As the National Ataxia Foundation enters its 55th year in serving ataxia families, the main focus and purpose of the Foundation as envisioned by its founder Dr. John W. Schut remains the same, supporting promising ataxia research and providing meaningful programs and services to ataxia families.

The National Ataxia Foundation was founded on the belief that working together, ataxia families, clinicians, researchers, and others can accomplish great things. Although the road the organization has traveled throughout its history has been challenging, its mission has always been clear. Here is our journey…

Thirteen people attended the organizational meeting of the National Ataxia Foundation on April 8, 1957. The first Officers included President Ellis J. Sherman, Vice President and Secretary Henry Schut, and Treasurer Robert Van Hauer. Dr. John W. Schut was appointed as the first Medical Director.

The first Annual Membership Meeting of the National Ataxia Foundation was held on April 16, 1958 in Minnesota. Nine of the 13 members were present. Three more were elected to the membership. Today, the NAF Annual Membership Meeting attendances range between 500 and 700 people from throughout the United States and other countries.

The National Ataxia Foundation struggled in the early years in terms of funding and creating ataxia awareness. However, in 1970, the Foundation offered its first ataxia clinic. Drs. Roger Rosenberg, Larry Schut, and William Nyhan participated in this first ataxia clinic in Sioux Falls, South Dakota on December 13, 1970. 95 people attended this clinic and 33 were examined. WCCO TV, based in Minneapolis, Minnesota, covered the clinic and aired a story about ataxia. The three doctors were invited to New York City for a press conference which was...
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Disclaimer
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The deadline for the Fall issue of Generations is August 10.
55 Years of Serving the Ataxia Community
Continued from page 1

attended by Time, Life, and the Associated Press. Time published an article on January 25, 1971 which resulted in letters pouring in from ataxia families across the country. NAF continued to sponsor ataxia clinics, free of charge, to patients throughout the 1970s and 80s. This multidisciplinary approach to ataxia clinics was a model for others to follow years later.

1971 saw a re-structuring and formation of the Medical and Research Advisory Board. In 1971 this advisory board totaled seven members. Today, this international roster of world-leading ataxia clinicians and scientists total over 25 members. In 1971 NAF introduced its first newsletter, “Light House News,” which became a quarterly newsletter in 1974. Today, the four-page “Light House News” has been replaced by the 48-page quarterly news publication “Generations.” Also in 1974, NAF offered its first brochure on ataxia.

Today, the Foundation is a world leader in providing current and accurate information through its many publications, books, videos, and web site.

On February 19, 1972 the 15th Annual Membership Meeting was held in Minneapolis. There were 38 members who attended the annual membership meeting. This was the same day of Dr. John W. Schut’s funeral, one of the original founders of the Foundation.

NAF’s first ataxia research symposium was held in Minneapolis on November 24, 1975, bringing researchers together to help accelerate ataxia research. These research symposiums continued throughout the 1970s, 80s and 90s and was the foundation for the establishment of NAF’s International Ataxia Investigators Meetings (AIM), which are offered every other year and bring together 120-140 leading ataxia clinicians and scientists from around the world to help accelerate world-wide ataxia research.

Funding challenges continued to face NAF with total contributions in 1976 of $41,350 compared to $6,537 in 1972. In 1978 the first ataxia research grant awarded by NAF was given to Dr. Robert Currier from Mississippi in the amount of $5,000. Two research grants were awarded in 1979, one grant to Dr. Currier in the amount of $3,250 and the other research grant to Dr. Kark in the amount of $2,500. Today, the Foundation offers five research programs and has funded millions of dollars over the past 13 years to more than 171 promising ataxia research studies in 13 countries. For fiscal year 2012, NAF made funding commitments for 19 research studies totaling nearly $900,000.

In 1982 the first annual membership meeting located outside of Minnesota was held in Jackson, Mississippi on February 20 celebrating the Foundation’s 25th year. Since that time the annual membership meetings have been held throughout the United States. The 40th annual membership meeting was held on February 14-16, 1997 in Jackson with an attendance of 357. The 50th annual membership meeting was held in Memphis, Tennessee, with attendance nearing 500. Attendance at the annual membership meetings continued to grow over the years, with members attending from as far away as England, Hong Kong, and Australia.

The National Ataxia Foundation is able to continue to support promising ataxia research and offer meaningful programs and services for ataxia families because of the kindness and generosity of our donors and volunteers. We gratefully acknowledge their tremendous contribution in these efforts. The vision of our original founders has been our guiding path as we journey forward to end ataxia.

Dr. John W. Schut
The NAF Board of Directors along with the Northeast Regional Support Groups would like to invite you to attend the

**National Ataxia Foundation**

**56th Annual Membership Meeting**

**March 15-17, 2013**

---

Join us in Detroit for the Annual Membership Meeting!

The Detroit Marriott at the Renaissance Center is pleased to provide the facilities for the 2013 National Ataxia Foundation Annual Membership Meeting. The Detroit Marriott is situated on the River Walk in downtown Detroit, overlooking the Detroit River and Canada, with easy access to shopping, restaurants, entertainment, and the People Mover.

— The NAF Group Rate at the Detroit Marriott is $139 + tax —

**For accessible rooms:** Reservations for accessible rooms begin on July 16 at Noon Central Daylight Time. You MUST contact the NAF office at (763) 553-0020 or lori@ataxia.org. Accessible room requests will be responded to in the order they are received. Accessible room requests received prior to Noon Central Daylight Time on July 16 will not be honored.

**For standard rooms:** Please visit the NAF group reservation website: [https://resweb.passkey.com/Resweb.do?mode=welcome ei_new&eventID=9525602](https://resweb.passkey.com/Resweb.do?mode=welcome ei_new&eventID=9525602) or call 1-877-901-6632 and request the National Ataxia Foundation group rate.

For more information on Detroit visit [www.visitdetroit.com](http://www.visitdetroit.com). For the latest information on reservations, conference registration, schedules, and area information, keep checking the National Ataxia Foundation website, [www.ataxia.org](http://www.ataxia.org).
For two-and-one-half days in March over 100 ataxia researchers from all over the world gathered in San Antonio, Texas to create a forum for presenting the latest developments in translational research on ataxia by senior and selected junior investigators.

The fourth annual event, entitled “Advancing Toward Therapeutics,” had three primary goals:
1) Identify common disease mechanisms;
2) Explore therapeutic strategies; and
3) Help establish future leaders of ataxia research.

Thirteen countries were represented, including Australia, Canada, France, Germany, Ireland, Israel, Japan, Netherlands, Portugal, South Africa, Sweden, the United Kingdom, and the United States.

The themes for this year’s meeting were:
• Cerebellar function and dysfunction in ataxia
• Pathogenesis of dominant ataxias
• Pathogenesis of recessive and other ataxias
• Toward therapies through disease mechanisms
• Working together to advance ataxia research and therapy

This important meeting could not have happened without the support of the following:
• An anonymous donor
• ApoPharma, Inc.
• Ataxia UK
• Ataxia Ireland
• Athena Diagnostics, Inc.
• A-T Children’s Project
• Bob Allison Ataxia Research Center (BAARC)
• Friedreich’s Ataxia Research Alliance (FARA)
• The Gordon and Marilyn Macklin Foundation
• National Institute of Neurological Disorders and Stroke (NINDS)
• Office of Rare Disease Research (ORDR)

We are grateful for the excellent leadership of Dr. Henry Paulson and Dr. Christopher Gomez, who served as Co-Organizers.

