Generations

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Stem Cell Research for Ataxia

By Clive Svendsen, PhD

The following was presented at the 2011 NAF Annual Membership Meeting in Los Angeles, CA and edited for publication in Generations.

At the Cedar Sinai Medical Center Regenerative Medicine Institute where I work, we're looking at regenerative medicine for treating a wide range of different disorders. Regenerative medicine is an emerging field that is becoming more and more interesting these days. It's aimed at eventually replacing organ transplants by using cells. You can either get the cells from stem cells using what's called "cellular therapy" (so instead of taking a pill you'll take a cell to treat your damaged organs). Or you can actually get your own tissues to regenerate. This is a very new area of biology – where you force your own tissues that are diseased or damaged to regenerate. We all have stem cells scattered all over our bodies that may be able to be activated. Through learning about stem cell biology we're actually learning how to perhaps activate cells with our own bodies that are damaged.

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Embryonic Stem Cells

Embryonic stem cells are derived from the fertilized egg and the sperm as it goes through a certain stage. In vitro fertilization clinics really opened the way to getting the sperm and the egg together in a test tube, [together they form] a blastocyst. In the blastocyst [after] about eight days you have [what's called] the inner cell mass, which contains pluripotent stem cells which are very powerful, embryonic stem cells. You have to destroy the embryo in order to get these stem cells out, which has been a big problem. But once you get the stem cells out you can grow them indefinitely in culture. You can grow them for many weeks, months, or even years. You can make as many cells as you want – you can make factories, essentially, as these cells divide and divide. And once you've made them, they can turn into just about any tissue in the body. Any of the 250 tissues that you have in your body can be produced from embryonic stem cells. You can make heart cells, blood cells, intestinal cells,

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muscle cells, and of course the one I'm interested in, is the brain cell. One way to look at stem cells for a therapy for ataxias and for other diseases that affect the nervous system, muscles and heart is to use these cells to perform transplants and replace damaged tissues.

The main hurdles for this field are ethical and political issues, and immune rejection. As many of you may know, there's an injunction that was filed last year to stop all human embryonic stem cell research from going forward. The NIH funding [for this work] is really the gold standard and it could be stopped completely if this lawsuit goes through. It's currently moving its way up through the courts. We predict this will be in the Supreme Court at the end and there will be a decision made on whether you're allowed to use excess embryos to generate stem cells to look at therapies for all diseases that we're looking at using embryonic stem cells for. This is a very hot political topic right now and has caused a lot of angst amongst our scientists. If you have a grant that's funded by the government in two months we could be closed down and stopped from using that money. So we'd have to fire people, send people out of our labs if this goes through. So it's like a dagger or knife hanging over your whole research lab if you work in embryonic stem cells.

Induced Pluripotent Stem Cells

Induced pluripotent stem cells (iPS) – this is one of the most remarkable scientific breakthroughs and discoveries I think in the last 10 or 15 years if not longer. [How they work is] you take a skin cell (could be from a patient with any disease for example, FA), you take the skin cell and you add genes to these skin cells from adult patients, and you can reverse those skin cells – you can change them from being adult to being embryonic by putting four genes in. And we're now finding that you can do it in different ways, not just with genes, you might be able to do it with proteins. But essentially when you look at these cells they're very, very similar to embryonic stem cells. There are some subtle differences, but on the whole they're remarkably similar to embryonic stem cells.

This has enormous implications for biology and has enormous implications for potential transplants. Because now one can take a cell from a patient, produce it in the dish, make it into these iPS (induced pluripotent stem cells) and those cells can be divided and expanded in the culture dish for many, many years. We can get as many cells as we want and they will be perfectly matched to you. So if we made them into a heart cell, we could put them back into your heart, if we made them into a brain cell, we could put them back into your brain. This has overcome one of the big hurdles for immune rejection, we hope. The second big hurdle of course is the ethics. The Federal government is very keen on funding this work because the ethics have now disappeared. However, having said that, we don't know if they're exactly the same, there are some issues with these cells that may be different for transplantation. So the gold standard is still embryonic stem cells and we need to keep using those cells in order to understand how this can be taken to patients as quickly as possible.

Modeling Diseases

What fascinated me when I heard about these iPS cells was yes, the therapy would be interesting and we're moving ahead with different types of therapy, but what about modeling diseases? The ability to reprogram these cells has massive implications for biology. Can we model diseases in the dish using these cells and learn what causes ataxia and other diseases? And why should we worry about this? First of all, humans are not mice or rats. A lot of people will say "why don't you use a mouse or rat to solve this problem?" For instance, the chromosome number in a

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human is 46, these are the DNA carrying chromosomes – in fact chimpanzees have 48, a fly has 8, a domestic pig has 38 and a lab mouse has 40. So you can see just at the basic level the biology is very different; we have different numbers of chromosomes. Many diseases of the brain such as ataxia don't occur and are difficult to reproduce in mice. Drug screening may be more relevant in human models. If we've got a novel drug compound we really want to make sure it works in human cells. It's no good if it cures the mouse – it's got to cure the human as well. So this is where these cells can be very important for biology.

We can use these cells for drug screening and I think that's probably going to be the most exciting aspect of this work is that we can develop drugs and test them in human cells before moving them into the clinic. I think we'll have a better hit rate by doing that than just using the old-fashioned mouse models. Regenerative medicine is very exciting and iPS cells have really opened up a whole new field. ❖

International Society for Stem Cell Research

The International Society for Stem Cell Research (ISSCR) is an independent, nonprofit organization formed in 2002 to promote and foster the exchange and dissemination of information and ideas relating to stem cells, to encourage the general field of research involving stem cells and to promote professional and public education in all areas of stem cell research and application. With more than 3,600 members worldwide, the ISSCR has become the voice of the stem cell research community.

For more information, visit *www.isscr.org*.

Events and Fundraisers for IAAD

International Ataxia Awareness Day (IAAD) will be celebrated on September 25. For more details and links, please visit the National Ataxia Foundation event calendar at *www.ataxia.org*.

Biking with Ataxia

Saturday, September 10, 2011

This event starts at 10 a.m. at Palisades Interstate Park. Ataxians along with others will pedal over hill and dale with the combined purpose of raising ataxia awareness and research funds to help support the important work of the National Ataxia Foundation (NAF). The ride will start and end at the Ross Dock Picnic Area in the shadow of the George Washington Bridge on the New Jersey side.

To register for Biking with Ataxia visit the event registration website at *www.active.com/cycling/fort-lee-nj/biking-with-ataxia-2011* or the events website at *http://BikingwithAtaxia.blogspot.com*. The registration fee is $40. There is a minimum fundraising commitment of $200 per participant. To start fundraising for this event please register on the event donation website *https://naf.myetap.org/bikeataxia/* to create your fundraising page and set your fundraising goal.

For volunteer and sponsorship opportunities contact Adam Payne, the ride organizer, at *BikingWithAtaxia@gmail.com*.

2nd Annual Minnesota Walk, Stroll n' Roll for Ataxia

Saturday, September 17, 2011

The event will be held from 9 a.m. to noon ▸▸

at Wolfe Park in St. Louis Park, MN. All proceeds benefit the National Ataxia Foundation.

To volunteer or for more information please contact Tom Sweeney at *gracieggb@msn.com*. *https://naf.myetap.org/11mnwnr/*

Auburn Walk n' Roll for Ataxia

Sunday, September 18, 2011

The event will be held from 10 a.m. to noon at Lamanski Park (aka Rocketland) in Auburn, MA. Event registration is free and registrants will receive a complimentary event t-shirt. Funds raised will benefit NAF.

To volunteer or for more information please contact John Mauro at *jmauro@hanover.com* or (508) 736-6084. *https://naf.myetap.org/fundraiser/11MAwnr/*

Golf 4 Ataxia

Friday, September 23, 2011

The event begins with a 1 p.m. tee time at Forrest Crossing Golf Course, 750 Riverview Dr., in Franklin, TN. The $100 entry fee includes dinner, green fees, and cart. Prizes will be given for Longest Drive/Putt and Closest to the Pin. We would appreciate silent auction donations and volunteers. Hole sponsorships are available.

For volunteer or sponsorship opportunities, please contact Jay Tyler at (615) 260-3968 or Vicki Tyler at (615) 496-3110. All proceeds benefit the National Ataxia Foundation. *https://naf.myetap.org/11Golf/*

1st Annual Denver Run, Walk n' Roll for Ataxia

Saturday, September 24, 2011

This event will be held from 9 a.m. to noon at Denver City Park, 17th St. & York St., in Denver, CO. Event registration is free. All proceeds benefit the National Ataxia Foundation.

To volunteer or for more information please contact Keri Naccarato at *kfragola@yahoo.com* or (720) 982-9562. *https://naf.myetap.org/fundraiser/11COwnr/*

6th Annual San Diego Walk n' Roll for Ataxia

Saturday, September 24, 2011

The event begins at 8 a.m. at Tuna Harbor Park in San Diego, CA. All proceeds benefit the National Ataxia Foundation.

To volunteer or for more information contact Earl McLaughlin at (619) 447-3753 or *sdasg@cox.net*. *https://naf.myetap.org/11SDWnR/*

The 2010 San Diego Walk n' Roll for Ataxia raised more than $32,000.

3rd Annual Central Texas Walk n' Roll for Ataxia

Saturday, September 24, 2011

This event will begin at 9 a.m. at San Gabriel Park in Georgetown, TX. Registration is $25 and includes an event t-shirt. All proceeds benefit NAF.

If you have any questions, comments, or suggestions please contact Linda Crawley at *lcrawley57@gmail.com* or (512) 635-9478. *https://naf.myetap.org/11TXWnR/*

3rd Annual LA/OC Walk n' Roll for Ataxia

Saturday, September 24, 2011

This event will be held at Long Beach Shoreline Park. All proceeds benefit the National Ataxia Foundation.

For more information Contact Daniel Navar

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at *dnavar@ucla.edu. https://naf.myetap.org/11OCLAWnR/*

3rd Annual Detroit Walk n' Roll for Ataxia

Saturday, September 24, 2011

Event will be held at Miliken State Park (1900 Atwater, between Orlean and St. Aubin). On-site registration will be held from 9 a.m. to 11 a.m. Receive a Walk n' Roll t-shirt with $25 registration fee. Walk begins at 11 a.m. followed by a raffle and picnic. All proceeds benefit NAF.

To volunteer or for more information, contact Tanya Tunstull at *tinyt48221@yahoo.com* or (313) 736-2827. *https://naf.myetap.org/fundraiser/11Detroitwnr/*

Northern CA Ataxia Support Group IAAD Picnic

Sunday, September 25, 2011

An Ataxia Awareness Picnic will be held on the University of California San Francisco (UCSF) campus on September 25 to celebrate IAAD. Our three goals for this event will be to educate ourselves about ataxia, to raise professional and public awareness, and to raise funds to put toward research that will improve the lives of patients with the many types of ataxia.

For more information, please contact Mike Fernandes at *fernandesml@comcast.net* or (925) 516-6906. Dr. Gail A. Kang, MD, Assistant Clinical Professor of Neurology at the Memory and Aging Center at UCSF, will help put on the event with the assistance of students and staff. UCSF has been approved to be a site for the National Ataxia Consortium, which is great news for our northern California ataxia patients and their families, as it will enhance research in the Bay area. *www.ataxia.org/chapters/NorthernCalifornia/default.aspx*

2nd Annual 2011 Virtual Walk n' Roll for Ataxia

Now through September 25, 2011

Visit the Virtual Walk n' Roll web page at *www.ataxia.org/11Virtualwnr* and click "register" to join us in raising funds to help support the important work of the Foundation. When you register you are automatically signed-up as a Virtual Walk n' Roll participant. Also, a personal fundraising page is created just for you, where you can upload pictures, write personal text, and set your own goal. Then you can forward your fundraising page link to your family and friends, and ask them to "sponsor" you to help you meet your fundraising goal. Check your fundraising page often to watch your pledge thermometer rise. A printable pledge form is available at the NAF website *www.ataxia.org*.

If you wish to contribute to this event without becoming a participant, please click "make a donation" to help our Virtual Walk n' Roll in meeting our fundraising goal.

For more details about the Virtual Walk n' Roll, contact the National Ataxia Foundation at *naf@ataxia.org*.

3rd Annual Seattle Walk n' Roll for Ataxia

Saturday, October 1 , 2011

Event will be held 9 a.m. to 1 p.m. at Alki Beach Park in Seattle, WA. Registration is $25 and registered participants will receive a free commemorative t-shirt. To volunteer or for more information contact Milly and Tony Lewendon at *ataxiaseattle@comcast.net*. All proceeds benefit NAF. *https://naf.myetap.org/fundraiser/11SeattleWnR/*

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CFC Number

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

Eight Steps to Future Care Planning for a Loved One with Special Needs

By Mary Anne Ehlert, CFP

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When a child or an adult is diagnosed with a disability, parents and caregivers immediately respond to deliver the special care required by the diagnosis. However, it is important to remember that all individuals with disabilities will benefit significantly from a special needs plan that provides for a safe, secure and fulfilling future. But because there is so much to handle in the here and now, many parents and caregivers put off proper planning. They say, "I'll do it tomorrow," and before you know it many "tomorrows" have passed, the future is here, and little or no planning has occurred. Now what? How are clothing expenses going to be paid? Where will a family find affordable housing with supportive services for their loved one with special needs? What transportation is available? How does one put in place a care plan that will provide a full and rewarding life, yet still provide the safety net that needs to be in place?

