning of the meeting and assured us that we could have the same room during 2007. See the Calendar of Events page for more details.

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Louisiana Chapter

By Carla E. Hagler

In October, the Louisiana Chapter held its first membership meeting since losing its office in 2005 due to Hurricane Katrina (board meetings did not cease).

All officers and board members were re-elected for another term. We are also very happy to have filled the office of secretary: Jill LeBlanc, sister of board member Kim Bourg, was unanimously elected.

We try to keep our website current, so for the latest news, please check us out.

……

Maine Ataxia Support Group

By June West

On January 14, we held our Annual Kickoff Luncheon at Newick's in South Portland. It was a great way to start the year as we all like to get together, visit and eat well, too.

On April 8, Michael Martignetti, co-founder of the New England Ataxia Support Group, reviewed the highlights of the 2006 NAF Annual Meeting in Boston. Michael did a wonderful job and answered many of our members' questions. We appreciated his traveling from Massachusetts to Maine to give his outlook on NAF developments.

On June 10, Roger Lister of our group gave a talk on "Accessibility Techniques for the Home." Roger has home-building experience and recently built a new home with accessibility considerations in mind. Roger's talk was not only entertaining, but the information he provided was very valuable to our membership.

On August 12, we held our Annual Picnic. As you can tell, we enjoy having a party every six months. The picnic was well attended and it was wonderful visiting with group members.

On Saturday, October 14, we will have our final meeting of the year. Our speaker will be attorney, Hylie A. West, JD. Attorney West's

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topic will be “Questions You Always Wanted to Ask an Attorney,” Our membership will have an opportunity to ask various legal questions that may be of concern to them or of interest in today’s world. It should be a lively session. All are welcome!

Our next meeting is scheduled for January 13 and is our 2007 Annual Kickoff Luncheon. We meet from noon to 2:30 p.m. on the second Saturday every other month throughout the year, except December. We appreciate the assistance of the Casco Bay YMCA, who makes their wonderful facilities available to us.

The most important aspect of the Ataxia Group of Maine is the camaraderie that exists among the membership. We welcome new members. Please e-mail us at *info@ataxiaME.com* for further information.

……

N.E. Florida Ataxia Support Group

By June McGrane

At our meeting in September our group discussed the upcoming NAF Annual Meeting. Several members are planning on attending and they will report back to the group.

Three speakers from Brooks Rehabilitation Centers presented information on diet, nutrition, swallowing, balance, control, and exercise. They handed out booklets and information on Brooks and its many activities and facilities. There was a question and answer period that was very informative.

Our group continues to grow and we welcomed and introduced several new members. Everyone had a great time socializing with other ataxians and caregivers. We look forward to seeing everyone, as well as any new or interested people, after the holidays. Our next meeting will be held on January 20, 2007 at the Ocean Grove Clubhouse in Ponte Vedra Beach.

Extra! Extra!
The deadline for the Spring issue of Generations is January 31

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Willamette Valley Ataxia Support Group

By Carmen Saunders and Minnie Knutson

In lieu of our regular monthly meeting, the Willamette Valley Ataxia support group held its annual picnic on July 9. Once again the Schrock Family hosted the event at their family farm in Harrisburg. Christina Schrock is an excellent baker and she always sends every family home with a gift. This year the gift was a batch of chocolate chip cookies to take home. Once again the event was a big success. Good food, good conversation, and good times were had by all.

The Willamette Valley Ataxia Support group at their annual picnic.

Although our group is small in number – about a dozen – we noticed several new faces in the crowd. Before feasting on all the goodies, we formed a circle and introduced ourselves and shared stories. One family was recently diagnosed with ataxia and learned about our support group on the web.

The meetings are held on the second Wednesday of each month at Albany General Hospital in Albany, OR. Malinda Moore is the group leader. The meeting is open to ataxia patients, caregivers, and concerned friends or family members wanting to obtain more information or just looking for support. ❖

NAF Chapters & Support Groups

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

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Web: www.geocities.com/HotSprings/Oasis/4988/

Louisiana Chapter
Carla Hagler, President
PMB 51056
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Slidell, LA 70461
(985) 643-0783
E-mail: ataxia1@earthlink.net
Web: http://www.angelfire.com/la/ataxiachapter

Mississippi Chapter
Camille Daglio, President
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Support Groups

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Birmingham, AL S.G.
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Chapters and Support Groups

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See Mississippi Chapter

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Electronic Support Groups

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E-mail: info@bcataxia.org
Web: www.bcataxia.org

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Help Us Help You

Please remember to send us your Chapter and Support Group News articles for each and every issue of *Generations*!

Your information helps others know what is happening in their area and inspires them to get involved.

The deadline to get your news into the spring issue of *Generations* is January 31, 2007.

Ambassador Listing

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

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Ambassadors
Continued from page 43

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Medications and What to Ask the Doctor
Continued from page 28

4. Keep all medicines out of sight and away from children and pets. Keep the phone number of the closest poison control center near the phone just in case there is a problem.