Over 100 ataxia researchers from around the world gathered for the 2012 Ataxia Investigators Meeting.

Fall Deadline
The deadline for submitting materials for the Fall issue of Generations is August 10. Please send stories, events and reports by e-mail to naf@ataxia.org or by mail to the NAF office address listed on page 2.
Johns Hopkins Ataxia Center Update

The Ataxia Center at Johns Hopkins was launched in early 2008 with initial support from the National Ataxia Foundation in collaboration with the Chesapeake Chapter-NAF through the generosity of the Gordon and Marilyn Macklin Foundation.

This multidisciplinary clinic provides patients with resources that include genetic counseling, physical therapy/occupational therapy, speech therapy, radiology, clinical counseling, supportive counseling, and the opportunity to participate in research. Patients are drawn from a large geographical area. The Ataxia Center is a patient care and clinical research institution, launched with the aim of providing comprehensive treatment to patients with ataxia.

The Ataxia Center at Johns Hopkins focused on patient care, outreach, and research. With this report we aim to provide an overview of the accomplishments of the Ataxia Center over the past few years and future directions for the center.

**Patient Care**

Our physicians saw 168 patients in 2011 and have conducted a total of 434 visits since the opening of the center in 2008. Many patients follow up with repeat appointments. Patients seen at the Ataxia Center come from a large geographical distribution and have 11 different, documented causes for their ataxia that we are able to test for, with the majority of the patients having an unknown cause for their ataxia.

**Outreach**

The ataxia center seeks to educate and support the ataxia community while building awareness of ataxia among the general population. The ataxia center conducts support group meetings every other month that attract 20–60 people and continue to gain popularity. Guest speakers are invited to share expert knowledge on key patient concerns – past meetings have covered everything from composing wills to practicing yoga. The center also hosts an annual ataxia picnic for patients of the center.

**Research**

Our ataxia researchers are conducting studies to better understand ataxia. Current research includes two studies aimed at tracking the progression of hereditary ataxias (contact Ann Fishman at mefc41@jeshmail.johnshopkins.edu), a motor control study, and a study of eye movements in patients with ataxia (contact Michelle Harran at michelleharran@gmail.com). Additionally, the center helps contribute to a database created at UCLA by Dr. Susan Perlman and her team. To date we have input medical data from 57 of our patients into the database.

**Future Directions**

The Ataxia Center will continue to strive for excellence in patient care, outreach, and research. In the coming years we seek to increase the center’s capacity to see patients, to work closer with partners in the community, and to further our involvement in ataxia research.

If anyone with ataxia desires an evaluation or has ideas for additional ways we may be of service to the community, please contact Ataxia Center coordinator Jillian Detherage at jdether1@jhmi.edu or (410) 955–4894.
Remembering Donna Gruetzmacher

It is with great sadness that we report to you that Donna Gruetzmacher, former Executive Director of the National Ataxia Foundation, passed away on May 14. Donna Mae Gruetzmacher was born in Hutchinson, Minnesota. She received her education in Cosmos, Minnesota and was a graduate of Cosmos Consolidated Schools. Donna furthered her education at Fairview Hospital Nursing School in Minneapolis and graduated in 1963, with a nursing degree.

Donna Gruetzmacher began as NAF’s Patient Services Director in the early 1970’s. In 1986 she was hired as the Foundation’s Executive Director, a position she held until her retirement in 2004.

Many of you remember Donna from past Annual Membership Meetings and other NAF functions. Others who may not have known her should know that Donna was a kind and generous person who placed the welfare of ataxia families above anything else. Fairness, honesty and organizational integrity were her guide and counsel.

Through Donna’s leadership, the Foundation saw tremendous growth in terms of both research and services. During her watch, the Foundation established two additional ataxia research programs which have brought NAF to the forefront in ataxia research.

Through her involvement, NAF’s quarterly news publication, Generations, grew from a four-page newsletter to a 48-page quarterly news publication.

Her commitment to the NAF Annual Membership Meetings brought ataxia families together from across the United States and beyond to share, learn, connect, and network. Her work was profound and impacted many ataxia families.

Donna is survived by her husband Arnie Gruetzmacher, who has been involved with the National Ataxia Foundation since the early 1970s as the past President and currently serves on the NAF Board of Directors and Executive Committee.

Donna was a wonderful friend, partner, and ally to ataxia families throughout her career. Our heartfelt condolences go out to Arnie Gruetzmacher, family and friends. Donna will be truly missed.

Employer Matching Gift Program

Many employers sponsor matching gift programs and will match any charitable contributions made by their employees to the National Ataxia Foundation. Please check with your Human Resources department and ask if your company matches employee donations.

If your company offers this program, request a matching gift form from your employer, and send it completed and signed with your gift. We will do the rest. Your gift to the Foundation may be doubled or possibly tripled depending upon your company’s policies. Some companies match gifts include contributions made by retirees or spouses, as well as volunteer hours.

NAF receives matching gifts from companies all over the country because of the generosity of our donors. Sometimes the matching gift is $2,000 or more. Please encourage your co-workers to also contribute. Their gifts will also double through the matching gift program. Thank you to all the donors who have already given and to the companies who have matched their gifts.
Events and Fundraisers for International Ataxia Awareness Day

International Ataxia Awareness Day (IAAD) will be celebrated on Tuesday, September 25. This day is an international effort from ataxia organizations around the world to raise ataxia awareness. Each participating country, state, or individual may have a specific plan for this event.

For more details and links, please visit the NAF event calendar at www.ataxia.org.

3rd Annual 2011 Virtual Walk N’ Roll for Ataxia

Now through September 25, 2012

Visit the Virtual Walk N’ Roll web page at https://naf.myetap.org/12vwmr/ and click “register” to join us in raising funds to help support the important work of the National Ataxia Foundation.

After you register through the event website 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 on the event website. 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. All proceeds benefit the National Ataxia Foundation.

2nd Annual Denver Run, Walk N’ Roll for Ataxia

Sunday, September 9, 2012

8 – 11 a.m. at Denver City Park, 17th Street & York Street, Denver, CO. All participants are requested to donate or raise a minimum of $30. To volunteer or for more information contact Keri Naccarato at kfragola@yahoo.com or (720) 982-9562. All proceeds benefit the National Ataxia Foundation. www.denverataxiawalk.org

Bowling Green Parks & Recreation IAAD Pull Up Competition

Saturday, September 15, 2012

10 a.m. at the City of Bowling Green Fitness Facility, 225 E. Third Ave., Bowling Green, KY. For more information contact Michael Carter at cartermw@yahoo.com.

2nd Annual Auburn Walk N’ Roll for Ataxia

Saturday, September 15, 2012

10 a.m. at the Pappas Recreation Complex, Auburn, MA. To volunteer or for more information please contact John Mauro at johnmauro@verizon.net or (508) 736-6084. All proceeds benefit the National Ataxia Foundation.