From education and housing to work and recreation, it can be overwhelming to think about all that needs to be done to develop a plan, making sure every aspect of life is covered. But if you take it one step at a time, it will get done. Just follow the simple steps below. It takes action on your part, but if you stay committed to a timetable the result will be a comprehensive future care plan.

I did it. As a matter of fact, I developed this eight-step process to help my parents plan for my sister, who was born with cerebral palsy. I watched my parents struggle with little help to plan her future. I noticed the families I work with professionally facing the same kind of fear, confusion and stress, so I wanted to develop a process that would work for other families who had a loved one with special needs. Over the years, it evolved to touch all aspects of life: family communication, legal considerations, potential government benefits, transition into adulthood, residential options, employment opportunities, recreational choices, and investment solutions. And with every step, the abilities of the individual with special needs are considered more than his or her disabilities, no matter the age. Let's get started.

1. Assess Candidly

Make an honest assessment of future care needs in light of the entire family's make-up and financial situation. This may be the first time many families address head-on their dreams, goals, and fears for their loved one with special needs, but it's worth taking some time to think through it. It's the first big step in starting to recognize the work you must do to achieve peace of mind.

For example, the following statements might come out of this assessment:

- "It is a family dream that our loved one with ataxia can continue their education"
- "It is a family goal that our loved one with ataxia lives independently"
- "It is a fear that my ataxia may place excessive burden my family members"

While working on your future care plan, it is helpful to come back to these statements to make

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sure that they have been addressed.

2. Organize Thoroughly

Identify all the life needs for your loved one with a disability, including a quality living environment, educational supports, medical needs and a wellness program, and recreational activities based upon the individual's ability to support him or herself in the future. To ensure that your list is as comprehensive as it can be it may be helpful to start with broad needs categories such as:

- Medical care
- Accessible living environment
- Education and work
- Recreation

From there, you can delve into further detail and make projections for the future.

The family develops a vision of what they see for the individual in the different stages of their life. Then, quantify, through various calculations, a cash flow for the entire lifetime of the individual on your and their vision. Seek out a qualified financial planner to assist in this step if you are uncomfortable working with numbers. Stay committed to refining this "Future Map" each year, as the individual with special needs get older and an understanding of their future needs are more apparent.

3. Explore Legal Options

Legal considerations are an important part of the process. Certain legal documents are critical and can assist in speeding up or slowing down care for your loved one. As a parent, spouse or sibling, consider guardianship and a special needs trust as part of an estate plan. Finding an attorney who understands the specifics of drafting these types of documents is important. But before seeing an attorney, think through carefully all of the legal decisions that have to be made. Many families see an attorney for an initial consultation but never finish their estate plan because the decisions they need to make feel too daunting. It's hard to grasp how much money is required to provide for a family member with special needs for present and future care. Many times, parents cannot decide how to best divide up their estate between their family member with special needs and the other children. If these decisions are made prior to the initial meeting with an attorney, it will help to keep the process moving, and you will see a future care plan come to fruition.

4. Tap into Government Services

Government benefits may make up a large part of the required financial support for an individual with special needs. Some families are hesitant to tap into them, but they are essential for everything- from housing to healthcare to job coaching. Identify social services, community, and government programs that will enhance and support the future care plan, including school, recreation, specialized doctors, and even research protocols. Individuals then can match up these needs with available government funding such as Supplemental Security Income, Medicaid, Social Security Disability Income (SSDI) and Medicare. With housing and healthcare costs subsidized, families will then need to reach into their pocket for such items as clothing, DVDs, recreational fees, and expenses over and above what the government programs will pay.

5. Document Important Information

With a lot of the hard work under your belt, relax a bit and spend time simply recording important information about your loved one with the disability. Document the individual's likes and dislikes, routines, and habits. This information is key information required by teachers, camp counselors, caregivers, as well as future guardians. This step is one most often put off by parents and family members because it can be time consuming, but this information can make a big difference in the future quality of life for your loved one. This process is often referred to as writing a special needs letter of intent. Guides with outlines to assist in compiling this information are available through various sources. ⏩

6. Transition into Adulthood and Transition out of the Workplace

In August, many families are preparing for another year of school, but for young adults with disabilities who have completed their education in the spring, they no longer fall under the protection of state-mandated educational benefits, which typically end at age 21 or 22, depending upon the state you live in. They now need your help in finding a place to live, work, and play, in addition to seeking out transportation support. In the past, parents counted on the school system to lead the way in finding the right resources, but now all of a sudden, they feel as if they are on their own. The amount of research that is needed to find the right programs can be overwhelming. The best way to ease into this period of life is to develop a network of professionals to share important information, and, of course, plan early. Develop these relationships when your child is in his/her teenage years. Keep a binder with resources and support groups in your area that you can refer to when the time comes for the transition into adulthood. This is not a step that should be left until your child is 18 or 21. It should be an ongoing process throughout your child's lifetime.

For working adults whose ataxia symptoms may prevent them from future work opportunities, indentify limited work options, volunteer opportunities, supported living arrangements and transportation options.

7. Fund the Future

After you have a clear picture of the past and the future (as clear as it can be at the point at which you are), think about your own financial plan and how you can best coordinate it with your loved one's future care plan. At the start of the year, you calculated how much it would cost to maintain a certain quality of life for your child through the years, so you need to make sure there's money to pay for it.

Before you begin with the basic savings plan, assess other resources first. You might be surprised at the money available to you and your family. Start by investigating current benefits offered by your employer for dependents and for yourself. Examine disability, long-term care, life and health insurance policies to see how they would help your family in the event of any kind of tragedy. Next, understand the government funding available to meet your loved one's basic needs. When you see how much money is potentially available in the immediate future, then you can plan more long-term through various investment options.

Be sure any planned inheritance or beneficiary designations go directly to your loved one's special needs trust. Any sum of money larger than $2,000 left in your loved one's name ($3,000 for a couple) will threaten his or her access to those much-needed government benefits.

8. Review and Renew

So now you have come full circle. Take some time to look back to see all that you have accomplished. Give yourself a pat on the back for making progress, and don't forget about respite to make sure everyone in the family is getting the care they need. Make a note or two on any changes you might want to make to your loved one's future care plan in the New Year. You will have a great foundation for managing current and future financial planning with your family.

Mary Anne Ehlert is the founder and president of Protected Tomorrows, Inc., the leader in enhancing the lives of families with members who have special needs. By guiding families through its comprehensive, proprietary planning process, Protected Tomorrows helps ensure the well-being of a loved one by creating a Future Care Plan™. Through their work with clients and the family's advisors, and alongside of other advocates and legislators, Protected Tomorrows addresses many concerns of families with special needs, such as future care funding, government benefits, legal considerations, residential options, employment opportunities, recreational choices, education options and family communication. For questions, contact info@protectedtomorrows.com or visit www.protectedtomorrows.com. ❖

Spinocerebellar Ataxia 17

By Angela Brown

Diagnosis

What's going on? I don't want to be in dance or tennis anymore. I no longer like to go on bike rides or rollerblade. I've become quieter with my friends and family. I am beginning to appear extremely shy, nervous, and insecure. School work is really getting hard for me. My mom keeps making me erase my school work and write it again because my handwriting is getting messy. These changes happened slowly when I was in junior high and ninth grade, but the year I changed the most was 2007.

After experiencing a series of several unexplained falls during a family vacation over the fourth of July in 2007, my family became increasingly concerned about me. After returning home from our vacation, my mom asked me questions about my feelings of dizziness and loss of balance. We decided to make an appointment with our family doctor, who after examining me, suggested I have an MRI. The MRI showed some atrophy of my cerebellum – which meant there was some shrinkage or deterioration of my cerebellum. There was no sign of any tumor or stroke. I was referred to a neurologist at the University of Minnesota who suggested we run some blood tests. After 11 different blood studies were done, we still did not have an answer. My blood was then sent to Athena Diagnostics for genetic testing. We were told it would be two to three months before we had the results. Waiting for the results was no big deal to me, but it was very hard on my parents.


Angela Brown

Two months later, we were back at the University of Minnesota to review my test results. I was diagnosed with Spinocerebellar Ataxia 17 (SCA 17). I continue to see a doctor at the University of Minnesota Ataxia Center. My family and I have learned a lot about SCA 17 and 2007 was definitely the year I changed the most.

Living with Ataxia

I am living with ataxia. It affects everything I do. Every movement I make is challenged by ataxia. There are things I cannot do anymore. I no longer rollerblade, bike, dance, play tennis or do any other sports. I cannot drive a car. My walking has been greatly affected. It is so frustrating for me when I know what it is that I want to do, but my body does not cooperate.

My writing has become difficult to read. My hands get very tired. I am no longer able to play my flute. I have tremors in my legs, arms, and mouth. Speaking loud and clearly takes a lot of effort. I always need to think about my breathing when I talk. It is difficult for some people to have a conversation with me. I think it is uncomfortable for them to see me struggle. I need to chew my food well to aid in swallowing it.

Everything I do takes a long time. My balance is very poor, making it very difficult for me to do things while I'm walking. I don't talk or look around while I'm walking because it requires all my concentration. I always need a rail when I use steps. Small stairwells are easier because I can use the rail with one hand while placing the other hand on the wall. I need to be focused on every step I take. My legs get tired. But I walk two miles on the elliptical every day. When I get out of bed I always sit up for a while before I stand while I wait for the dizziness to go away.

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My spinocerebellar ataxia is progressive. Hopefully the progression will be very slow. I'm uncertain of what will happen to me if it worsens. Two years ago, my neurologist said there will be huge advancements within 10 years. There's a trial for a drug that could be used for the treatment of ataxia. The trial is going on right now and is in the third stage of testing. The research for the treatment or cure for ataxia is moving fast – this is very exciting!

One Day at a Time

Wondering what my future holds, thinking about getting older – these thoughts cause a lot of different feelings to surface. Although none of us knows what tomorrow holds, there are many milestones to look forward to, many reasons to have hope.

I have to admit that I am kind of scared to get older. I don't know what's around the next corner. As of right now, college is my next plan after I graduate from high school.

Ataxia has not damaged my faith or taken away my ability to love. I live with ataxia; it's now a part of who I am. I need to stay positive. I will put my faith in God and my trust in the doctors. I will have hope. I will live one day at a time. ❖

Gratitude

By Juliana J. Helmke, 2011 Travel Grant Recipient

I am so grateful to the National Ataxia Foundation for awarding me a travel grant to attend their Annual Membership Meeting in Los Angeles. Without a grant, I would not have been able to attend. The AMM was appropriately entitled "Bringing the Ataxia World Together." I was ecstatic when I was notified that I had received a grant. I gasped audibly when I opened the e-mail notification, which frightened the family I live with! They asked if I was alright and I said that I was and started crying with gratitude.

Besides being a source of the most recent information and cutting-edge research findings, the conference is a time of camaraderie. I am confident that all of my fellow ataxians would agree that the conference environment is one of complete acceptance. Regardless of the stage or progression of one's ataxia, the overall experience of the conference fosters validation. All people – ataxians, caregivers, researchers, etc. – are treated respectfully. Disabilities or any physical limitations become "invisible" to judgment; in its place is encouragement.

We all face the day-to-day challenges of living with ataxia. Ataxia's debilitating and progressive nature can dampen our spirits. The conference serves as a necessary "booster shot" to inoculate us for awhile against the natural tendency to become complacent. For me, seeing a teenager wheelchair bound re-emphasizes the importance of perspective. I remind myself to be grateful that I am still able to walk. Attendance at the conference gives all participants the opportunity to "count their blessings."

The social interactions are such a vital part of the conference. It was so important for me to attend. Some of us see people for the first and only time all year. Many of us "know" each other online, but have never met in person. This recognition of commonality creates instant bonding. Regardless of the extent of our progression, we embrace each other with friendship and understanding. How cool is that! Teamwork really does make the dream work.

I would like to publicly thank the Foundation for another great conference. For me, it is important to not take this organization and its efforts for granted. The behind-the-scenes work efforts and the logistical nightmares to organize and pull off a conference of this magnitude are immense and stressful. We appreciate all that is done. Kudos! ❖

Creating Accessible Homes:

A Checklist for Accessibility

By Ramesh Gulatee

Ramesh Gulatee is a U.S. and Canadian registered architect who is NCARB certified and specializes in fully accessible, ADA compliant designs for individuals with disabilities. He sits on the sustainability membership governing committee of the International Code Council (ICC) which sets building code for all design and construction in the United States. His firm, LifeCare Design Studio, LLC, is an Illinois-based architectural firm with across-USA certification. The firm's team of architects and builders work together to design and build accessible environments. For more information on the LifeCare Design Studio visit www.lifecaredesignstudio.com or contact Mr. Gulatee at rgulatee@protectedtomorrow.com, rtulatee@lifecarestudio.com, or by phone at (847) 522-8086 ext. 211.

In an analysis of living space, we are considered to be restricted or inconvenienced in our use or enjoyment of a facility if there are barriers that restrict our access to the usage of the space. Unfortunately, most physical environments have been designed with a certain population in mind. More often than not, the design is based on an assumption that people using a given space do not have disabilities. This assumption is, at best, misguided due to the fact that the vast majority of people will experience physical limitations sometime during life.

The most desirable design for living space would be where the user is assumed to be unknown, allowing for all possible special needs considerations to be accommodated through flexibility in design. This is the concept of universal design, which, if considered and followed through in the early planning stages, eliminates costly modifications later.