5. Wear a medical alert bracelet or carry a card that lists the medications a person is currently taking. This can save their life in an emergency situation.

More Choices for Medicare Drug Benefits

The number of companies offering Medicare prescription-drug plans will increase in 2007. Also, more plans will feature zero deductibles. Beneficiaries who are satisfied with their current Medicare prescription-drug coverage will not have to take action. The average premium will remain at about $24 per month.

For more information, call 800-Medicare (800-633-4227) or visit the Medicare website at *www.cms.gov*.

To see if you, or the person in your care, is one of the approximately eight to 12 million older adults eligible for some public or private assistance and currently are not getting it, visit: *www.benefitscheckuprx.org*.

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Calendar of Events

January 2007

1 Spokane Area S.G. Meeting from 5:30 to 7:00 p.m. at Sacred Heart Hospital’s Mary Bead Room in Spokane, WA

10 Willamette Valley Ataxia S.G. Meeting from 11:00 a.m. to 12:30 p.m. at Albany General Hospital in Albany, OR

13 Northern CA S.G. Meeting at 11:30 a.m. at Our Savior’s Lutheran Church’s Recreation Hall, 1035 Carol Lane, Lafayette, CA. Contact Deborah Taylor Omictin.

13 Maine Ataxia S.G. Annual Kickoff Luncheon

13 Los Angeles Ataxia S.G. Meeting from 2:00 to 4:00 p.m. at The Westside Center for Independent Living, 12901 Venice Beach

13 North Texas Ataxia S.G. Meeting at 10:00 a.m. at Las Colinas Medical Center

13 Tampa Bay Area Ataxia S.G. Meeting from noon to 3:00 p.m. at Feather Sound Community Church, 13880 Feather Sound Drive, Clearwater, FL

13 San Diego Ataxia S.G. Meeting from 1:00 to 3:00 p.m. at Sharp Rehabilitation Center, 2999 Health Center Drive (behind Sharp Memorial Hospital)

13 Orlando Ataxia S.G. Meeting from noon to 3:00 p.m. at Dr. Phillips Library, 7255 Della Drive, Orlando, FL

16 Twin Cities S.G. Meeting at 7:00 p.m. at Presbyterian Home in Roseville (located off 35W on Co Rd D). Contact Lenore H. Schultz for more information.

20 Orange County Ataxia S.G. Meeting from 2:00 to 5:00 p.m. at Orange Coast Medical Center, 9920 Talbert Avenue, Fountain Valley, CA

21 Chicago Area Ataxia S.G. Meeting at Good Samaritan Hospital’s White Oak Room, 3815 Highland Avenue, Downers Grove, IL

30 SE Pennsylvania Ataxia S.G. Meeting from 10:00 to 11:30 a.m. at Mercy Suburban Hospital’ 2nd Floor Gerber Room, DeKalb Pike, Norristown, PA

February

5 Spokane Area S.G. Meeting from 5:30 to 7:00 p.m. at Sacred Heart Hospital’s Mary Bead Room in Spokane, WA

10 North Texas Ataxia S.G. Meeting at 10:00 a.m. at Las Colinas Medical Center

10 SE Pennsylvania Ataxia S.G. Meeting from 10:00 to 11:30 a.m. at Mercy Suburban Hospital’s 2nd Floor Gerber Room, DeKalb Pike, Norristown, PA

10 Tampa Bay Area Ataxia S.G. Meeting from noon to 3 p.m. at Feather Sound Community Church, 13880 Feather Sound Drive, Clearwater, FL

10 Kansas City Ataxia S.G. Meeting from 2:00 to 4:00 p.m. at NE Library, 65 Wilson Ave, Kansas City, MO

10 Orlando Ataxia S.G. Meeting from noon to 3:00 p.m. at Dr. Phillips Library, 7255 Della Drive, Orlando, FL

14 Willamette Valley Ataxia S.G. Meeting from 11:00 a.m. to 12:30 p.m. Albany General Hospital, Albany, OR

17 Chesapeake Chapter Annual Medical Meeting from 9:00 a.m. to mid-afternoon. at Theater Arts Center, Montgomery College, Rockville, MD Campus. Contact Carl Lauter for more information.

17 Orange County Ataxia S.G. Meeting from 2:00 to 5:00 p.m. at Orange Coast Medical Center, 9920 Talbert Avenue, Fountain Valley, CA.

20 Twin Cities S.G. Meeting at 7:00 p.m. at Presbyterian Home in Roseville (located off 35W on Co Rd D). Contact Lenore H. Schultz for more information.