2nd Annual Concord Walk, Roll N’ Swim for Ataxia

Saturday, September 15, 2012

9:30 a.m. – 2 p.m. at Montecito Oakmont Senior Living & Newhall Park, 4756 Clayton Rd. & 5000 Newhall Parkway, Concord, CA. For more information contact Brian Petersen at (925) 953-3733 or smileypetersen@yahoo.com. All proceeds benefit the National Ataxia Foundation.
3rd Annual Minnesota Walk, Stroll N’ Roll for Ataxia
Saturday, September 15, 2012

9 a.m. registration (refreshments and social), 10 a.m. walk begins, 10:45 a.m. program (speakers and drawing) at Wolfe Park in St. Louis Park, MN. To volunteer or for more information please contact Terry Sweeney at (612) 760-9320 or mnataxiawalk@yahoo.com. All proceeds benefit the National Ataxia Foundation. https://naf.myetap.org/12MN WNR/

2nd Annual Atlanta Walk N’ Roll for Ataxia
Saturday, September 22, 2012

Registration at 9:30 a.m. and walk 10 a.m. at Shorty Howell Park, 2750 Pleasant Hill Rd., Duluth, GA 30096 (I-85 to Exit 104, traveling southbound turn right or northbound turn left, the park is 1.5 miles on right). Event T-shirt for each participant collecting $50 or more! To volunteer and for more information please contact atlantaataxia@gmail.com or (404) 822-7451. All proceeds to benefit the National Ataxia Foundation. https://naf.myetap.org/12LAOCWNR/

4th Annual LA/OC Walk N’ Roll for Ataxia
Saturday, September 22, 2012

Registration begins at 8 a.m. Walk N’ Roll starts at 9 a.m. at Shoreline Aquatic Park, Long Beach, CA. Reserve your Walk N’ Roll T-shirt by registering early. For more information please contact Daniel Navar at danieln27@gmail.com or (323) 788-7751, Cindy DeMint at (714) 329-4437 or chatdots@sbcglobal.net, or Sherry McLaughlin at (626) 791-1558 or cherilynmc@yahoo.com. All proceeds benefit the National Ataxia Foundation. https://naf.myetap.org/12LAOCWNR/

4th Annual Detroit Walk N’ Roll for Ataxia
Saturday, September 22, 2012

On-site registration 9 – 11 a.m. Walk begins at 11 a.m. followed by Raffle and Picnic. At William G. Miliken State Park, 1900 Atwater (between Orlean and St. Aubin). To volunteer or for more information, contact Tanya Tunstull at tinyt48221@yahoo.com or (313) 736-2827. All proceeds benefit the National Ataxia Foundation. https://naf.myetap.org/12DEPAwrnr/

1st Annual Kansas Walk n’ Roll for Ataxia
September 22, 2012

Location to be announced. For more information contact Jalean Retzlaff at (316) 303-2351 or jlrrolls@yahoo.com.

1st Annual DE/PA Walk, Roll N’ Run for Ataxia
Saturday, September 29, 2012

8:30 a.m. – 1 p.m. at Glasgow Park, 2199 Pulaski Hwy, Newark, DE. To volunteer or for more information please contact Christina Rakshys at (610) 395-6905 or rakshys@ptd.net. All proceeds benefit NAF. https://naf.myetap.org/12DEPAwrnr/

2nd Annual BINGO for Ataxia
Saturday, September 29, 2012

5:30 p.m. at the Berlin Fire Co., 214 N. Main St., Berlin, MD 21811. For more information contact Dana Simpson at dsimpson2478@yahoo.com or (410) 251-2478. All proceeds benefit the National Ataxia Foundation.

Continued on page 10
International Ataxia Awareness Day
Continued from page 9

3rd Annual Tea Time for Ataxia
Saturday, September 29, 2012

Two sittings are available at 11 a.m. – 1 p.m. or 1:30 – 3:30 p.m. at the Aubrey Rose Tea Room, La Mesa, CA. Cost is $35 per person. For more information or to RSVP contact Jane Jaffe at (619) 286-9745 or sicilianmother@cox.net. All proceeds benefit the National Ataxia Foundation.

4th Annual Northern CA Walk N’ Roll & ‘Exercise and Mobility Matters’ Faire
Saturday, September 29, 2012

To expand the purpose of IAAD, the Northern California Ataxia Support Group will be putting on a Faire from 11:30 a.m. – 3 p.m. at the Fellowship Hall on the campus of Our Savior’s Lutheran Church at 1035 Carol Lane, Lafayette, CA. Special guest Dr. Thomas Clouse will be demonstrating his mobility and exercise techniques along with other professionals who work specifically with people with “movement disorders.” Those attending the Faire will be invited to participate. We will have an instructor teaching yoga and chair yoga, a physical therapist, a chiropractor, and a strength trainer, all whom have worked with individuals who have movement disorders.

The Walk N’ Roll will be part of our Faire. Registration for the day will be $25. Lunch will be included in the registration. There will be raffle items to win. The winner of a drawing to win an Apple iPad will be announced.

For more information please contact Joanne Loveland at joanneloveland@gmail.com. All proceeds benefit the National Ataxia Foundation. https://naf.myetap.org/12NCAWnR/

6th Annual San Diego Walk N’ Roll for Ataxia
Saturday, September 29, 2012

Registration from 7 - 8 a.m. Walk starts at 8 a.m. at Tuna Harbor Park (next to the Midway Museum), San Diego, CA. To volunteer or for more information contact the event committee by phone at (619) 442-0415, fax at (619) 442-0592, or by e-mail at sdwnr@ataxia.org. All proceeds benefit the National Ataxia Foundation.

4th Annual Central Texas Walk N’ Roll for Ataxia
Saturday, October 6, 2012

9 a.m. at San Gabriel Park (Area A), Georgetown, TX. 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. All proceeds benefit the National Ataxia Foundation. https://naf.myetap.org/12TXWnR/

4th Annual Dewayne’s Walk, Run N’ Roll for Ataxia
Saturday October 6, 2012

7:30 a.m. at the First Baptist Church, 441 Lewie St, Gilbert, SC 29054. For more information or to volunteer contact Anna Hite at (803) 532-2447 or doca35@att.net. All proceeds benefit the National Ataxia Foundation.

How Did You Participate in IAAD?

The 13th Annual International Ataxia Awareness Day will be held on September 25, 2012. Please document your individual or group efforts to bring ataxia awareness to the public.

Send us your articles, photos, and proclamations so the entire NAF community can relive this historic day in a future issue of Generations.

Please email information to naf@ataxia.org, or mail to NAF, Attn: Generations Editor, 2600 Fernbrook Lane, Suite 119, Minneapolis, MN 55447-4752. Thank you.
The Vexing Ataxia Lexicon

By Brent L. Fogel, MD, PhD

Program in Neurogenetics, Department of Neurology
David Geffen School of Medicine, University of California Los Angeles

“Genetic” means a change in a person’s DNA caused the ataxia to develop. There are also a few diseases where the specific type of ataxia is known, but the actual basis of the disease is still scientifically unclear, such as multiple system atrophy (MSA). Doctors call these diseases “idiopathic.” Lastly, in some patients, a cause is not yet found despite extensive testing. For the time being, the ataxia in these patients can be called “unknown.” An experienced clinician can sort through these possibilities to determine which of these causes need to be looked for in a specific patient and, if possible, assign a specific diagnosis for their ataxia.

3) No one else in my family has cerebellar ataxia. Does that mean it is acquired and not genetic?

Having a history of ataxia in your relatives is a significant clue for doctors that the cause is likely genetic, but not having such a history does not rule it out. Dominant genetic diseases (like the spino-cerebellar ataxias or SCAs), caused by a single copy of a defective gene, are often passed from parent to child, but occasionally the family history is unclear. However, other genetic diseases are recessive (for example, Friedreich ataxia) and require two defective gene copies. In this case, ataxia isn’t seen in the parents because they are “carriers,” and have only one defective copy. This does not mean that every patient with cerebellar ataxia needs genetic
testing, but that question must be answered individually with the aid of an experienced clinician, a (neuro)geneticist, and/or a genetic counselor.

4) Some members of my family have balance problems so does that mean it is definitely genetic and not acquired?