The checklist on page 13 will allow you to individually determine the work that would need to be done to make one's home accessible for an individual with a disability. Considering the various items on the checklist is a great first step in analyzing the accessibility of a particular space.

Watch for additional articles exploring the topic of accessible design in future issues of *Generations*.

Matching Gifts

Many employers will match your gift to the National Ataxia Foundation through a Matching Gifts Program.

This valuable benefit will allow you to have twice the impact on the lives of families touched by ataxia when you make a donation to NAF.

Please ask your employer if they have a matching gifts program. If they do, your gift and the gifts of your co-workers will double in value.

Thank you for your support.

iSearchiGive.com

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Please sign up today and indicate that the National Ataxia Foundation is your favorite cause. *iSearchiGive.com* is totally free, with no hidden fees and provides valuable support for the important work of the Foundation.

Thank you for searching and shopping.

Accessibility Checklist

	Yes	*No*
PROPERTY		
• Ranch style home	☐	☐
ENTRY		
• Sidewalk/curb	☐	☐
• Front steps or steep ramp	☐	☐
• Guard rails/hand rails on the steps	☐	☐
• Non-slip surface on the ramp	☐	☐
PORCH		
• Front door steps	☐	☐
• Shelf for temporary grocery holding	☐	☐
• Door bell/chime	☐	☐
• Roof over porch	☐	☐
• Porch lights	☐	☐
HOUSE		
• Entry steps	☐	☐
• Heavy entry door	☐	☐
• Door width 34" or 36"	☐	☐
• Door lever	☐	☐
HALLWAY		
• Width 48"	☐	☐
• Carpet	☐	☐
• Good lighting	☐	☐
KITCHEN		
• Free floor space of 60" width	☐	☐
• Counter top height 34" / pull out boards at varying heights	☐	☐
• Working countertop space on either side of sink/oven	☐	☐
• Under counter knee space in front of the sink and oven	☐	☐

	Yes	*No*
KITCHEN (cont.)		
• Counter space on latch side of the refrigerator	☐	☐
• Operating controls on front panel of oven	☐	☐
• Ceramic hot plates or staggered burners	☐	☐
• Adjustable pullout shelving below counter	☐	☐
• 12" high kickspace along countertop	☐	☐
• Rocker type faucets	☐	☐
• Overhead cabinet storage	☐	☐
BATHROOMS		
• Door threshold	☐	☐
• Door width 32"	☐	☐
• Free floor space of 60" diameter in front of fixtures	☐	☐
• Non-slip flooring	☐	☐
• Grab bars for toilet and bathtub	☐	☐
• Walk in bathtub	☐	☐
• Flexible shower hose	☐	☐
CLOSETS		
• Reach all items while seated in wheelchair	☐	☐
• Easy to reach light utility outlets	☐	☐
• 27" above floor		
• Appliances/devices within 6" of outlets	☐	☐
• Extension cords	☐	☐
• Night lights	☐	☐
WINDOWS		
• Crank operation	☐	☐
• Tilt turn windows	☐	☐

Caregiver's Corner

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

Controlling Infection

Does Your Home Get a "C" for Cleanish?

Controlling the spread of infectious germs around the house doesn't have to be an overwhelming task. Following some simple rules can drastically cut the chance of illness:

Prevent cross-contamination. Use a different implement (broom, mop, sponges) for each cleaning task in the kitchen and bathroom.

Disinfect cutting boards after each use. And use separate cutting boards: One for vegetables and fruits, and one exclusively for meats. Or, mark each side of one board: One side for vegetables and fruits, the other side for raw meats.

Replace sponges frequently. Sponges and scrubbers provide the warm, moist conditions and trapped food particles on which bacteria thrive. Bacteria multiply rapidly, increasing from a few to millions in a matter of hours. Between uses, clean sponges with an antibacterial cleaning product and let air dry or microwave a wet, not dry, sponge for two minutes.

Empty the vacuum. Dangerous organisms, such as Salmonella, could be multiplying in the vacuum cleaner bag, waiting to be released into the air every time you vacuum. Bagless vacs should be emptied after every use. For vacs with collection bags, empty at least monthly.

Disinfect the garbage can. Germs that grow in your garbage can don't always stay there. It's common for plastic liners to leak, allowing waste to collect in the bottom of the can or bin. Then, when someone empties the container and sets the bag on the floor, counter, or chair, bacteria spread to that surface, as well as to his or her hands. Clean and disinfect the garbage can weekly, and use anti-bacterial bags.

Clean the can opener. That little bit of juice or food left on the blade after you open a can invites bacterial growth.

Change the towels. The average person sheds 1 million skin cells an hour. Bath towels harbor those cells and their bacteria, and can serve as a terry-cloth Petrie dish if they're folded and left in a damp bathroom. Hang towels unfolded to let them air dry, and replace them with clean towels after three uses.

Protect your toothbrush. Every time an open toilet is flushed, a fine mist of fecal matter and bacteria sprays 20 feet in the air. Keep your toothbrush in a drawer or cabinet. You should also sanitize your toothbrush daily by rinsing it with peroxide or mouthwash. Even though the germs on your toothbrush are your own, but they can multiply to enormous numbers between uses.

Source: http://www.medicalnewstoday.com; Centers for Disease Control.

Clean Hands Are Healthy Hands

Wash your hands. It's the *single most important way to prevent the spread of infectious diseases.* We all should know the importance of washing after using the toilet, yet less than 50 percent of people actually do it – and almost no one does it properly.

Wash your hands *frequently*. Always after toileting, after handling raw foods, whenever you've been in contact with anything or anyone "suspicious," and periodically throughout the day. Our bodies naturally carry on them germs. Most of these germs are harmless, and some are even essential to our health! However, germs from other sources, such as raw meat, can also survive on hands, and these can be easily transferred to other surfaces, increasing the risk of ⏩

cross-contamination. Because our hands are in frequent contact with our eyes, nose, and mouth, it's easy to see how dirty hands spread germs and illnesses, everything from the common cold, to the flu, to food poisoning.

Wash for 20 to 45 seconds – about the time it takes to sing "Happy Birthday" through twice. Rub hands together vigorously and scrub between fingers and under nails. It's even a good idea to lather, rinse, and repeat.

As important as it is to properly wash your hands, it's equally important to **dry them correctly** too. The bacteria and viruses that are left on your hands after even a good washing thrive on moist skin, so until you dry your hands thoroughly after each wash, you can't prevent germs from spreading.

Hot-air hand dryers aren't necessarily the best way to dry hands, primarily because most people give up before their hands are really dry. Wiping your still-damp hands on your clothes is a no-no! Researchers found that the most effective way of reducing hand-borne bacteria is to dry thoroughly washed hands on clean paper towels.

Hand sanitizer gels can be used to kill germs, but they should not replace hand washing. Hand sanitizers can build up on skin, so wash your hands the regular way – with soap and warm water – after every fourth use.

Source: WebMD; Centers for Disease Control.

Handling Soiled Laundry

As a caregiver you are around a lot of soiled laundry. So make it safe by:

- Always use latex gloves when handling soiled laundry.
- Carry dirty linens away from your body.
- Never shake soiled linens. (Germs may contaminate the floor and be spread throughout the house on the soles of shoes.)
- Use a leak-proof plastic bag, tied shut, for linen that contains body fluids or waste.
- Bag soiled laundry in the same place where it is used.
- Wash soiled linen separately from other clothes.
- Fill the machine with hot water, add ¼ cup bleach and detergent, rinse twice, and then dry.
- Clean the washer by running it through a cycle with one cup bleach or other disinfectant.
- Remember, wash your hands before going on to another task!

Quick Quiz

When caring for an elderly person or someone with weakened immunity, it is especially important to follow rules for good hygiene. Read the issue and answer True or False to the questions below.

1. Controlling the spread of infectious germs in the house can drastically cut the chance of illness. *T F*
2. Cross-contamination happens when the same sponge is used for the kitchen and bathroom. *T F*
3. Bath towels don't hide bacteria because our bodies are clean when we use them. *T F*
4. Correct hand washing is the single most important way to prevent the spread of infectious diseases. *T F*
5. Because our hands are in frequent contact with our eyes, nose, and mouth, dirty hands spread germs and illnesses. *T F*
6. It doesn't matter how hands are dried after hand washing. *T F*
7. Keeping to a regular schedule is important for an elderly person. *T F*
8. Dirty linens should be carried away from the body. *T F*
9. Gel hand sanitizers can replace hand washing. *T F*
10. Germs from raw meat can survive on hands and be transferred to other surfaces. *T F*

Key: 1. T; 2. T; 3. F; 4. T; 5. T; 6. F; 7. T; 8. T; 9. F; 10. T

❖

From the Desk of the Executive Director

The summer is a very busy time at the National Ataxia Foundation. Plans have begun for the 2012 Annual Membership Meeting and the 2012 Ataxia Investigators Meeting. The 2012 AMM will be held March 16–18, 2012 at the Grand Hyatt in San Antonio, TX. NAF-discounted rooms are selling out fast, so please make your hotel reservation today. In addition, the Foundation is in the process of developing a new website to be launched later this fall.

The Foundation's Annual Membership Drive has also begun. Membership support is essential in providing programs and services to ataxia families. Your membership dollars work hard every day. Web development, printing and publications, representation at medical conferences and Ability Expos, and support group development are just a few of the ways in which membership support helps. NAF welcomes new, renewing, and pledging members.


Michael Parent

NAF has introduced two new research programs this year due to the generosity of an anonymous donor. These two new research programs will focus on translational research into the SCAs, as well as Young Investigator Awards for the SCAs.

This extraordinary donation – $1.5 million over three years – will have a profound impact in furthering our research efforts and in bring new investigators into the field of ataxia research. We are truly grateful to the donor for this exceptional anonymous research gift. While we will certainly honor the donor's anonymity, we publicly thank you for your outstanding commitment in moving ataxia research forward. Your amazing gift changes the landscape in ataxia research and gives us all renewed hope and a promise for a brighter future.

This fall NAF will be the patient advocacy group sponsor for a symposium on childhood ataxia during the Child Neurology Society's Annual Meeting in Savanna, GA. Each year, a topic in the field of children's neurological diseases is chosen by the Neurobiology of Disease and Children (NDC), and a symposium is held in the fall during the Child Neurology Society's Annual Meeting. The topic for the 2011 symposium is Childhood Ataxia. The NDC Symposium is a forum for top investigators assembled to discuss recent accomplishments and future directions with a large audience of child neurologists.

The National Ataxia Registry, which began in March 2010, now has nearly 950 total registrants and continues to grow. Thank you for your commitment to research and in your participation. The purpose of the patient registry is to collect basic information on individuals with all types of ataxia. This information will be used to help facilitate and expedite clinical trials. The registry plays a crucial part in clinical trials to help find effective treatments for ataxia. NAF encourages you to register today at *www.NationalAtaxiaRegistry.org*.

In closing, I wish you a wonderful summer, enjoyed with family and friends.

A New and Easy Way to Give

Support the National Ataxia Foundation by Establishing a Recurring Gift

The National Ataxia Foundation invites you to become part of our newly launched Recurring Gifts donation program, which allows donors to contribute to the Foundation automatically through a banking or credit card account. Donations are scheduled as a monthly or quarterly payment and donors may discontinue their contribution schedule at any time.

The programs provides a number of benefits:

- Reduces NAF's administrative activity and cost incurred by processing checks or following up on past-due commitments
- Consistent donations help NAF perform more accurate budget projections
- Setting up a recurring gift is easy and the donation is secure
- Once established, a recurring gift does not require any maintenance or updates by the donor

To create a recurring gift schedule simply fill out the form on page 18 or 19 and fax or mail it to the NAF office. Alternatively, you can visit the NAF website donation page for electronic versions of the forms.

If you have any questions, please contact NAF's finance director Julie Braun at *julie@ataxia.org* or (763) 553-0020.

❖

$1.5 Million Given for SCA Research

The National Ataxia Foundation recently received a $1.5 million funding commitment for Spinocerebellar Ataxia (SCA) research. This gift was made possible through an anonymous donor who has made a three-year funding commitment to the National Ataxia Foundation. The funds will be used to support translational spinocerebellar ataxia research, funding for additional young SCA ataxia investigators, and support of the 2012 Ataxia Investigators Meeting (AIM).

The National Ataxia Foundation is truly overwhelmed by the donor's generosity of this anonymous gift. This donation will have a profound impact on NAF's efforts in moving ataxia research forward and in bringing young investigators into the field of ataxia research.

NAF encourages others to follow this donor's exceptional lead by supporting the important research efforts of the National Ataxia Foundation. It is only through continued research that we will be able to find more answers in developing effective treatments and in finding a cure.

As to the wishes of the donor, this gift will remain anonymous. However, the impact of this gift will be felt world-wide. The National Ataxia Foundation wishes to extend to the donor our sincerest and heartfelt thank you.

❖

Vehicle Donation

Donating a vehicle to the National Ataxia Foundation will help support the important work that is being done on behalf of all who are affected by ataxia.

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

Credit/Debit Card Authorization Form

Yes, I want to save time & money in supporting the National Ataxia Foundation.