25 San Diego Ataxia S.G. Pizza Party

March

5 Spokane Area S.G. Meeting from 5:30 to 7:00 p.m. at Sacred Heart Hospital’s Mary Bead Room in Spokane, WA

10 North Texas Ataxia S.G. Meeting at 10:00 a.m. at Las Colinas Medical Center

10 Denver Area Ataxia SG Meeting from 1:00 to 4:00 p.m. at Swedish Hospital, Englewood, CO

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Calendar of Events

Continued from page 37

10 Los Angeles Ataxia S.G. Meeting from 2:00 to 4:00 p.m. at The Westside Center for Independent Living, 12901 Venice Beach

10 SE Pennsylvania Ataxia S.G. Meeting from 10:00 to 11:30 a.m. at Mercy Suburban Hospital's 2nd Floor Gerber Room, DeKalb Pike, Norristown, PA

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18 Chicago Area Ataxia S.G. Meeting at Good Samaritan Hospital's White Oak Room, 3815 Highland Avenue, Downers Grove, IL

20 Twin Cities S.G. Meeting at 7:00 p.m. at Presbyterian Home in Roseville (located off 35W on Co Rd D). Contact Lenore H. Schultz for more information.

22 NAF Leadership Meeting in Memphis, TN

23-25 2007 NAF Annual Membership Meeting in Memphis, TN

25 Seattle Area Ataxia S.G. Meeting at the Federal Way 320th Library, 848 S 320th Street, Federal Way

April

2 Spokane Area S.G. Meeting from 5:30 to 7:00 p.m. at Sacred Heart Hospital's Mary Bead Room in Spokane, WA

11 Willamette Valley Ataxia S.G. Meeting from 11:00 a.m. to 12:30 p.m. at Albany General Hospital, Albany, OR

14 North Texas Ataxia S.G. Meeting at 10 a.m. at Las Colinas Medical Center

14 SE Pennsylvania Ataxia S.G. Meeting from 10:00 a.m. to 11:30 a.m. at Mercy Suburban Hospital's 2nd Floor Gerber Room, DeKalb Pike, Norristown, PA

14 Kansas City Ataxia S.G. Meeting from 2:00 to 4:00 p.m. at NE Library, 65 Wilson Avenue, Kansas City, MO

14 San Diego Ataxia S.G. Meeting from 1:00 to 3:00 p.m. at Sharp Rehabilitation Center

14 Orlando Ataxia S.G. Meeting from noon to 3:00 p.m. at Dr. Phillips Library, 7255 Della Drive, Orlando, FL

21 Orange County Ataxia S.G. Meeting from 2:00 to 5:00 p.m. at Orange Coast Medical Center, 9920 Talbert Avenue, Fountain Valley, CA

28 New England Ataxia S.G. Meeting from noon to 3:00 p.m. at Mass General Hospital ❖

NAF Receives 4 Star Rating

For the third consecutive year the National Ataxia Foundation has received a 4 star rating from Charity Navigator, America's largest independent evaluator of charities.

Charity Navigator salutes the charitable efforts of the National Ataxia Foundation in receiving four out of a possible of four stars. According to Charity Navigator, the four star rating indicates that the Foundation excels, as compared to other charities in America, in successfully managing the finances of the organization in an efficient and effective manner.

Charity Navigator also stated that the consistency of the Foundation's rating is an exceptional feat given the economic challenges many charities have had to face in the last year. The report is available on-line at *www.CharityNavigator.org*.

The National Ataxia Foundation is a non-profit 501(c)(3) organization established in 1957 and is dedicated in serving ataxia families through research, education, and support services.

Memorials and In Your Honor

The National Ataxia Foundation is grateful to those who have made contributions in memory or in honor of their friends and families whose names are listed below. This list reflects contributions made from August 2006 through October 2006. We are sorry that we cannot separate the memorial contributions from those made in honor of someone, as sometimes the person making the contribution does not let us know if the contribution is a memorial or in honor of their friend or family member.

Virginia Ahrens
Bernice Anderson
Robert Anderson
Millie Ann
Bill Ardoin
Brittany Ates
Olga Azurdia
Barbara Bain
James Baldwin
Thomas Ballance
Vicki Balogh
Donald Banta
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Kimberly Glickman
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Lawrence Graner
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James Hankins
Jim Hankins
David Hartman Jr.
Chet Hedgecoth
Bernie Helbling
Ila Holstein
Todd Huck
Carlynn Huffer
Howard Hunnius
Pauline Jackson
Randy Jackson
Tereess Jackson-Bastion
Lisa Jaffe
Dianne Johnson
Frances Johnson
Vivian Johnson
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Carol Mullen
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Mark Ojeda
Cathryne Overstreet
Darrell Owens
Laura Owens
Alan Palmer
Richard Palmer
Joe Parker
Paula Partilla
Norma Payne
Neil Perkins
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Mark Peterson
Patrick Pisano
Alice Pogorzelski
Drumond Porteus
David Price
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M/M Peter Reidlinger
Joyce Robbins
Jennifer Robinette
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Gloria Rosenzweig-Herman
Jeremey Ryan
Dolly Sachs
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Gerald Tremblay
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Ginger Vail
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Mary VanVleet-Stein
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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 a special occasions like birthdays, graduations, anniversaries, and holidays. NAF will acknowledge your gift without reference to the amount.

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

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

My contribution is:

☐ In Memory ☐ In Honor ☐ Gift Membership

Name ______________________________
Occasion ______________________________

Send Acknowledgment Card to:
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Address ______________________________
City/State/Zip ______________________________

From:
Name ______________________________
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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

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