Balance problems are unfortunately quite common and, unless a genetic cause is known within a family, there may be different reasons behind the ataxia in each family member. Furthermore, especially in older adults, acquired and genetic causes can coexist and worsen the symptoms (for example, vitamin B12 deficiency in a person with SCA3). As acquired causes are sometimes treatable, identifying them may help. Finally, knowing the genetic cause of a cerebellar ataxia can be important for participation in clinical treatment trials or research studies.

5) My doctor says I have sporadic cerebellar ataxia. What is that?

When ataxia develops in a person for no obvious reason and there is no obvious family history, doctors may call that “sporadic.” The term describes how the disease arose (“out of the blue”) but says nothing about cause (such as “genetic” or “acquired”). Sometimes the term “sporadic” ataxia is mistakenly used for “unknown” or “idiopathic” ataxia but these are not the same. “Unknown” means the cause has not yet been found (all that is known for sure is the patient has the symptom of cerebellar ataxia). “Idiopathic” means the cause is known but doctors don’t know why it happens (for example, MSA). Sporadic ataxias can be known or unknown. In fact, all acquired ataxias occur sporadically by definition! In some cases, genetic ataxias can also occur sporadically. An experienced clinician will consider all these possibilities.

6) My doctor doesn’t know why I have cerebellar ataxia. Does that mean what I have is unknown?

Because there are so many acquired, genetic, and idiopathic causes for cerebellar ataxia, it is important to get a thorough evaluation to determine if a cause can be found. Just as there are specialists for the heart, the lungs, and the kidneys, there are neurologists who specialize in the cerebellum. These doctors can evaluate the various potential causes as well as determine whether genetic testing is needed and, if so, what tests are most appropriate. In general, almost all patients with sporadic ataxia require an MRI of the brain and a few basic blood tests. In some patients, such as those with a family history, or those with certain specific symptoms, genetic testing might also be recommended, but in many cases this is usually considered later on.

Acknowledgment

The author wishes to thank Dr. Susan Perlman for a critical reading of the manuscript and for helpful suggestions.

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iSearchiGive

iSearchiGive.com is a search engine powered by Yahoo! Search and iGive.com. It is the Internet’s first online shopping mall where a portion of each purchase is donated to a charity of your choice. When you use iSearchiGive to search the web, your favorite cause receives money for every qualified search.

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

Submitted anonymously

Everyone in life has obstacles to overcome, be it mental or physical. In order to do something and achieve something in life, you have to fight against all odds, get out of your comfort zone, have a positive frame of mind, and be focused. This involves taking risks and doing a lot of experiments in life. People who have succeeded in life have never given up and in no way let failures prevent them from what they wanted to achieve.

In order for this to happen we do have to accept the various complexities of life. We have to learn to live life to the fullest and enjoy it. As you know, life only comes once and one should try to make the most out of it. There is no reason to feel frustrated or down about something, because you do not achieve anything through it.

In my opinion the two things which play a crucial role in one’s life are positive thinking and self determination. It is very important in life to be able to struggle for something even though you may not succeed. Just the ability to struggle shows the qualities of a person, whether one gives up easily in life or is willing to fight it out. There are countless examples of people who have been a failure in their youth, but have never given up and have gone on to become the most famous people in history.

I am talking about Thomas Edison, the inventor of the light bulb and motion camera being among his many inventions. He did not have much success at school. The teachers used to refer him as being confused or mixed up. He also had hearing problems at an early age, but that did not stop him from becoming one of the most famous inventors. He also founded General Electric one the most publically traded companies in the world.

Similar is the case of Sir Isaac Newton, who is said to be one of the most influential persons in human history. He was thrown out of school at an early age but asked to return to school to complete his education. He later went on to become an English physicist and mathematician. His Law of Gravity being one of the top most discoveries in the world. The point is that one should never give up in life and always have a positive frame of mind. These two examples clearly illustrate and define these qualities.

I will now talk about people who have some sort of disability or some type of disease and excelled in life through their immense willpower and never-say-die attitude. The one person who immediately comes to my mind is Stephen Hawking. Hawking has a motor neuron disease which has progressed over the years leaving him totally paralyzed. Despite his limitations, what he has achieved is for the world to see: being a famous British professor at Cambridge and excelling in the fields of cosmology, physics, and mathematics. Also being the author of many best sellers, including “A Brief History of Time.” He has travelled all over the world giving lectures and is the recipient of many famous medals including The Presidential Medal of Freedom, which he received from President Obama in 2009. In 2007...
Professor Hawking took a zero-gravity flight in space, becoming the first quadriplegic to travel in space. He showed the world what can be achieved in life in spite of his being paralyzed. This clearly defines positive thinking.

I have always felt that people who have some sort of disability tend to make more use of their inner strength which leads them to do improbable things. As we saw, Hawking accepted the way he was and decided to live life on his own terms.

There is one more individual I would like to mention, W. Mitchell, a motivational speaker and author of many books. 65% of his body was burnt by a fiery motor cycle accident and an airplane crash later took away his ability to walk. He also could have given up very easily and accepted life as it was, but he fought his way to success. “It is not what happens to you. It is what you do about it.” This is his slogan and what he tells people to do.

It is very important to have a positive mindset when you are faced with an obstacle. I can simply go on-and-on about how people having disabilities have overcome all obstacles through determination and having a positive mindset. When you have such inspiring stories in front of you, it becomes easier to try to follow in their footsteps.

I would like to briefly talk about the problems I have faced. Being diagnosed with Friedreich’s Ataxia at the age of 12 and being transferred into a wheelchair at 20 resulted in all my dreams being shattered. It naturally was a very frustrating time for me. Seeing a wheelchair for the first time was not something I had dreamt about and I was told I would never be able to walk again. This wheelchair felt like a prison for me in the beginning, preventing me from doing what I wanted to do and confining me from where I wanted to go.

Like all my role models whose examples I’ve given, I decided to fight, never give up, and have a positive frame of mind. I succeeded in becoming a motivational speaker and my inspiration came from W. Mitchell. Like Mitchell I wanted to share my story with other individuals and my slogan is the same as Mitchell’s: “It is not what happens to you. It is what you do about it.” I wanted to tell the world who I am and not run away from my problems. It does require a lot of hard work and patience. I would say that I do not have any regrets in life and having Friedreich’s Ataxia instilled in me a stronger willpower and the ability to struggle in life at all times.

My message to all people out there, and particularly the youth out there, would be to always have a positive mind set and the courage to face up to life and its problems. One should always be who you are and not be afraid to admit your shortcomings. Pretending to be someone who you not are will always bring failure to you.

The three qualities which have helped me overcome obstacles are:
1. Never give up in life.
2. Have faith in God.
3. Believe in your abilities.

If you are able to achieve these qualities, I am sure you will be successful in life.
The National Ataxia Foundation provides fact sheets on various forms of ataxia, information on genetic testing, how to prepare for a visit with a neurologist and other topics that are relevant for the ataxia community.

At each Annual Membership Meeting, there is a presentation on medications for ataxia symptoms. Dr. Joseph Savitt gave the presentation at the meeting in San Antonio. The information was of such value that with the oversight of NAF’s Medical Director, Dr. Susan Perlman, and input from many of the leading ataxia neurologists, a fact sheet was compiled titled “Medications for Ataxia Symptoms.” This fact sheet has been organized by a list of some of the common symptoms associated with ataxia followed by off-label medication that have been used for those symptoms and have been reported in the medical literature and by ataxia clinicians.