Fill out and mail or fax form to:

National Ataxia Foundation
Attn: Finance Dept
2600 Fernbrook Ln N, Ste 119
Minneapolis, MN 55447-4752

FAX-763-553-0167 Attn: Finance Department

Personal Information (*Required Fields)

*Name on Card: ____________________

*Address: ____________________

*City: ____________ *State: ______ * Postal Code: ____________

*Country: ____________ Email: ____________

*Phone: ____________________

Gift Information

I Authorize the National Ataxia Foundation to charge my credit card. (Please select one choice below)

One Time Charge of		$ ____________	(One Time amount authorized)
Monthly	5th of each month ($10.00 a month Minimum)	$ ____________	(Monthly amount authorized)
Quarterly	5th of March, June, Sept & Dec ($30.00 a Quarter Minimum)	$ ____________	(Quarterly amount authorized)

Notes: ____________________
(Designate Gift Towards)

Credit Card Information

Visa MasterCard Discover Debit

*Credit Card Number: ____________________

*Expiration Date: ____________ CVV Code: (3-4 digit code on back) ____________

By signing this form, you authorize the National Ataxia Foundation to charge the credit card listed above for the amount instructed. The recurring charge will stay in effect until you chose to cancel giving 15 days written notice or by submitting updated information. Your gift will appear on your credit card statement automatically. Each **January** you will receive a statement from NAF showing the amount you have donated **during the calendar year (January-December). Save this statement for tax documentation.**

____________________ ____________

*Signature of card holder (required) *Date

The National Ataxia Foundation is a 501 (C) (3) non-profit organization, our Federal Tax ID # is 41-0832903. All donations to NAF are tax deductible to the extent allow by law. Phone: 763-553-0020

<u>Please keep a copy of this authorization form for your records & Thank you.</u>

Date Received: ____________ Date Initiated: ____________

Electronic Funds Transfer (EFT) Authorization Form

○ Yes, I want to save time & money in supporting the National Ataxia Foundation through EFT.

Fill out & mail or fax form **with a Voided Check or for savings account a voided deposit slip to:**
National Ataxia Foundation
Attn: Finance Dept
2600 Fernbrook Ln N, Ste 119
Minneapolis, MN 55447-4752 FAX-763-553-0167 Attn: Finance Department

Personal Information (*required fields)

*Name on Account: ____________________

*Address: ____________________

*City: ____________________ *State: __________ * Postal Code: __________

*Country: ____________________ Email: ____________________

*Phone: ____________________ ____________________

Gift Information

*I Authorize the National Ataxia Foundation to deduct from my ○ Checking ○ Savings account.

○ **One Time Charge of** $ __________(one time amount Authorized)

Monthly ○ 5th of each month $ __________(Monthly amount authorized)
($10.00 a month minimum)

Quarterly ○ 5th of March, June, Sept & Dec $ __________ (Quarterly amount authorized)
($30.00 a quarter minimum)

Notes: ____________________
(Designate Gift Towards)

Bank Information

*Financial Institute: ____________________

*City: ____________________ *State: __________ *Phone: ____________________

*Routing Number: ____________________

*Account Number: ____________________

By signing this form, you authorize the National Ataxia Foundation to instruct your financial institute to debit your account as directed. This deduction will remain in effect until you chose to cancel giving 15 days written notice or by submitting an updated EFT authorization form if any information changes. Your gift will appear on your bank statement automatically. Each **January** you will receive a statement from NAF showing the amount you have donated **through our EFT program during the calendar year (January-December)**. **Save the statement for tax documentation.**

____________________ ____________________
*Account Owner Signature (required) *Date

The National Ataxia Foundation is a 501 (C) (3) non-profit organization, our Federal Tax ID # is 41-0832903. All donations to NAF are tax deductible to the extent allow by law. Phone: 763-553-0020

Please keep a copy of this authorization form for your records & Thank You.

Date Received: ____________________ Date Initiated: ____________________

Management of Neurogenic Bladder

By Andrea Staack, MD, PhD

The following was presented at the 2011 NAF Annual Membership Meeting in Los Angeles, CA and edited for publication in Generations.

The bladder is under dual control. First from the autonomic nerve system – that means that nerves coming from the spinal cord go directly to the bladder. When the bladder gets full it receives signals, and the signals are sent back to the brain. The brain is our central nerve control system and it can choose voluntarily when it is an appropriate time to empty the bladder. Both can be altered by either age or a neurological disease.

The bladder muscle and the sphincter are supported by the pelvic floor. In patients with bladder problems the bladder may send different signals back to the brain causing this muscle to work involuntarily. It can contract even when we do not want it to contract. But if the pelvic floor is strong, this can compensate for this contraction. In patients where this pressure gets so high or the pelvic floor is too weak, urinary leakage will occur.

Patients with [ataxia and] neurogenic bladder disorders most likely suffer from incontinence or bladder over-activity than from difficulties to empty the bladder, but this also could happen.

Symptoms

The patient could say "I am experiencing a strong urge to go to the bathroom" and the doctor would translate this into "this patient has urinary urgency." Or the patient could say "I am going to the bathroom very frequently, [my bladder wakes me up at night]" and the urologist will call this "urinary frequency – day or nighttime." The patient also could say "I'm losing involuntary urine, accompanied with a strong desire to void." And the doctor would translate this as a symptom "urge urinary incontinence."

Evaluation

First you have to make an appointment. At the appointment you will be asked all kinds of questions. You will be asked about your:

- Fluid intake
- Number of continent or incontinent episodes during the day and during the night
- Nighttime urgency
- Voiding pattern – (how is your stream? are you able to empty your bladder to completion?)
- Alteration in bowel habits
- Changes in sexual function
- OB/GYN history
- Medication
- Neurological history

Back pain, back surgeries, stroke, numbness, weakness, and balance problems [are] all important [to note] in addition to your neurological history.

The physician will also ask you to conduct a voiding diary for one day and one night at least. You have to document how much you drink – you have to accurately measure it. Then you will need to quantify your urine output and document if you lose urine day or night, uncontrolled. You will be asked about the degree of your urge that brings you to the bathroom, and if you use pads and how many.

Physical Examination

The pelvic floor, genitalia, and rectum will be examined to check for any growth or a prostate enlargement, etc. A favorite test of the urologist is the Urodynamic test. This is a little bit of an invasive study where the patient has a very small catheter in the bladder and one into the rectum. This test is excellent to study the bladder muscle. It can tell everything about this muscle – ⏩

it can document uncontrolled contractions, whether the urethra and pelvic floor is competent to hold sufficiently the bladder content during the filling phase, and it studies the bladder during voiding. Also at the end, since it's a study done with X-ray, left-over urine can be measured.

Otherwise, laboratory tests are indicated for evaluation. Urine tests are very important to rule out hematuria and to rule out any bladder growth or bladder stones. Also urinary infections have to be ruled out. Many patients who are not able to empty the bladder sufficiently would be at risk for urinary tract infections [which need] to be treated.

Blood work, as appropriate [includes] blood sugar for diabetes, and the PSA test for prostate cancer. Sometimes a bladder scanning with a small camera called cystoscopy is necessary to look inside the bladder. Other imaging studies are ultrasound, X-ray studies, or MRI.

> "Certain fluids can irritate the bladder and you have to be aware of it"

Considerations for Patients

Once your physician has evaluated you and looked at your symptoms and if there are any problems that need to be addressed, now is the time to put you to work.

You have to make sure that you drink adequately. Not too much to avoid frequency and not too little to avoid bladder irritations and to prevent urinary tract infections. Also, it's important to drink less during the evening to reduce the evening fluids to manage nighttime urination.

Certain fluids even can irritate the bladder and you have to be aware of it. Carbonated drinks, citrus juices, caffeinated drinks – including soda, tea, coffee, and alcoholic beverages are dangerous for your bladder.

Dietary adjustments would be very beneficial because fruits and vegetables are a high source of potassium, vitamin D and vitamin B which have been shown to be bladder-protective for bladder over-activity. A high-fiber intake is also important for bowel regulation. Because even the bowel could put pressure by constipation [and] could irritate the bladder and lead to over-activity.

If people could stop smoking that would be great for many other reasons too. But in this specific scenario it would reduce chronic coughing which creates a lot of pressure on the pelvic floor and this can weaken your ability to hold urine. Also if people would lose weight this would reduce pressure on the pelvic floor and on blood vessels and nerves.

Bladder Exercises

A strong pelvic floor can help you to hold urine and pelvic floor exercises help to calm down and relax the bladder. This all improves stability and helps to reduce the feeling of urgency.

Kegel Exercises

Even if somebody is not bothered with a bladder [problem], [Kegel exercise] is a wonderful exercise to strengthen the pelvic floor. The pelvic floor muscles [are located in] kind of the bicycle area. When you do this exercise you have to be aware of exactly this area between your rectum and the clitoris in women and the penis in men. And then you have to squeeze up as hard as you can for a couple of seconds and hold. And then relax. The relaxation time is also very important. Do many sets of repetitions start with five, squeeze, hold, relax – do it 10 minutes during the day and then increase your repetitions in length and in intensity and do it every other day at least.

Biofeedback

If a patient really has trouble in finding the pelvic floor, biofeedback therapy helps. It monitors the correct muscular contraction to develop

Continued on page 22

Management of Neurogenic Bladder
Continued from page 21

conscious control of the pelvic floor muscles to increase the outcome of Kegel exercises.

Bladder Training

In addition to training the pelvic floor you also can train your bladder. Schedule voiding at set times during the day. You use your muscles in between the times to prevent urine loss and increase the voiding intervals after the initial goal is achieved. So try to prolong the phases in between going to the bathroom. When you are not sure, keep an input and an output chart and write down the times – and try to hold on longer.

Other Therapies and Strategies

Alternative therapies can be hypnotherapy, yoga, and acupuncture – all can relax the bladder and strengthen the pelvic floor. There are six steps for managing incontinence:

- drink less than five glasses a day
- stop drinking water after dinner
- elevate your legs to get out excess fluid
- try timed-voiding
- do your regular pelvic floor exercises
- keep a voiding diary

Medication

Unfortunately there are very few options to treat an overactive bladder. Some patients may have heard of anticholinergics – they target the bladder and block nerves to relax the bladder function. But they have side effects because they are not very bladder-specific. Side effects could be dry mouth, constipation, and blurred vision.

And you have to be aware of the side-effects of drug interactions. Some patients might take a beta-blocker or amantadine; these will increase the side effects with drowsiness, dizziness, confusion, and blurred vision. That's why the urologist might help you with other options in addition to exercise, dietary changes, and medication.

Other Interventions

Botox

Some people might have heard about Botox. It not only treats wrinkles, it can also help the bladder to relax. It's a neurotoxin that comes from a bacterium, Clostridium Botulinum. Injections occur under direct vision into the bladder muscle with a small camera. This chemically blocks the nerve ends in your bladder. After two days people can see improvement in urgency and frequency. Duration can last between three and six months. It is not approved yet for neurogenic bladder dysfunction, but it is widely used. It is not indicated for patients who cannot empty their bladder sufficiently because this would make the problem worse. Local side effects could be excessive bladder muscle relaxation without being able to empty the bladder, pain, infection, and bleeding. General side effects could be muscular weakness, [and the therapy can be] less effective during prolonged time (some people build up a resistance).

Neuromodulation

Electrical stimulation of the tibial nerve is a pretty new therapy and last year it was approved by the FDA. It is the least invasive form of neuromodulation to treat your bladder muscle through nerve stimulation. A small acupuncture needle is injected in your foot nerve and this can indirectly stimulate the bladder nerve. It is recommended to do it over 12 weeks, and each session where this nerve gets stimulated is about 30 minutes long.

Pacemaker for the Bladder

Another option is sacral neuromodulation. The company Medtronic offers this therapy, which is also called pacemaker for the bladder. It treats urgency, frequency, urinary incontinence, and urinary retention. It is efficient in patients where exercise, behavior changes, and medications have failed. For over 14 years it has been FDA approved and has been used worldwide. Parkinson's disease, multiple sclerosis, and spinal cord injury patients have benefitted from sacral ⏩

neuromodulation.

How does it work? The sacral pelvic nerves will get stimulated through leads, and the leads are connected to a battery. The leads float next to the bladder nerves and are connected to a battery which is placed in the fat tissue in your buttocks and sends electrical impulses to stimulate or inhibit your bladder. This can be discontinued anytime (it is reversible). Side effects could include skin irritation through the incision from the placement of the battery, some people have pain, and wire movement could diminish the effect. People with the battery should not receive an MRI because they have matter in their body.

Surgery

Other interventions are surgery such as bladder augmentation in which a pouch made out of bowel is attached to the bladder to make a larger reservoir which would decrease the bladder pressure and help hold more urine. This is the last resort when nothing can be done anymore – when the bladder does not receive signals.

Your bladder matters. There is help; you just have to make your appointment. ❖

Rare Disease Research Goes International

In April the following statement was posted on the Office of Rare Diseases Research (ORDR) website, *www.rarediseases.info.nih.gov*:

The International Rare Diseases Research Consortium (IRDiRC)

Today, the diagnosis for most patients affected by rare diseases remains a challenge and most are lacking dedicated therapies. Recent progress in human genomics and other scientific advances increases the prospect for developing effective interventions. Progress will require increased coordination and renewed efforts among multiple stakeholders across the world.

Over the last days (April 8-9, 2011) a group of research funders, patient advocacy groups, researchers, industry and regulatory agencies continued their work at the second meeting of the International Rare Disease Research Consortium, IRDiRC. The success of this meeting was the endorsement by many stakeholders of the objectives to deliver by 2020 diagnostic tests for most rare diseases and 200 new therapies for patients affected by rare diseases.

This ambitious vision will be realized though an unprecedented cooperation at the international level. The International Rare Disease Research Consortium invites public and private partners with shared commitments from across the globe, to join our efforts and alleviate the suffering of individuals affected by diseases for which today there are no treatments available.