The fact sheet was designed for educational purposes only and is not intended to serve as medical advice. However, it may serve as a useful tool to discuss with your doctor.

To receive a copy of this new fact sheet, please email us at naf@ataxia.org or call (763) 553-0020 and request the “Medications for Ataxia Symptoms” fact sheet. This fact sheet, along with all of NAF’s fact sheets and several booklets can be downloaded from www.ataxia.org.

All medications may have serious side effects and should only be used under a doctor’s supervision.

New Fact Sheet on ‘Medication for Ataxia Symptoms’ is Now Available

Macy’s ‘Shop for a Cause’ Discount Card Benefits National Ataxia Foundation

Purchasing a Macy’s “Shop for a Cause” discount card for $5 and help the National Ataxia Foundation. Your special Macy’s “Shop for a Cause” card gives you access to a special one-day-only sales event at Macy’s stores nationwide on Saturday, August 25.

Card holders receive a 25% discount on regular, sale, and clearance items, including home – even on most brands usually excluded! You will also save 10% on electronics, watches, furniture, and rugs. Exclusions apply. Card holders are also eligible to register to win a $500 Macy’s gift card. NAF will sell the discount cards until August 10.

You can purchase a discount card online at www.ataxia.org or by sending a check made payable to the National Ataxia Foundation to 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.
For the second year in a row, the National Ataxia Foundation exhibited at the American Academy of Neurology Foundation’s Brain Health Fair. This daylong event was attended by over 1,000 patients, family members and caregivers from the New Orleans area who are affected by a neurologic disorder or interested in learning about the brain. Attendees had the opportunity to hear from national experts about breakthroughs in brain research and new directions in neurologic medicine that are relevant to patients. This lay-oriented symposium helps make the complexity of brain health and brain disease understandable. The focused activities for kids and teens were fun while also educational.

The Foundation’s exhibit table provided materials on ataxia, understanding genetics, and a booklet of true stories of children who are affected by ataxia. Visitors to the table could sign up to be in a drawing for an “Ataxia is Not a Foreign Cab” canvas grocery bag filled with NAF materials and t-shirt.

NAF is grateful to Louisiana Chapter member Margaret Waterson, who volunteered at the NAF exhibit, providing answers to the question often asked “What is ataxia?” The Brain Health Fair is a marvelous opportunity to raise ataxia awareness and highlight the work of the National Ataxia Foundation.

In addition to exhibiting at the Brain Health Fair, NAF also had an exhibit during the American Academy of Neurology meeting. This annual meeting was attended by over 12,000 neurologists. For four days during the meeting, neurologists have the opportunity to visit the Exhibit Hall, which includes exhibits from pharmaceutical and gene testing companies, labs, healthcare organizations, and disease specific patient advocacy groups. Neurologists who stop by the NAF booth are interesting in materials that they can provide to their patients, ataxia research funding opportunities, and learning more about the services of the Foundation.

Volunteers from the Louisiana Chapter helped staff the booth. A sincere thank you goes out to Bill and Sue Avery, Mark and Joanie Daigle, Denise Drake, and Elizabeth Tanner for the time and energy they committed to this important endeavor. The following comments were made by two of the volunteers:

“We enjoyed participating in the Foundation’s work at the AAN meeting in New Orleans. Our conversations with neurologists from around the world left us encouraged that answers will be found that will someday put an end to the damage done by ataxia in general, and MJD in particular. Thank you for allowing us to help.”

“It was such an enjoyable and educational time volunteering at the AAN. Everyone stopping by was so kind and sincere. As a person directly affected by ataxia it’s refreshing to hear and see genuinely interested folks attending.”

*At the meeting it was announced that the American Academy of Neurology Foundation is changing its name to the American Brain Foundation to reposition itself to become the world’s leader in raising money for research to cure brain diseases. The organization supports vital research and education to discover causes, improved treatments, and cures for brain and other nervous system diseases.

Please support the work of the National Ataxia Foundation by becoming a member or by making a donation online at www.ataxia.org

The National Ataxia Foundation Raises Awareness in New Orleans
According to Jude

By Jude Lally

All anyone can say about having a physically degenerative disease is that it’s tough. Not only does it have a detrimental effect on the body, but it’s devastating to one’s psychological well-being. The loss of physical abilities is one thing, but the constant anxiety and anticipation of the condition’s progression is heart-wrenching. Dealing with the realization of it worsening is a constant battle.

Different people have different methods they use to deal with this prospect. In psychology courses in school one learns about “The Coping Process,” which has three distinct phases: #1 is Anger, which occurs when one first finds out that he or she has the condition. #2 is Learning, which is when one finds out as much about the ailment as possible in order to feel more “powerful” in fighting it. #3 has to do with its Acceptance, or, what is referred to as “taking it all in stride.” Sometimes, though, there’s a stumble in the stride.

It is common knowledge that the phases of this process don’t go in sequential order, that you may have accepted a chronic illness for a long time but still experience anger every so often. Furthermore, we know they’re not mutually exclusive; it’s possible to experience more than one phase simultaneously, or to exhibit a little of each phase all at once. As I said, the techniques people use to cope with a chronic condition are different, as different as the people themselves.

Before I discuss my methods, allow me to introduce myself. My name is Jude Lally and I am 28 years old. I have lived in Central and Eastern Kentucky my entire life. I reside in Lexington, Kentucky, where I’ve lived most of my life, so I consider it my hometown.

In the summer of 1998, I was diagnosed with Friedreich’s Ataxia after experiencing gait irregularities and excessive clumsiness for about a year. While on a family vacation, some relatives whom I hadn’t seen in a couple years saw me walking from afar and noticed the anomaly. They asked my father what was the matter and if I’d ever been taken to see a specialist or neurologist. From that day forward my life changed, in more ways than one.

Several things, however, have never changed. My mind is fully functional, fully capable of comprehending and executing cognitive tasks as before. Only the way that I think about doing physical tasks and how I relate to the world is different. The love and unwavering support of my family and close friends, as always, is incredible. Without it, this struggle would be too much. I couldn’t bear it. Also, my drive and relentless independence is stronger than ever. My routines are evidence of this.

I try to exercise, in one form or another, every day. I try to read a little every day, no matter what it is: a novel, a short story, some poems, a magazine or online article, or even a joke book (I am an adamant joke teller). I make a point to write something every day: a poem or a bit of a letter, an e-mail, or even just a Facebook message. Sometimes I just write my thoughts or about my dreams.

Speaking of routines, when I wake up every morning the first thing I try to do is put on my shoes. That way, I can use the toilet on my own. I need shoes because I need grip on the floor when I transfer from my chair to the commode. When I’m not able to do it by myself, my bowels will not move. This goes back to that relentless sense of independence I have.

One thing that’s important to remember about
According to Jude
Continued from page 17

routines is that it’s okay to break them every now and then. And when you’re speaking about goals, especially fulfilling goals in a given time frame, you must remember that if you have a disability certain things take longer for you than for most. And besides, it doesn’t really matter anyway. What matters is that you’re actually doing it.

I graduated from the University of Kentucky five years ago with a Bachelor’s of Business Administration. Like so many others, I’m not employed in the field of which I studied. In fact, I’m not “employed” per se, at all. I’m a writer, at least that’s what I say when asked the definitive question: What do you do? Poetry is my forte; I had my first collection of poetry published a year ago. Once in a while, I may be motivated to write a short story, essay or article (such as this).