The group will next develop the scientific and policy framework to guide the research activities and foster collaboration among the stakeholders to systematically explore all the opportunities to accelerate the development of diagnostics and therapies for rare diseases. The next meeting of IRDiRC will take place in Montreal, Canada in October 2011. Continued efforts until the next meeting will include strengthening the cooperation among the consortium members and to reach out for new partners.

Stephen Groft, Pharm.D., Director of the ORDR said, “This is the first time that high-level government people from many countries have come together to identify issues that rare disease research faces. This venture will raise rare disease research up one level.”

The National Ataxia Foundation is excited to announce that Dr. Groft will present the activities of this group as well as the work of the Office of Rare Disease Research during the General Sessions of the 2012 Annual Membership Meeting in San Antonio.

Research Participants Needed

The National Ataxia Foundation has reviewed the research titled "The relationship between sleep and cognitive and affective functioning in movement disorders" which involves completion of an online survey regarding the effects of cerebellar ataxia on daily life and quality of sleep.

This study has been reviewed and approved by the University of Massachusetts Amherst Institutional Review Board (IRB) and NAF has reviewed the survey and confirmed the legitimacy of this research. If you are interested, you may participate in this study. Below you will find the recruitment announcement:

Do you have cerebellar ataxia? Would you like to participate in an online survey?

The Cognition and Action Lab at UMass-Amherst is recruiting individuals with cerebellar ataxia for an online survey.

The survey includes questionnaires that are related to the symptoms you experience, the effect of the disease on your daily life and your quality of sleep. The survey will take you about 60 minutes to complete and can be done in multiple sittings. You are also free to withdraw at any time. Please use this web page to complete the survey: *www.surveymonkey.com/s/2YV2W98*

If you would like to participate in this research please call (413) 545-4831 or e-mail *siestalab@gmail.com*.

Research conducted by Dr. Rebecca Spencer, University of Massachusetts, Amherst Department of Psychology, 419 Tobin Hall, Amherst, MA. Approved by the UMASS Psychology Department Human Subjects Review Committee and the UMASS IRB (Study #2011-0929). Expiration 05/01/2013.

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Clinical Research: A Reality for the Ataxias

The Rare Diseases Clinical Research Network (RDCRN), funded by the National Institutes of Health (NIH) and the Office for Rare Diseases Research (ORDR), was created to facilitate collaboration among experts in many different types of rare diseases. The goal is to contribute to the research and treatment of rare diseases by working together to identify biomarkers for disease risk, disease severity and activity, and clinical outcome, while also encouraging development of new approaches to diagnosis, prevention, and treatment.

The National Ataxia Foundation is the patient advocacy group for two of these consortia: Clinical Research Consortium for the Spinocerebellar ataxias (CRC-SCA) and Clinical Investigation of Neurological Channelopathies (CINCH), which studies episodic ataxia. Between the two consortia, 16 sites across America and one each in Canada and the UK are studying the ataxias. This collaborative effort has its challenges, but with a rare disease such as ataxia, it is essential that ataxia researchers work together to share information and not duplicate efforts. A multitude of research sites gives patients across the country more locations to participate in longitudinal studies and clinical trials.

Because of the importance of patient participation in translational and clinical research, it is important for those affected by any type of ataxia to sign up on the contact registries. This can be done quite simply at *http://rarediseasesnetwork.epi.usf.edu/registry/index.htm.*

"Spotlight on Rare Diseases" is the quarterly newsletter that informs and promotes awareness of the Network's activities to the advocacy, medical, and NIH community. You can receive complimentary e-copies by sending an e-mail to *RDNwebmaster@epi.usf.edu* and request to be added to the mailing list for "Spotlight."

The NAF Board of Directors along with the Central Texas, Houston, and North Texas Ataxia Support Groups would like to invite you to attend the

National Ataxia Foundation

55th Annual Membership Meeting

March 16-18, 2012

Join us in San Antonio where we'll be "Roundin' Up a Cure to Give Ataxia the Boot"

Early Registration opens at the end of December 2011 and runs until mid-February. To take advantage of the discounted room rate of $139 per night at the Grand Hyatt San Antonio, visit *https://resweb.passkey.com/go/NationalAtaxia* or call 1-888-421-1442.

For all ADA room reservations you must contact the National Ataxia Foundation at (763) 553-0020 and ask for Lori, or e-mail her at *lori@ataxia.org*.

For the latest information on conference registration, schedules, and area information, keep checking NAF's website, *www.ataxia.org*.

For more information about San Antonio, visit *www.visitsanantonio.com/meeting*.

We look forward to seeing you in San Antonio!

Caregiver's Corner

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

Hospice Care and Crushing Grief

Qualifying for Hospice Care

To qualify for hospice, the person must be certified as terminally ill by his doctor and the hospice medical director. "Terminally ill" means having a life expectancy of six months or less if the disease runs its normal course.

Hospice care is offered for two periods of 90 days, followed by an unlimited number of 60-day periods, as long as the physician recertifies that the patient is still terminal. A patient may leave hospice care if his condition improves, and reenter if it worsens.

Principles of Hospice Care

Hospice recognizes the importance of including the ill person, family, and other loved ones in the care plan.

Hospice services provide expert, compassionate care and make it possible for a dying person to remain at home. The earlier hospice care begins, the more it can help loved ones enjoy the best quality of life as a family unit.

Sometimes a doctor and hospice program don't agree on who should get hospice care, especially when a patient does not have a clearly defined illness or "terminal condition." If this happens, ask the doctor to explain why she believes the person is eligible and why the hospice does not. Or, try another hospice.

Once the decision is made for hospice care, a doctor must sign an order requesting it.

What Hospice Care Provides

Hospice delivers comfort and support to people in the final stages of a terminal illness – and to their families. The hospice team are specially trained medical professionals who focus on easing pain and managing symptoms. They provide medical, emotional, psychological, and spiritual care to the person and family. They assist the family in coping with their coming loss and their grief afterward.

Most hospice care is delivered in the home, but it can also be provided in nursing homes, some assisted living facilities, and hospice facilities. The person who is ill and the family are the core of the hospice team and are at the center of all decision making.

Although a family member or other caregiver cares for the person on a daily basis, a hospice nurse is available 24 hours a day to provide advice and make visits.

Grief – Coping with Reminders After a Loss

Anniversary reactions happen when something reminds a person of the loss of a loved one. Grief doesn't just end at a certain point after a loved one's death. Reminders can bring back the pain of loss, even years later.

Holidays, certain places, birthdays, sights, sounds, or smells can make grief come back. This isn't a bad thing; it's a sign that the loved one was cherished. If you know what to expect, you can help the person in your care cope better.

Anniversary reactions can last for days or weeks often causing:

- Sadness, loneliness and crying spells
- Anger
- Anxiety
- Lack of interest in usual activities
- Trouble eating and sleeping, including stomach upset and nightmares
- Memories of events surrounding their loved one's death

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Dealing with Returning Grief

Be prepared. Don't let the person dread upcoming anniversary days. Grief is often worked through on these days and it becomes a time for healing.

Plan distractions. Arrange a short trip or a visit with friends or family.

Reminisce. Encourage the person to talk about shared good times.

Start a new tradition. Make a donation or plant a tree in honor of the loved one.

Connect with others. Talk about loss with people who were special to the loved one. Support also comes from religious and social groups, as well as bereavement support groups.

Feel. Celebrate special times; you might find both of you crying and laughing.

When Grief Becomes Overly Intense

If the grief of the person in your care is getting worse over time, or interferes with daily life, consult a grief counselor or other mental health provider. With professional help, you can help the person return to the path toward healing.

Source: www.mayoclinic.com; The Comfort of Home: A Complete Guide for Caregivers

Taking Care of Yourself – Talk Things Through

Caregiving for someone who is dying can be demanding, and it's important for everyone involved to take proper care of his or her needs. A leading cause of depression is not talking about your feelings. Your spirits lift after talking to a friend or therapist because you've shared your feelings. Try writing your thoughts in a journal when you feel down, and always maintain close contact with others who you can talk to.

Note

If a person with Alzheimer's is able to retain the information that a loved one has died, then he should be told. However, since it is a disease of severe memory loss, repeating information that only causes painful emotions may be unnecessary.

Resource for You

- Hospice Foundation of America – 1-800-854-3402; *www.hospicefoundation.org*
- National Hospice and Palliative Care Organization – 1-800-658-8898; *www.nhpco.org*

These organizations provide information and referral service, resources on end-of-life care, brochures on hospice, volunteering, and bereavement.

Call your local Social Security Administration, State Health Department, State Hospice Organization, or call 1-800-633-4227 (Medicare Hotline) to learn about hospice benefits.

Dying at Home

Most people would prefer to die at home. Hospice gives them that choice. When setting up a home for hospice care, try to keep it as familiar and "homey" as possible, to make the person feel most at ease. If possible, consult with the person in your care to find ways to keep things comfortable and familiar.

Where a person dies may be as important as when they die. People who die at home, receiving hospice or palliative care (care that eases suffering but does not try to cure) experience less pain and distress than those who die in a hospital. Their friends and family suffer less too. And, less pain, distress, and emotional upset may even prolong life, giving the family more time to enjoy each other.

Sometimes, of course, a person's symptoms cannot be managed at home. In these cases, no one should think that going into a hospital for care is a failure. The dying person's comfort is the most important goal in end-of-life care.

Source: Coping with Cancer Study, Boston Dana-Farber Cancer Institute; New England Journal of Medicine; American Society of Clinical Oncology; USA Today

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BOOKS

— ATAXIA RESOURCES —

Evaluation and Management of Ataxic Disorders for Physicians

by Susan Perlman, M.D.

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

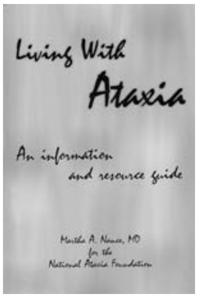
Healing Wounded Doctor-Patient Relationships

by Linda Hanner with contributions by John J. Witek, M.D. and doctors and patients around the nation

This book is packed with information that anyone who ever goes to a doctor for any reason deserves to know and that every professional who wants to maximize his or her healing power must understand. $10

Living with Ataxia: An Information and Resource Guide

by Martha Nance, M.D.



This illustrated book provides a compassionate, easy to understand explanation of ataxia with ideas on how to live well with ataxia. It is an excellent tool for building awareness for those who do not know what ataxia is or how it affects a person who has ataxia. This second edition was published in 2003. $14

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

by G.N. Rangamani, Ph.D. with contributions from Douglas E. Fox, M.S.

This 60-page booklet is an excellent resource for those who struggle with speech and/or swallowing problems. It is an easy to understand booklet with straight-forward and realistic suggestions for speech and swallowing management. This second edition was updated in 2006. $7.50

— FICTION & PERSONAL STORIES —

Summer Born: A Life with Cerebellar Ataxia

By Cheryl Wedesweiler

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

Ten Years to Live

by Henry J. Schut

The story of the Schut's family struggle with hereditary ataxia and the impact it had on this extended family. It is dedicated to the author's brother, Dr. John W. Schut, who was committed to the cause of finding a cure for ataxia, which claimed his life. $8.75

There's Nothing Wrong with Asking for a Little Help … and Other Myths

by Dave Lewis

The story about one man's experiences in living with Friedreich's ataxia. Dave spent the last three years of his life writing his memoir to provide information and inspiration to countless others. Proceeds from the book purchased through NAF will be used to support promising Friedreich's ataxia research. $15.95

— COOKBOOKS —

Recipes and Recollections

by Kathryn Hoefer Smith

Dedicated to the memory of her daughters who had Friedreich's ataxia, Kathryn Hoefer Smith has taken the handwritten cookbook her mother-in-law made for her sons and their families and duplicated it in 2003. It is full of delicious recipes and recollections. Perfect for FRDA research fundraisers. $10

Cooking for a Cause

by Julie Karjalahti for FRDA research

This 177-page cookbook has kid's recipes, fun craft recipes, along with the usual desserts, breads, beverages and other recipes you would expect from a good cookbook. $12

Recordings of presentations from the 2011 Annual Membership Meeting are now available to order. See page 27 of this issue of *Generations*.

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SHIRTS/MISCELLANEOUS

International Ataxia Awareness Day T-Shirt
Available in youth L, and adult small to XXX-large. $10

2011 Annual Membership Meeting T-Shirt
Gray, short-sleeved with the "Bringing the Ataxia World Together" logo. Sizes medium to XX-large. $10

NAF Shoulder Bag
Blue with white NAF logo. 11x15x2 inches. $10

NAF Polo Shirts
Mens – Royal blue w/white embroidered NAF logo. Sizes medium to XXX-large. Womens – Light blue w/ navy embroidered NAF logo. Sizes small to XX-large. $25

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

"Ataxia is Not a Foreign Cab" T-Shirt
White. New design. Sizes small to XXX-large. $10

"Ataxia is Not a Foreign Cab" Sweatshirt
White. Sizes small to XXX-large. $20

Window Cling or Bumper Sticker
$1 ea. or 6 for $5

NAF Ataxia Awareness Band Blue
One size. $2

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

Reusable Grocery Bag with NAF Logo
$5

VIDEO/CD

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

"Together There is Understanding" VHS or DVD
A discussion of ataxia. 50 minutes. VHS $20 or DVD $25

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

ORDER FORM

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

SUBTOTAL: ______________________

Shipping within U.S.: **Add $5.00**

Shipping outside U.S.: **Add $15.00**

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PLEASE ALLOW 4-6 WEEKS FOR DELIVERY

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E-MAIL: ______________________

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EXP DATE: ______________________

SIGNATURE: ______________________

Ataxia Awareness and Education Opportunities Abound at American Academy of Neurology Meeting

The National Ataxia Foundation's work was well represented at the American Academy of Neurology (AAN) meeting, which was attended by 8,070 neurologists from April 9-14 in Honolulu, Hawaii.