Before I go any further, I need to talk a little about the other well-known process that people sometimes go through when they’re dealing with a tragedy or substantial loss. It too is a series of phases: Denial, Anger, Bargaining, Depression, and Acceptance. These are known as the “Five Stages of Grief.” When first introduced, this theory specifically applied to people suffering from a terminal illness. Which brings up a very important question: Is Friedreich’s Ataxia considered a terminal illness? To some extent, I think it is. Statistically, people who have it live much shorter than those who don’t, but of course, that’s not always the case. You could argue that life is a terminal illness; there’s no way you’re getting out alive!

In a sense, I believe that each phase of “The Coping Process,” as well as the “Five Stages of Grief,” has its own phases, or levels. These can manifest themselves at any given point and can occur, become non-factors, and then recur innumerably.

Back on that fateful day when my relatives saw something off in my walking and mentioned it to my dad, who then mentioned it to me – that I would see a doctor to determine the abnormality – on one level I was hysterically upset (Anger), but at the same time I was relieved to know that it was definitely something causing it, although I’m not sure if “relieved” would be the right word here. But just because I acknowledged the presence of something perverse doesn’t mean I’d “accepted” it. But to a certain extent I did. To a certain extent I faced a little bit of every stage right there, in the loft of our cabin, crying my eyes out. I remember it vividly.

Or, like when I’m writing (typing). I “accept” the fact that it’s going to be a slow and tedious task getting the words down, but it still makes me angry. Sometimes the realization of an arraignment or shortcoming doesn’t become evident, or isn’t accepted, until it actually happens. For instance, I remember hearing that I would be confined to a wheelchair soon after my diagnosis. I was aware of it then, but it wasn’t until after I actually started using a wheelchair that I finally accepted it.

Also, it’s important to realize that Acceptance is not the same as “giving up.” The literature says that people often feel like giving up during the Depression stage. But with me, depression comes and goes. I don’t believe Acceptance totally absolves you from Depression. I’m sad about not being able to go places on my own anymore, about having to live with someone who has to take care of me. But I’ve accepted it, and often I feel fortunate that someone is there. But sadness still occurs occasionally.
Now a little bit of self-revelation: Earlier we talked about the second phase of “The Coping Process,” Learning – where the person researches the illness as much as possible. But I soon found that the more research I did, the more depressed and angry I became. Once I read that I’d be lucky to see my 50th birthday, that was it! Now, all I want to know is that people are working on a cure, which they are. My mom has taken over the task of learner; I know if there are any new developments in treatment, she’d pass the word to me in a flash!

All I’m concerned with is what I have to do to live with this disease. When a problem arises, I deal with it. One day at a time, that’s my motto; that’s how I cope. And, of course, I cope through writing. Completing a “written” piece is very gratifying and fulfilling. Furthermore, it gives me the sense of achievement that pulls me through my grief. Don’t misunderstand, I still get depressed sometimes, but when I write it acts as a fail-proof pick-me-up that keeps my depression at bay and my grief from getting the best of me.

Another thing I read said that the harder a person fights death, the more likely he or she will be to stay in Denial. Who knew? I’ve been stuck in Denial this whole time! But isn’t it human nature to resist death?

I had never really given much thought to the idea of my own mortality (aside from my “research”) until watching a movie recently called “The Cake Eaters,” in which one of the main characters is a girl with Friedrich’s Ataxia. During a scene where she had just fallen and her mother vehemently insists that she take her wheelchair with her, the daughter utters, “I’m the one dying of this, not you.” This line really hit home for me.

After some in-depth thought and soul-searching, here is what I’ve decided: I’m not dying of Friedrich’s Ataxia, I’m living with it. To some degree, I am grieving. I’m grieving the loss of my bodily abilities. I’m grieving the loss of walking and writing (scribing, that is), of being able to speak clearly without having to repeat myself. I’m grieving not being able to drive, not being able to play video games, not being able to hear very well in crowds of people, nor speak. I’m grieving not being able to see very well, not being able to follow the words in a book, on a computer screen or to spot falling stars because my eye-movement lacks precision.

Likewise, besides grieving over all these things, I am simultaneously coping with them. When you think of the word “grief” you associate it with loss – of a loved one, or in my case, ability. But the word “cope” makes you think of learning to live without the person, or the ability. So which is it, coping or grieving? Well, I think it’s a little bit of both. But a man I “talked” to on the Internet said, “We are learning to cope with our grief.” Well put, sir.

Electronic Check Conversion Notice

When you donate by check, you authorize the National Axatia Foundation either to use information from your check to make a one-time electronic fund transfer from your account or to process the payment as a check transaction.

When we use information from your check to make a one-time electronic fund transfer (EFT), funds may be withdrawn from your account as soon as the same day we receive your payment, and you will not receive your check back from your financial institution. Your check will be destroyed.

Thank you for your donations by check. If you have any questions about this process, please contact Julie Braun at julie@ataxia.org or call (763) 553-0020.
— 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 straightforward and realistic suggestions for speech and swallowing management. This second edition was updated in 2006. $7.50

— FICTION & PERSONAL STORIES —

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

To place your order, please call (763) 553-0020, fax (763) 553-0167 or mail a copy of this form to
National Ataxia Foundation
2600 Fernbrook Lane, Suite 119
Minneapolis, MN 55447
# SHIRTS/MISCELLANEOUS

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**ORDER FORM**

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**VIDEO/CD**

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# National Ataxia Foundation

## 55th Annual Membership Meeting - Recordings

**March 16-18, 2012**  
**Grand Hyatt San Antonio Hotel - San Antonio, TX**

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A **Free Session View** from the 54th Annual Membership Meeting
The 2012 National Ataxia Foundation Membership Drive – “55 Years of Serving the Ataxia Community”

The National Ataxia Foundation depends on the support of our members to continue to bring quality programs and services to the ataxia community. The NAF Annual Membership Drive has begun. If your membership has lapsed or you are currently not a member, please join today. If you are a current member, thank you for your support. You may also consider giving a Gift Membership to a friend or family member.

Why Become a Member?
Membership fees help the National Ataxia Foundation to provide programs and services that strengthen and support the entire ataxia community. NAF members have a choice in becoming an individual, household, patron, or lifetime member, as well as a professional member.

Who May Become a Member?
NAF membership is open to any individual, family, medical professional, nonprofit organization, association, or business who is interested in helping ataxia families.

What Are the Membership Benefits?
Becoming a member of the National Ataxia Foundation provides you with discount registration fees in attending the annual membership meeting as well as receiving NAF’s quarterly 48 page news publication “Generations.” Members who attend the annual membership meeting tell us that the discounts they receive more than cover the cost of their annual membership.

How Do I Become a Member?
Becoming a member is easy. You can become a member by filling out the membership form on the back page of this issue of Generations, or you can become a member by going on-line at www.ataxia.org and click “Donate Now.” You will also be receiving a membership drive letter in the mail which you may complete and mail to the National Ataxia Foundation. Thank you.

ShopNAF.org for the Perfect Gift
No matter whether you are looking for the perfect gift for a special someone, or for items for your everyday needs, ShopNAF.org has you covered.

The site allows you to shop securely online at a variety of partnering stores for all your needs – gifts, home, office, health and beauty, and clothing – and have a portion of each purchase help support the National Ataxia Foundation. Visit ShopNAF.org today!

GoodSearch Is Good for NAF
Did you know that donating money to the National Ataxia Foundation is as easy as changing your Internet search engine?

GoodSearch.com idonates 50 percent of its revenue to the charities designated by its users. Simply go the the site’s home page and follow the easy steps to make NAF your charity of choice.