The AAN Foundation held a kick-off public education event, the Brain Health Fair on Saturday, April 9. It was the first public outreach in AAN history to connect patients with caregivers, tools, and resources. Complimentary exhibit space was provided to the National Ataxia Foundation. Patients, caregivers and families were able to explore tools and resources regarding brain health. Awareness of the benefits of nutrition, emotional health and health screenings were part of the educational activities available. Free admission to this event provided attendees with brain games, memory tests, tests for balance and risk of falling as well as the opportunity to meet a seizure detection dog.


Dr. Henry Paulson

Over 1,400 people of all ages, including students from all grade levels, attended, many of whom stopped at the NAF table asking the usual question: "What is ataxia?" Newly designed memo tablets with the NAF slogan, "Ataxia is not a foreign cab" were well received by the attendees.

James and Carole Manuwa, members of NAF, assisted by volunteering at the exhibit table at the Brain Health Fair on Saturday, as well as during the next week when they staffed the NAF table at various times during the full AAN meeting. Many neurologists stopped by the NAF exhibit table to gather patient information and ask about NAF funded research opportunities.

During the AAN meeting, there were several interactive and information-sharing opportunities in which NAF participated.

One of the CME (continuing medical education) opportunities for neurologists to attend was "Update on Ataxias" presented by faculty members Dr. Henry Paulson and Dr. Christopher Gomez, both members of the NAF Medical Research Advisory Board. As a supporter of this course, a representative of NAF was present and able to provide a copy of "Evaluation and Management of Ataxic Disorders: An overview for Physicians" to the approximately 100 doctors in attendance for their practices.


Dr. Christopher Gomez

Dr. Henry Paulson said, "I am grateful that NAF helped to sponsor this event. Its obvious success leads me to think we will see this type of update session again in future years at the AAN meeting."

The Integrated Neuroscience Sessions (INS) provide in-depth subspecialty concentration around a topic using a format of scientific sessions, short poster talks, discussions, invited ▸▸

lecturers and poster sessions. Dr. Massimo Pandolfo, a member of NAF's Medical Research Advisory Board was the coordinator for the session titled "Cerebellar Diseases."

Dr. Henry Paulson, NAF's Associate Research Director stated, "The INS session on cerebellar diseases was a tremendously exciting event. Experts from around the world, and importantly junior scientist and training clinicians too, gathered to discuss the latest findings about the causes and potential treatment of various ataxias."

A representative from NAF was present to visit with the investigators and provide information about the work of the Foundation, specifically the research funding opportunities.

Dr. Tetsuo Ashizawa

With so many neurologists in attendance at this meeting, it was a logical place to hold the Clinical Research Consortium on the Spinocerebellar Ataxias meeting of which Dr. Tetsuo Ashizawa, is the Principal Investigator. Dr. Ashizawa also serves on NAF's Medical Research Advisory and NAF is the patient advocacy group for this NIH funded initiative.

At this meeting investigators and research coordinators from the 13 research centers across the country discussed the on-going research initiatives and their collaborative work. Discussion of the future direction of research studies and clinical trials for the SCAs took place. The benefit of these face-to-face meetings is the renewed enthusiasm for the collaborative work that these investigators and coordinators are pursuing as they seek treatments for these ataxias.

Thank you to event volunteers Carole and James Manuwa, who helped NAF achieve the full value of the meeting.

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Carol and James Manuwa

Reflections on the AAN Meeting

We are grateful to James and Carole Manuwa for volunteering their time at the Brain Health Fair and the AAN meeting. Below are their reflections of their time spent assisting at the National Ataxia Foundation Exhibit booth:

"Overall we thought that meeting so many neurologists in one location was fantastic! I think that we really touched many of the professionals who attended. In particular, many doctors from other countries were especially happy to see NAF and all the information that was offered. These doctors in particular were very interested in adding their names to the roster of treating and studying physicians and seeing the websites. They are all looking forward to getting updates on research and staying in touch. Perhaps the National Ataxia Foundation will become the International Ataxia Foundation! These doctors shared with us how they have many, many patients affected with ataxia and seeing our table seemed to be such a relief to them.

We also had many U.S. physicians who stopped by the booth wondering what the National Ataxia Foundation does, and it was a pleasure sharing information with all of them. They were all very curious and genuinely interested.

Our own interest was piqued too, looking at all the vendors, researchers and specialists all together in one location.

We both really enjoyed our time."

Informational Links

The following is a list of topical websites that you may find helpful in managing aspects of life with ataxia. This listing is for information only and does not imply specific endorsement of these companies, organizations, or sites by the National Ataxia Foundation.

ACCESSIBLE TRAVEL

TSA – Travelers with Disabilities
www.tsa.gov/travelers/airtravel/specialneeds

Special Needs at Sea
www.specialneedsatsea.com

Splore: Accessible Outdoor Adventures
www.splore.org

The Society for Accessible Travel and Hospitality
www.sath.org

Wilderness Inquiry
www.wildernessinquiry.org

ASSISTIVE TECHNOLOGY

AbleData – Information on assistive technology
www.abledata.com

Camera Mouse
www.cameramouse.org

National Registry of Rehabilitation Technology Suppliers
www.nrrts.org

Pass it On Center – A National Assistive Technology Reuse Center
www.passitoncenter.org

United States Society for Augmentative and Alternative Communication
www.ussaac.org

Tobii Products
www.tobiiati.com

Gus Communications Inc.
www.gusinc.com

ZYGO Industries, Inc.
www.zygo-usa.com

PRC (Prentke Romich Company)
www.prentrom.com

DynaVox Mayer-Johnson
www.dynavoxtech.com

DISABILITY BENEFITS

Social Security and Disability Resource Center
www.ssdrc.com

Social Security Disability
www.ssa.gov/pgm/disability.htm

Americans with Disabilities Act
www.ada.gov

Benefits.gov
www.benefits.gov

Interagency Committee on Disability Research (ICDR)
www.icdr.us

EMPLOYMENT, EDUCATION AND INVOLVEMENT

Incight – Resources for Self-Empowerment
www.incight.org

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AOA2 Research

There is a research study currently underway at the University of Minnesota, Minneapolis campus. Patients with AOA2 are being recruited for this study. Travel expense reimbursement is available up to a certain dollar amount.

If you, or someone you know has AOA2, please contact Diane Hutter at hutte019@umn.edu for more information, or call the National Ataxia Foundation (763) 553-0020 and ask for Sue Hagen.

Job Accommodation Network (JAN)
http://askjan.org

Genetic Alliance
www.geneticalliance.org/how-to

FINANCIAL PLANNING

Protected Tomorrows
www.protectedtomorrows.com

Disabled and Alone
http://disabledandalone.org

HEALTHCARE ASSISTANCE

Healthwell Foundation
www.healthwellfoundation.org

Patient Access Network Foundation
www.panfoundation.org

Co-Pay Relief
www.copays.org

MEDICAL INFORMATION

Palliative Care
www.getpalliativecare.org

Office of Disease Prevention and Health Promotion
www.healthfinder.gov

National Institute on Deafness and Other Communication Disorders
www.nidcd.nih.gov

National Center for Biotechnology Information
www.ncbi.nlm.nih.gov

National Institutes of Health
www.nih.gova

National Institutes of Rare Disorders
www.rarediseases.org

PHYSICAL THERAPY

National Center on Physical Activity and Disability (NCPAD)
www.ncpad.org

North American Riding for the Handicapped Association (NARHA)
www.narha.org

American Physical Therapy Association (APTA)
www.apta.org

Wii-hab – Using your Nintendo Wii to Improve Strength, Balance, and Coordination
www.wii-hab.com

SERVICE DOGS

Assistance Dogs International, Inc.
www.assistancedogsinternational.org

Canine Companions for Independence
www.cci.org

Assistance Dog United Campaign
www.assistancedogunitedcampaign.org

Top Dog Service Dog Training
www.topdogusa.org

TRAVEL ASSISTANCE FOR MEDICAL/RESEARCH PURPOSES

Air Charity Network
http://aircharitynetwork.org

Wings of Hope
www.wings-of-hope.org

Angel Flight
www.angelflightatnih.org

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TISSUE DONATION

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

Arnulf Koeppen, MD
Professor of Neurology
VA Medical Center
113 Holland Ave., Albany, NY 12208
Phone: 518.626.6377 Fax: 518.626.6369
E-mail: Arnulf.Koeppen@va.gov

Chesapeake Chapter's Annual Medical Meeting

By Carolyn Davis

The 28th Annual Medical Meeting of the Chesapeake Chapter was held March 26, on the Rockville campus of Montgomery College in Maryland. The theme was "The Promise of Treatments from Research." Speakers included Ron Bartek, Dr. Henry Paulson, Dr. Joseph Savitt, Dr. Vikram Shakkottai, and Dr. Katrina Gwinn.

Mr. Bartek, President of Friedreich's Ataxia Research Alliance (FARA), spoke on the momentum towards treatment of recessively inherited Friedreich's ataxia. With six clinical trials underway and three more coming, there is confidence among the researchers that a U.S. approved clinical treatment will come. Each clinical trial, even when it doesn't result in a therapeutic treatment, does move us closer to a treatment because of what is learned. FARA provides research structure through the funding of basic discovery science and of translational and clinical research. They also facilitate collaboration among scientists, drug companies, National Institutes of Health (NIH), Food and Drug Administration, Congress, other advocacy organizations, patients and families.

Dr. Paulson, Professor of Neurology at University of Michigan, spoke on the search for therapies for dominantly inherited ataxias. Potential therapeutic targets include reducing the disease protein expression, enhancing clearance of the mutant protein, and blocking formation of toxic oligomers. Advances have been made in understanding the disease, and collaborative studies have been spurred through the Clinical Research Consortium for Spinocerebellar Ataxias.

Dr. Shakkottai, Assistant Professor of Neurology at University of Michigan, spoke about how changes in physiology are a novel target for the treatment of ataxia through symptomatic or neuroprotective therapies. Although not a cure, some of his research has shown improvement in symptoms in mice. Stopping degeneration is another target of research.

Dr. Savitt, Director of the Ataxia Center at Johns Hopkins, gave an update. With a grant from the Gordon and Marilyn Macklin Foundation, Johns Hopkins has set up a multi-disciplinary center for the treatment of ataxia patients. It also provides a framework for research through a database/registry and fosters ataxia awareness among other medical staff, students, and the community. Patient resources include insurance and social worker support, referrals, a website, publications, and a support group.

Dr. Gwinn, Program Director of the Extramural Research Program at NIH/NINDS, gave an overview of NIH with its 25 Institutes and Centers. Congress oversees NIH and sets its budget. The Intramural Research Program is comparable to an academic medical center, and the Extramural Research Program manages research programs and administers grants. Additional sources of research funding include other government agencies, pharmaceutical companies, and foundations. NIH funded $69 million in ataxia research in 2010, including $17 million in NINDS-funded inherited ataxia research. Ataxia research is moving forward and is poised to move "from the bench to the bedside."

Additional discussion was led by Libby Labash, Chapter Vice President, "Ask not what CC-NAF can do for you; ask what you can do for CC-NAF," and by Joe DeCrescenzo, Chapter Treasurer, about a proposed raffle fundraiser. ❖

Chapter and Support Group News from Around the Country

Northern California Ataxia Support Group Update

By Joanne Loveland

The NCASG had its first 2011 meeting on April 9 at Our Savior's Lutheran Church in Lafayette. The meeting began with a "mix and mingle" time, followed by lunch brought by Mike Fernandes. We had four first time attendees and 18 members attend.

After lunch we had a brief business meeting. Joanne Loveland distributed a summary of the ACARM meeting and commended Mike for lining up the event's cutting-edge research speakers.

A report of the NAF Annual Membership Meeting held in Los Angeles was given by Joanne Loveland, with input from other members who attended. Many of us attended and gained a lot of knowledge and renewed hope from the excellent researchers and speakers. It was another great conference.

Our guest speaker was Dr. Jordan Taylor, a post-doc from UC Berkeley's Ivry Lab for Cognition and Action Research. His topic was entitled, "Cognitive Strategies to Compensate for Motor and Learning Impairment." Jordan has attended the last two NAF Annual Membership Meetings and has an active interest in ataxia patients and the cognitive progression of the disorder. His presentation showed us that it is possible to improve motor movements by repetition and focused concentration. It is also seen in the lab with ataxia patients, that when there is a distraction (e.g., having a conversation when walking) the movement challenges get worse. The experiments and recent studies in the lab indicate that automatic learning and strategic learning operate in parallel. Most interestingly, it appears that individuals with ataxia rely almost entirely on the strategic-based system. Dr. Taylor has published a paper this year showing that strategic learning does not involve the cerebellum. He and others at the lab suspect that the critical part of the brain for strategy use is in the frontal part of the cerebral cortex.

Dr. Taylor created a lot of interest with his presentation, and many good questions were asked by the group following the presentation. The Ivry Lab is actively recruiting for their research and studies. If you have an interest in participating, send an e-mail to *jordan.a.taylor@berkeley.edu* or call (510) 642-0135.

In July we will have Dr. Gail Kang from the Memory and Aging Center at UCSF as our speaker. She trained with Dr. Perlman at UCLA and is actively building awareness about ataxia with her colleagues, staff and students.