Then use GoodSearch as you would any other search engine. You’ll make a difference in the lives of those with ataxia!
“I Am the Strength Behind Ataxia”© Award Nominations

Do you know someone who has made a difference in the ataxia community? Tell us about them! The National Ataxia Foundation will be honoring outstanding ataxia community members in March at the 2013 NAF Annual Membership Meeting. In print and online, we will shine a spotlight on those who give back to the ataxia community every day. Nominations are due by November 1.

Submissions deadline: November 1

Selected nominees will be notified: November 30 and announced at the 56th Annual Membership Meeting and in the Spring 2013 edition of Generations. Selected nominees will be awarded an “I Am the Strength Behind Ataxia” Award, be featured in Generations, included on our website, and posted on NAF social media networks!

Who should I nominate?

You’re welcome to nominate yourself or anyone that you feel has made a difference in the ataxia community. Whether it’s a person with ataxia who has inspired you, an advocate for ataxia research, a friend who has taken on the cause, a caregiver who is an endless source of encouragement, a healthcare provider who constantly works to make your life easier, or an ataxia researcher searching for more answers – we want to hear their story! You can even honor the memory of a loved one by telling us how they contributed to the fight against ataxia.

How do I nominate someone?

Write a few paragraphs (250 words or less) about the person you’re nominating. In your submission tell us why your nominee is the Strength Behind Ataxia. Be specific and give examples of how your nominee is changing lives for people with ataxia. Then fill out the entry form. The entry form can be found on the NAF website and in this issue of Generations. You can then e-mail or mail in your essay with the entry form to lori@ataxia.org or NAF, 2600 Fernbrook Lane N, Suite 119, Minneapolis, MN 55447. Please send a photo of the person you are nominating with the entry form along with your essay.

What will happen to my entry?

Your entry will be reviewed by the award committee after the submissions deadline in November. You may be contacted if additional information is needed about the individual you have nominated for this award.

Who is chosen for the award?

All nominees will be considered, but two outstanding nominees will be selected to receive an “I Am the Strength Behind Ataxia” (SBA) Award! These individuals will receive the SBA Award at the 56th NAF AMM and will also be spotlighted on the Foundation’s website and in Generations. See the Award Nomination Rules on page 25 for more details.

Selected nominees will be featured at the NAF 56th NAF Annual Membership Meeting in Detroit, MI on March 15-17, 2013.

How are the awarded nominees selected?

The NAF Award Panel will carefully review all the nominations and select the awarded nominees by November 21. NAF will contact the selected nominees by November 30.

Great! What’s the deadline?

The deadline for submitting nominations is November 1.

Is there anything else I need to know?

Read the Award Nomination Rules for additional information.

I still have questions. Who do I contact?

Please contact Lori Shogren, Special Projects Coordinator at lori@ataxia.org or (763) 553-0020.
I Am the Strength Behind Ataxia® Award Nomination Rules

1. ELIGIBILITY: Each entry must nominate a different person and must be submitted separately. Entries must be completed in English.

2. PUBLICITY: All materials submitted become the property of the National Ataxia Foundation (NAF) and may be used in the development of other marketing collateral.

3. LIABILITY: NAF is not responsible for errors or failure to receive entry information. NAF reserves the right to cancel or modify the award nomination process. By participating in the NAF “I Am the Strength Behind Ataxia” (SBA) Award Nomination Program, you agree to release and hold harmless NAF and its directors, officers, staff and agents, from any and all losses, damages, rights, claims, and actions of any kind in connection with the SBA Award Nomination Program including, without limitation, property damage, and claims based upon publicity rights, or invasion of privacy, whether suffered by you or a third party. By participating, entrants agree to be bound by these Official Rules and the decisions of NAF, and waive any right to claim ambiguity in the SBA Award Nomination Program or these Official Rules. The names, logos, and icons identifying the products and services of NAF are proprietary marks of NAF. The rules of this program are subject to change at any time without notice.

4. SBA AWARDS: Two nominees will be selected to receive the SBA Award. The award recipients will be honored at the 2013 NAF Annual Membership Meeting and be featured in the Spring 2013 issue of the NAF newsletter, Generations. The award recipients will be chosen by the NAF Award Panel by November 21, 2012.

The award recipients will be required to complete a publicity release, which must be returned within the time period specified upon notification or NAF, in its sole discretion, may select an alternate recipient. Award recipients agree to release NAF, its affiliates, directors, officers, staff, and agents from any and all liability for any injuries, losses, or damages of any kind caused resulting from acceptance, possession, use, or misuse of any award.

Continued on page 26

PATIENTS WITH SCA1, SCA2, SCA3, SCA6 and MSA-C
needed for an MRI study

to evaluate the chemistry of the brain in ataxias

at the Center for Magnetic Resonance Research at
University of Minnesota

You will lie in the scanner for ~1.5 hour while listening to music of your choice. Expenses will be covered and you will be reimbursed for your time.

If you are interested or have questions, please call
Diane Hutter @ (612) 625-2350 or email hutte019@umn.edu.
I Am the Strength Behind Ataxia® Award Nomination Form

Your Information
Name: _______________________________________________________________________
E-mail Address: _________________________ Phone Number: ______________________
Address line 1: _________________________________________________________________
Address line 2: _________________________________________________________________
City: __________________________________ State: ________ Zip Code: ____________
My affiliation with NAF: ________________________________________________________
My relationship to the nominee: __________________________________________________

Your Nominee’s Information
Name: _______________________________________________________________________
E-mail Address: _________________________ Phone Number: ______________________
Address line 1: _________________________________________________________________
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Essay (a separate document can be used and attached to this form)
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Please initial the following:
I have included my essay and photo of nominee with my entry form: _____
I agree to the “I Am the Strength Behind Ataxia” Award Nomination Rules: _____

Submit Your Entry
Either e-mail or mail your essay with the entry form to lori@ataxia.org or National Ataxia
Foundation, 2600 Fernbrook Lane, Suite 119, Minneapolis, MN 55447. Please send a photo of
the person you are nominating with the entry form and essay.
MJD/SCA3 Symposium in Rhode Island

A program is being run for patients and families interested in Machado–Joseph disease (MJD) on Saturday, September 15.

The program will consist of a brief talk on the history of MJD, given by the founding Dean of the Medical School of Brown University, Stanley Aronson, MD, the author of a weekly column on medicine and history in the Providence Journal and eminent neuropathologist; a talk on caregiving for people with neurodegenerative disorders by Gary Epstein Lubow, Assistant Professor of Psychiatry and Human Behavior at Alpert Medical School of Brown University and Assistant Unit Chief of the Senior Treatment Unit at Butler Hospital; and the major address, by Henry Paulson, MD, PhD, Lucile Groff Professor of Neurology at the University of Michigan Medical School, one of the world’s leading experts on the molecular biology of MJD, and RNA interference as a possible therapy. Dr Paulson will supply an update on MJD research, progress towards therapies, and will answer questions.

The educational program will begin at 9 a.m. and there will be a free clinic in the afternoon, starting at 1 p.m.

The program is being jointly run by Joseph Friedman, MD, Lewis Sudarsky, MD, Professors of Neurology at Harvard Medical School, Brigham and Women’s Hospital; and Lee Corwin, MD, neurologist in Plymouth, MA. The program is sponsored by Butler Hospital and by the Prince Henry Society of New Bedford.

The program will be held in the Ray Conference Center of Butler Hospital, 345 Blackstone Blvd., Providence, RI. The clinic will be held in the Movement Disorders Program, a short walk from the conference center.