Los Angeles Ataxia Support Group Update

By Sherry McLaughlin

The Los Angeles Support Group met on Saturday May 14 at the Azusa Public Library to hear a presentation on "Everyday Living Skills" from Lyn Walsh, Occupational Therapist. Lyn presented lots of great ideas on how to reinvent small items you already have in your house. These were simple and very useful ideas.

Our special guest turned out to be just as handsome as we promised. "Coby," an assistance puppy in his first stage of training, was brought to us by trainer Debra Prough. Coby visited

Continued on page 36

Chapter and Support Group News

Continued from page 35

with everyone and lavished kisses on many of us. Debra described the intensive training process that Coby has in front of him. We all wish Coby luck and we know the person who receives him will have a very special friend.

Our next meeting is the annual barbeque at the home of Jim and Selina Fritz in Venice Beach on July 9. Everyone is invited to join us. Call (626) 791-1558 for information.

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Cincinnati Ataxia Support Group Update

By Jennifer Mueller

We had a meeting on April 16 at a local library after a nearly two year hiatus. But we came back strong! I now have a co-leader, Julia Soriano. She is fantastic and full of ideas. More than 25 people were in attendance at the meeting , which is a phenomenal turn-out. Some attendees came from as far as two hours away. There was also a good mixture of ataxias and age groups.

Members of the Cincinnati Ataxia Support Group at their April meeting.

Our main focus of this meeting was to have a kind of show-and-tell, where many people brought a device or two that helps them in their daily lives with ataxia. Some objects were assistive devices, step stools, and poetry. This worked out very well, and we hope it can continue to be a segment of every meeting. Doing this encourages participation among group members and gives us all the opportunity to use each other as resources.

We plan to have guest speakers for our next meeting.

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Northeast Florida Support Group Update

By McGready Kelso

The Northeast Florida Support Group had another great meeting at Baptist Hospital South. Our meeting was held on May 14 at 1:30 p.m. with 15 members in attendance. Group members introduced themselves and welcomed two newcomers. The group discussed the type of ataxia each member has, the onset of their disease, medications prescribed, and to which doctor each goes.

Other discussion topics included the latest on stem cell research and adapting to changes as the disease progresses. Steve Brown strongly encouraged everyone who had not signed up for the National Ataxia Registry to do so.

The next topic of business was assigning a guest speaker coordinator for our group. Wayne Mayo was appointed to this new position. At the close of the meeting two members were invited to discuss briefly the pros and cons of their new Dashaway Walker. After the meeting, all members were invited to gather at Applebee's to talk and enjoy the company of new and old friends, family and significant others.

Our next meeting will be held on Saturday, August 13, at 1:30 p.m. at Baptist Hospital South.

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The deadline for the Fall issue of Generations is August 12

NAF Directory of Chapters, Support Groups and Ambassadors

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

If you or a loved one has been newly diagnosed with ataxia, please contact the NAF leader nearest you. If there is not a group in your area, we encourage you to visit our online social networks. You may also consider starting a support group in your area or becoming an NAF ambassador. If you are interested in these volunteer positions please contact Lori Shogren of the NAF staff at *lori@ataxia.org* or (763) 553-0020.

The use of these names and contact information for any purpose other than requesting information regarding NAF or joining a chapter or support group is strictly prohibited.

Social Networks

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

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

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

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

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

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Calendar of Events

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

SUPPORT GROUP MEETINGS

— Saturday, July 9 —

Central Texas Ataxia Support Group Meeting

Time: 11 a.m. – 1:30 p.m.

Location: The Dell Children's Medical Center of Central Texas, 4900 Mueller Blvd., Austin, TX 78723.

Details: We will meet in Central Conference Room 4E.031 A&B (located between 4N&4C) on the fourth floor. The medical center's main number is (512) 324-0000. For more information contact Linda Crawley at (512) 635-9478 or *calebsnana2@msn.com*. *www.ataxia.org/chapters/Linda/default.aspx*

Los Angeles Area Ataxia Support Group Annual Barbecue

Time: 2 p.m. – 4 p.m.

Details: For meeting location and general information, contact Sherry McLaughlin at (626) 791-1558 or *ccherilynmc@yahoo.com*. *www.ataxia.org/chapters/LosAngeles/default.aspx*

North Texas Ataxia Support Group Meeting

Time: 10 a.m. – noon

Location: The Las Colinas Cancer Center, 7415 Las Colinas Blvd. Irving, TX. Parking is free and the building is handicap accessible. We meet in the front lobby of the Las Colinas Cancer Center. There is a map on their website *www.LasColinasCancerCenter.com*.

Details: Most of the meeting time is for sharing and asking questions. Occasionally we have an outside speaker address concerns from the caregivers, patients and families. For additional information contact David Henry Jr. at *cheve11e@sbcglobal.net*. Check our web page for updates. *www.ataxia. org/chapters/NorthTexas/default.aspx*

Northern California Ataxia Support Group Meeting

Time: 11:30 a.m.

Location: Our Savior's Lutheran Church (Recreation Hall) 1035 Carol Lane, Lafayette, CA. Phone: (925) 516-6906.

Details: For registration information contact Mike Fernandes at (925) 516-6906 or *fernandesml@comcast.net*. *www.ataxia.org/chapters/NorthernCalifornia/default.aspx*

San Diego Ataxia Support Group Meeting

Time: 1 p.m. – 3 p.m.

Location: Sharp Rehabilitation Center, 2999 Health Center Dr. On the East side of Hwy 163 between Genessee Ave. and Mesa College Dr. behind Sharp Memorial Hospital. There is plenty of free parking.

Details: For more information contact Earl McLaughlin at (619) 447-3753 or *sdasg@cox.net*. *www.ataxia.org/chapters/SanDiego/default.aspx*

Southeast Pennsylvania Ataxia Support Group Meeting

Time: 10 a.m. – 11:30 a.m.

Location: Mercy Suburban Hospital at the Walkup room on the second floor. The meeting is followed by lunch at Applebee's across the street.

Details: Attendees must RSVP to Liz Nussear by Friday before the meeting at (610) 272-1502 or *lizout@aol.com*. *www.ataxia.org/chapters/SEPennsylvania/default.aspx*

West Central Florida Ataxia Support Group Meeting

Time: 12 p.m. – 3 p.m.

Location: USF Morsani Center, 3000 Medical Park Drive (MDC 25) Tampa, FL 33613.

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

— Wednesday, July 13 —

Willamette Valley Ataxia Support Group Meeting

Time: 11:30 a.m. – 1 p.m.

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

Details: For more information contact Ivy Stilwell at (541) 812-4162 or *istilwell@samhealth.org*. *www.ataxia.org/chapters/Willamette/default.aspx*

— Thursday, July 14 —

Tri-State Ataxia Support Group Meeting

Time: 6 p.m. – 8 p.m.

Location: Beth Israel, Phillips Ambulatory Care Center (PACC), second floor conference room #3, 10 Union Square, New York, NY.

Details: For more information contact Denise Mitchell at (212) 844-8711 or *markmeghan@* ⏩

aol.com. *www.ataxia.org/chapters/Tri-State/default.aspx*

— Saturday, July 16 —

Central New York Ataxia Support Group Meeting

Time: 1 p.m. – 3 p.m.

Location: North Syracuse Community Center.

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

Denver Area Ataxia Support Group Meeting

Time: 1 p.m. – 4 p.m.

Location: Swedish Medical Center, 501 E Hampden Ave., Englewood, CO 80113. Meeting Room: Spruce A & B.

Details: For more information contact Charlotte Depew at (720) 379-6887 or *cldepew77@comcast.net*. *www.ataxia.org/chapters/Denver/default.aspx*

Greater Atlanta Ataxia Support Group Meeting

Time: 1 p.m.

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

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

Twin Cities Ataxia Support Group Meeting

Time: 10 a.m.

Location: The Presbyterian Homes of Roseville at 1910 West County Road D, Roseville, MN 55112.

Details; For more information contact Lenore Healey Schultz at *schultz.lenore@yahoo.com*. *www.ataxia.org/chapters/TwinCities/default.aspx*

— Sunday, July 17 —

Chicago Area Ataxia Support Group Meeting

Time: 1 p.m.

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

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

— Saturday, July 23 —

Detroit Area Ataxia Support Group Meeting

Time: 1 p.m. – 4 p.m.

Location: Harper University, 3990 John R, Detroit 48201. Wertz Classroom 1237, near the main entrance off of John R.

Details: For more information contact Tanya Tunstull at (313) 736-2827 or *tinyt48221@yahoo.com*. *www.ataxia.org/chapters/Detroit/default.aspx*

— Sunday, July 24 —

New England Ataxia (North Shore) Support Group Meeting

Time: 1 p.m. – 3 p.m.

Location: The food court of the North Shore Mall in Peabody, MA.

Details: These coffee club meetings are very casual. We just meet and chat over lunch. Everyone is welcome to attend. For more information contact Donna Gorzela at (978) 475-8072. *www.ataxia.org/chapters/NewEngland/default.aspx*

— Saturday, August 6 —

Central Texas Ataxia Support Group Meeting

Time: 11 a.m. – 1:30 p.m.

Location: The Dell Children's Medical Center of Central TX, 4900 Mueller Blvd., Austin, TX 78723.

Details: We will meet in Central Conference Room 4E.031 A&B (located between 4N&4C) on the fourth floor. The medical center's main number is (512) 324-0000. For more information contact Linda Crawley at (512) 635-9478 or *calebsnana2@msn.com*. *www.ataxia.org/chapters/Linda/default.aspx*

— Wednesday, August 10 —

Willamette Valley Ataxia Support Group Meeting

Time: 11:30 a.m. – 1 p.m.

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

Details: For more information contact Ivy Stilwell at (541) 812-4162 or *istilwell@samhealth.org*. *www.ataxia.org/chapters/Willamette/default.aspx*

— Saturday, August 13 —

Kansas City Area Ataxia Support Group Meeting

Time: 2 p.m. – 4 p.m.

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

Details: For more information contact Lois Goodman at (816) 257-2428 or Jim Clark at (816) 468-7260 or *clarkstone9348@sbcglobal.net*. *www.ataxia.org/chapters/KansasCity/default.aspx*

North Texas Ataxia Support Group Meeting

Time: 10 a.m. – noon

Location: The Las Colinas Cancer Center, 7415 Las Colinas Blvd. Irving, TX. Parking is free and the

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Calendar of Events
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building is handicap accessible. We meet in the front lobby of the Las Colinas Cancer Center. There is a map on their website *www.LasColinasCancerCenter.com*.

Details: Most of the meeting time is for sharing and asking questions. Occasionally we have an outside speaker address concerns from the caregivers, patients and families. For additional information contact David Henry Jr. at *cheve11e@sbcglobal.net*. Check our web page for updates. *www.ataxia. org/chapters/NorthTexas/default.aspx*

Northeast Florida Ataxia Support Group Meeting

Time: 1:30 p.m.

Location: Baptist Hospital South. Directions to Baptist South: From I95, take exit 335 which is Old St. Augustine Rd. Go East. Follow the signs to the hospital. We are less than half a mile off of the interstate. Directions to the conference rooms from the main entrance: come in the main entrance and make a right. Go past the first hallway on the left and the Azalea, Begonia and Camellia conference rooms will be the next doors. All meetings will be in the Azalea and Begonia rooms.

Details: For more information please contact Ann Mayo at *annwaynemayo@bellsouth.net* or (904) 471-4579. *www.ataxia.org/chapters/NortheastFlorida/default.aspx*

San Diego Ataxia Support Group Picnic

Details: For more information contact Earl McLaughlin at (619) 447-3753 or *sdasg@cox.net*. *www.ataxia.org/chapters/SanDiego/default.aspx*

— Saturday, August 20 —

Greater Cincinnati Area Ataxia Support Group Meeting

Time: 1 p.m. – 3 p.m.

Location: Meeting room in the Groesbeck Branch of the Cincinnati Public Library at 2994 W. Galbraith Rd. Cincinnati, OH, phone (513) 369-4454 *www.cincinnatilibrary.org/branches/groesbeck.html*

Details: For more information contact Jennifer Mueller at *jenmu@yahoo.com*.

Orange County Ataxia Support Group Meeting

Time: 1:30 p.m. – 4 p.m.

Location: Orange Coast Memorial Medical Center (Breast Center Bldg, Room 1A), 9900 Talbert Ave., Fountain Valley, CA 92708.

Details: For more information contact Daniel Navar at *dnavar@ucla.edu*. *www.ataxia.org/chapters/OrangeCounty/default.aspx*

Twin Cities Ataxia Support Group Meeting

Time: 10 a.m.

Location: The Presbyterian Homes of Roseville at 1910 West County Road D, Roseville, MN 55112.

Details: For more information contact Lenore Healey Schultz at *schultz.lenore@yahoo.com*. *www.ataxia.org/chapters/TwinCities/default.aspx*

— Sunday, August 21 —

New England Ataxia (North Shore) Support Group Meeting

Time: 1 p.m. – 3 p.m.

Location: In the food court of the North Shore Mall in Peabody, MA.

Details: These coffee club meetings are very casual. We just meet and chat over lunch. Everyone is welcome to attend. For more information contact Donna Gorzela at (978) 475-8072. *www.ataxia.org/chapters/NewEngland/default.aspx*

— Saturday, August 27 —

Tarheel North Carolina Ataxia Support Group Meeting

Time: 1 p.m. – 3 p.m.

Location: Wake Forest Baptist Medical Center in the Hanes Shopping Mall (upper level), Winston-Salem, NC.

Details: Pre-register by calling Best Health at (336) 713-2378. For more information contact Jerry Hauser at *deaconwfu@msn.com* or (336) 998-2942.

— Saturday, September 3 —

Central Texas Ataxia Support Group Meeting

Time: 11 a.m. – 1:30 p.m.

Location: The Dell Children's Medical Center of Central TX, 4900 Mueller Blvd, Austin, TX 78723.

Details: We will meet in Central Conference Room 4E.031 A&B (located between 4N&4C) on the fourth floor. The medical center's main number is (512) 324-0000. For more information contact Linda Crawley at (512) 635-9478 or *calebsnana2@msn.com*. *www.ataxia.org/chapters/Linda/default.aspx*

West Central Florida Ataxia Support Group Meeting

Time: 12 p.m. – 3 p.m.

Location: USF Morsani Center, 3000 Medical Park Drive (MDC 25).

Details: IAAD Activity Planning. For more information please contact Cindy Steever-Ziegler at ▸▸

(239) 878-3092 or *csteever@msn.com*. *www.ataxia.org/chapters/TampaBay/default.aspx*

— Saturday, September 10 —

Detroit Area Ataxia Support Group Meeting

Time: 1 p.m. – 4 p.m.

Location: Harper University, 3990 John R, Detroit, MI 48201 in Wertz Classroom 1237, near the main entrance off of John R.

Details: For more information contact Tanya Tunstull at (313) 736-2827 or *tinyt48221@yahoo. com*. *www.ataxia.org/chapters/Detroit/default.aspx*

Los Angeles Area Ataxia Support Group Meeting

Time: 2 p.m. – 4 p.m.

Details : We meet the second Saturday of every other month. For meeting location and general information, contact Sherry McLaughlin at (626) 791-1558 or *ccherilynmc@yahoo.com*. *www.ataxia.org/chapters/LosAngeles/default.aspx*

North Texas Ataxia Support Group Meeting

Time: 10 a.m. – noon

Location: The Las Colinas Cancer Center, 7415 Las Colinas Blvd. Irving, TX. Parking is free and the building is handicap accessible. We meet in the front lobby of the Las Colinas Cancer Center. There is a map on their website *www.LasColinasCancerCenter.com*.

Details: Most of the meeting time is for sharing and asking questions. Occasionally we have an outside speaker address concerns from the caregivers, patients and families. For additional information contact David Henry Jr. at *cheve11e@sbcglobal.net*. Check our web page for updates. *www.ataxia. org/chapters/NorthTexas/default.aspx*

Southeast PA Ataxia Support Group Meeting

Time: 10 a.m. – 11:30 a.m.

Location: Mercy Suburban Hospital, Walkup room on the second floor. The meeting is followed by lunch at Applebee's across the street.

Details: Attendees must RSVP to Liz Nussear by Friday before the meeting at (610) 272-1502 or *Lizout@aol.com*. *www.ataxia.org/chapters/SEPennsylvania/default.aspx*

— Wednesday, September 14 —

Willamette Valley Ataxia Support Group Meeting

Time: 11:30 a.m. – 1 p.m.

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

Details: For more information contact Ivy Stilwell at (541) 812-4162 or *istilwell@samhealth.org*. *www.ataxia.org/chapters/Willamette/default.aspx*

— Thursday, September 15 —

Tri-State Ataxia Support Group Meeting

Time: 6 p.m. – 8 p.m.

Location: Beth Israel, Phillips Ambulatory Care Center (PACC), 2nd floor conference room #3, 10 Union Square, New York, NY.

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

— Sunday, September 18 —

Chicago Area Ataxia Support Group Meeting

Time: 1 p.m.

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

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

— Saturday, September 24 —

Alabama Ataxia Support Group Meeting

Time: 10 a.m. – 2 p.m.

Location: Covenant Presbyterian Church, Homewood, AL.

Details: For more information please contact Becky Donnelly at (205) 987-2883 or *donnelly6132B@aol.com*. *www.ataxia.org/chapters/Birmingham/default.aspx*

AWARENESS & FUNDRAISING EVENTS

— Saturday, August 27

Macy's Shop for a Cause

Purchase a "Macy's Shop for a Cause" discount card today for $5 and help the National Ataxia Foundation. This special discount card gives you access to a special one-day-only sales event at Macy's stores nationwide on Saturday, August 27. NAF will sell the cards until August 12. To purchase your discount card today you can order online through NAF's online store at *www.ataxia.org/macyscard* or by sending a check made payable to the National Ataxia Foundation, 2600 Fernbrook Lane, Suite 119, Minneapolis, MN 55447. Write "Macy's Card" in the memo line. You may also call the NAF office at (763) 553-0020 to place an order or for more information.

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Calendar of Events
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— Saturday, September 10 —

Biking with Ataxia

Time: 10 a.m.

Location: Palisades Interstate Park, Henry Hudson Drive, Fort Lee, New Jersey. The ride will start and end at the Ross Dock Picnic Area of Palisades Interstate Park in the shadow of the George Washington Bridge on the New Jersey side.

Details: Participants will pedal through the beautiful, but little known Palisades Interstate Park, over hill and dale with the combined purpose of raising ataxia awareness and research funds to help support the important work of the National Ataxia Foundation (NAF). The ride will be held rain or shine. The route is about 53 miles long and will take six to nine hours to complete.

Event Registration: To register for Biking with Ataxia visit *www.active.com/cycling/fort-lee-nj/biking-with-ataxia-2011* or the events website *http://BikingwithAtaxia.blogspot.com*. The registration fee is $40. There is a minimum fundraising commitment of $200 per participant. To start fundraising for this event please register on the event donation website *https://naf.myetap.org/bikeataxia/* to create your fundraising page and set your fundraising goal.

Contact: For volunteer and sponsorship opportunities contact Adam Payne, the ride organizer at *BikingwithAtaxia@gmail.com*. *http://BikingwithAtaxia.blogspot.com*

— Saturday, September 17 —

2nd Annual Minnesota Walk, Stroll n' Roll for Ataxia

Time: 9 a.m. – noon

Location: Wolfe Park in St. Louis Park, MN.

Details: All proceeds benefit the National Ataxia Foundation. To volunteer or for more information please contact Tom Sweeney at *gracieggb@msn.com*. *https://naf.myetap.org/11mnwnr/*

— Sunday, September 18 —

Auburn Walk n' Roll for Ataxia

Time: 10 a.m. – noon

Location: Lamanski Park (Rocketland) in Auburn, MA

Details: Event registration is free and all registrants receive an event t-shirt. Come and learn about ataxia while having fun raising funds for NAF. To volunteer or for more information please contact John Mauro at *jmauro@hanover.com* or (508) 736-6084. *https://naf.myetap.org/fundraiser/11MAwnr/*

— Friday, September 23 —

Golf 4 Ataxia

Time: 1 p.m. (tee time)

Location: Forrest Crossing Golf Course, 750 Riverview Dr., Franklin, TN 37064.

Details: The event entry fee is $100 and includes dinner, green fees, and cart. Prizes will be given for Longest Drive/Putt and Closest to the Pin. We appreciate silent auction donations and volunteers. Hole Sponsorship is available. For volunteer or sponsorship opportunities contact Jay Tyler at (615) 260-3968 or Vicki Tyler at (615) 496-3110. All proceeds benefit the National Ataxia Foundation. *https://naf.myetap.org/11Golf/*

— Saturday, September 24 —

1st Annual Denver Run, Walk n' Roll for Ataxia

Time: 9 a.m. – noon

Location: Denver City Park, 17th St. & York St., Denver, CO.

Details: Event registration is free. All proceeds benefit the National Ataxia Foundation. To volunteer or for more information please contact Keri Naccarato at *kfragola@yahoo.com* or (720) 982-9562. *https://naf.myetap.org/fundraiser/11COwnr/*

3rd Annual Central Texas Walk n' Roll for Ataxia

Time: 9 a.m.

Location: San Gabriel Park, Georgetown, TX.

Details: Registration is $25 and includes an event t-shirt. If you have any questions, comments, or suggestions please contact Linda Crawley at *lcrawley57@gmail.com* or (512) 635-9478. *https://naf.myetap.org/11TXWnR/*

3rd Annual Los Angeles/Orange County Walk n' Roll for Ataxia

Location: Long Beach Shoreline Park.

Details: All proceeds benefit the National Ataxia Foundation. For more information Contact Daniel Navar at *dnavar@ucla.edu*. *https://naf.myetap.org/11OCLAWnR/*

6th Annual San Diego Walk n' Roll for Ataxia

Time: 8 a.m.

Location: Tuna Harbor Park, San Diego, CA.

Details: All proceeds benefit the National Ataxia Foundation. To volunteer or for more information contact Earl McLaughlin at (619) 447-3753 or *sdasg@cox.net. https://naf.myetap.org/11SDWnR/*

3rd Annual Detroit Walk n' Roll for Ataxia

Time: On-site registration 9 a.m. – 11 a.m.

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Location: William G. Miliken State Park (1900 Atwater, between Orlean and St. Aubin)

Details: All proceeds benefit NAF. Receive a Walk n' Roll t-shirt with $25 registration fee. Walk begins at 11 a.m. followed by a raffle and picnic. To volunteer or for more information, contact Tanya Tunstull at *tinyt48221@yahoo.com* or (313) 736-2827. *https://naf.myetap.org/fundraiser/11Detroitwnr/*

— Sunday, September 25 —

International Ataxia Awareness Day (IAAD)

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

Saturday, October 1

3rd Annual Seattle Walk n' Roll for Ataxia

Time: 9 a.m. – 1 p.m.

Location: Alki Beach Park, Seattle WA

Details: Registration is $25. Free commemorative t-shirt for each registered participant. To volunteer or for more information contact Milly and Tony Lewendon at *ataxiaseattle@comcast.net*. *https://naf.myetap.org/fundraiser/11SeattleWnR/*

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Memorials and In Your Honor

The National Ataxia Foundation is grateful to those who have made contributions in memory or in honor of their friends and families whose names are listed below. This list reflects contributions made from March through May 2011. 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.

Verne Apke
Alex Atzeff
Paul Aust
Maria Avelar
Charles Balogh
Subhash Batra
Betty Beck
Clair Beck
Philip Bennett
Mary Bircher
Stephanie Blake
Alec Brown
Marty Burke
Collin Capistraint
Brielle Caruso
John Caruso
Rebecca Cockrell
Robert Coffey, Sr.
Judith Coleman
Rose Constance
Kim Cook
Jackie Cowan
Robert Currier
Theresa DelSecco
Raffaela Deluca
Bonita DeTata
Jillian Detherage
Wade Doares
Barbara Doogan
Dawn Dudley
William Dugal, Jr.
Richard Eustache
Larry Federspiel
Stephanie Fojtik
Gregson Gann
Peggy Golminas
Fred Gooch
Givens Goodspeed
Israel Green
Wolfie Green
Charles Greener
Chuck Greener
George Hacke
Jenice Harris
Richard Hinman
Lynda Howell
Lloyd Howell
Krista Humes
Robert Jackman
Lisa Jaffe
Florence Jensen
Jesse Jerke
Elizabeth Johnson
Jamie Kosieracki
Richard Lewis
Rita Powell-Lobascio
Machado Family
Amy Maranowicz
Zoltan Mari
Lawrence Massanova
Brent Masserant
Bob McCleery
Robert McCleery
Bill McCorkle
Kimberly McCorkle
William McCorkle
Charley McLaughlin
Earl McLaughlin, Jr.
Patricia Messigian
Vergie Miller
Jack Moore
Jackie Moore
Patrick Moore
Daniel Navar
Louis Neuendorf
Matthew Oetting
Trent Pavelec
Tyrell Pavelec
Alyn Platt
Rolando Ramos
Janet Riley
DeNiece Roach
Hoy Robinson
Nathan Robinson
George Rody, Jr.
Michael Rooth
Liana Rosenthal
Sally Ross
Melanie Rosthauser
Thomas Sander
Joseph Savitt
Ankita Saxena
Anne Schumacher-Vaphiadis
Robin Schwagerman
Derek Semler
Francine Shriber
Arlie Smith
Shawn Smyth
Joseph Stamer
Douglas Statham
Linda Talt
Christopher Tatti
Tommy Tatum
Joe Thell
Alan Tindal
M/M Tony Trinta
James Torres
Margaret Tseng
Rudy Van't Hoff
Daryl Walton
Matt Wassiety
Randall White
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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 special occasions like birthdays, graduations, anniversaries, and holidays. NAF will acknowledge your gift without reference to the amount.

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

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

My contribution is:

☐ In Memory ☐ In Honor ☐ Gift Membership

Name ____________________
Occasion ____________________

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

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

MEMBERSHIP

Yes, I want to help fight ataxia! Enclosed is my membership donation. *(Gifts in US Dollars)*

☐ Lifetime membership	$500
Annual memberships:	
☐ Patron membership	$100-$499
☐ Professional membership	$55
☐ Individual	$35
☐ Household	$55

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

Name ____________________
Address ____________________
City/State/Zip ____________________
Phone ____________________
E-Mail ____________________

☐ *Yes, sign me up for NAF e-mails*

PAYMENT INFORMATION

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

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

Total Amount Enclosed $ ____________________
Credit Card: ☐ Visa ☐ MasterCard ☐ Discover
Name on Card ____________________
Card # ____________________
Exp. Date ____________________
Signature ____________________
Phone Number ____________________