Please call the Movement Disorders Program at (401) 455-6669 with questions or for more information.

Vehicle Donation for Ataxia

Did you know that donating a car, boat or RV could make a difference to those with ataxia?

We Make It Easy
Call 1-800-240-0160 and a donation specialist will schedule your pick-up appointment. If you would rather have someone call you, fill out our quick and easy online form at www.donateacar.com/affiliate-National-Ataxia-Foundation.php.

Benefits of Donating
• Fast – Next day pick-up appointments if called in by 2 p.m.
• Free – We will pick up your donation at no cost to you
• Convenient – We will pick up your car from wherever it is (home, work or auto shop)
• Tax Deductible – Your donation is tax deductible to the full extent of the law
• Save Time – Save yourself the time and hassle of trying to sell it yourself
• Feel Great – Know that donating your car will help further our mission

We work with a reputable donation processor, Car Program, who will make all the arrangements at no cost to you, handle the title transfer requirements and provide you with a tax-deductible donation receipt when they pick up your car.

Need More Information?
Visit www.donateacar.com/affiliate-National-Ataxia-Foundation.php or call our car donation program 24 hours a day at 1-800-240-0160.
2012 Chuck and Duck Dodgeball Tournament

By Andrew Haluska

The gym at Charlton Heights Elementary was rocking April 27 as third-, fourth- and fifth-grade students participated in the third annual Chuck and Duck Dodgeball Tournament.

Staff members, parent volunteers, and students raised almost $3,000 for the National Ataxia Foundation in honor of former student Jacob Van Buren.

Jacob learned of this rare disease when he was a third-grade student at the school in Charlton, NY. His family has since moved to Florida where he attends sixth grade.

“Jacob is such a great kid,” said teacher Alison Donofrio. “We wanted him to know that we have not forgotten him and will be there to support him even though he is 1,200 miles away.”

This year’s event was kicked off by Jacob himself via Skype. Students who might not have gotten to meet Jacob got to see both him and his family.

Plans are already in the works for next year’s event. Event planners are thinking of new ways to make the event bigger and better.

“We want this dodgeball event to become part of the Charlton Heights culture,” said Andrew Haluska, a third-grade teacher. “We want to create a buzz surrounding the event, but at the same time, remember we are raising money and awareness for a disease that many people do not know exists.”

Ornaments for Ataxia

By Megan McClure

Over the last two years, I have gained a new view of life as a thing both precious and urgent. I began dating a boy who had been diagnosed with ataxia at the age of seven.

At times, the future looks dark and hopeless, but more importantly the present seems undeniably more valuable. Knowing that it will be a miracle for him to be walking after the age of 25 or breathing after age 45, I cannot ignore my sense of fear and trepidation. Yet, I have remained as proactive as possible; the more I learned about ataxia, the more I knew I had to do something.

Several months ago, I purchased 160 clear, spherical, glass Christmas ornaments. Over the summer of 2011 I gathered a few friends and we spent many hours meticulously stuffing and painting the ornaments in unique designs. Last December, I sold the ornaments for $5 each while spreading awareness about ataxia in my school, church, and community. Through purchases and donations, I raised $750 dollars.
Our Cerebellum Is Shrinking

By Blanche Capriolo

Not time to be a shrinking violet though... There is so much yet to do if you will force yourself to grow.

Eight years ago I was diagnosed with Spinocerebellar ataxia (SCA). At 69 I was an active mover and shaker, teaching in a community college, the mother of three and grandmother of 10. One good thing – I now had a name for what I was experiencing. Friends used to look at me funny when I slurred my speech and seemed a bit clumsy. I called it the “martini syndrome” and it gave us all a laugh. In fact, I used to like an occasional martini.

Life is different now and more magical then I ever dreamed it could be. I belong to an athletic club and take a water aerobics class. When in the water you no longer have ataxia. You are a mermaid and can do anything. The deep water class with a belt is heavenly. The past two years I have added gentle yoga and even have my husband going. I do many poses using a wall and sometimes a chair. The quiet, gentle music and meditation is medicinal.

My message is to live in the present, a gift for all, and that is why we call it a present. Learn to sew, knit, paint, play Scrabble and chess. Don’t know how? Learn. Play the piano, dance. Our cerebellums may be shrinking, but our minds and hearts are growing.

Read my blogs if you like at www.justblanche.com.

Editor’s Note: Blanche is a member of the Chesapeake Chapter and has been in a research study at Johns Hopkins.

My Flannel Shirt

By Donna Gorzela

At a recent gathering, several of us discussed the difference between when we are merely trying our best – making the effort, and working our existing capabilities – versus just being stubborn and irresponsible.

When do we use the cane, walker, or wheelchair? I can get by with just hand rails on stairs for the most part, but when I go out to eat, or go some place where I’m going to have to deal with crowds, I take my cane. I’m afraid that if used my cane all the time, I’d become too complacent. However, when I need it, I need to put the pride aside, and admit it! It seems to be a fuzzy line that we all need to constantly interpret and then re-interpret as our symptoms change.

Putting on one of my favorite shirts this morning, I was reminded of this debate. That shirt was a chore to put on! It was all buttons! I have to admit that occasionally frustration gets to me and I just want to throw all those shirts with buttons away.

But isn’t it sometimes worth the struggle? Maybe I just need to remind myself of the price I have to pay? A little extra time to get ready in the morning? A pretty small price to pay, in my opinion. For instance, if I never make the effort to do all those buttons, could I lose that ability? Maybe “practice” may never make “perfect,” but maybe in this case “practice” can keep things in the “realm of possibility.”

Where do we draw the line between “worth the effort” and “foolish”? In my opinion, trying is a good thing but sometimes we just need to admit we need help. On the other hand, button-fly jeans would be “just plain stupid”!
From the Desk of the Executive Director

Many of you may recall the film, “It’s a Wonderful Life,” the classic holiday story about a man named George (played by Jimmy Stewart) who was shown by his guardian angel, Clarence, that his life had made a profound impact on others. Throughout the film Clarence shows George all the lives he has touched and how different life in his community would have been if he had never been born.

What If NAF Was Never Established?

1) There would be no NAF support groups, ambassadors or chapters to provide local support and a setting for ataxia families to learn, network, and share.

2) Research would not nearly be at the level it is today. Over the past 13 years the NAF has invested millions of dollars in 171 ataxia research studies in 13 countries to help end ataxia.

3) There would be far fewer researchers involved with ataxia. Through the NAF Young Investigator Awards, NAF helps bring in new investigators into the field of ataxia research and helps support established investigators.

4) Collaboration with researchers around the world would be greatly reduced. Initiative such as the International Ataxia Investigators Meeting (AIM) brings researchers together to encourage collaborations and cooperation. Because of AIM, researchers are working together around the world to help accelerate world-wide research.

5) There would be less information available about ataxia. NAF is a world leader in providing current and accurate information on ataxia through publications, books, videos, and on its web site. In fact, www.ataxia.org gets millions of hits each year with hundreds of thousands of visitors from more than 125 countries.

6) Connecting and networking within the ataxia community would be reduced because of support groups, chapters, the NAF Bulletin Board, chat rooms, Facebook, Twitter, our Pen Pal Program, and the annual membership meeting, ataxia families are better connected.

7) The amount of research dollars for ataxia would be greatly reduced... not only in terms of funding from the National Ataxia Foundation, but also funding from NIH. Researchers who receive funding from NAF are better able to acquire funding from NIH once their initial research has been established. Many times NAF sees the initial research investment increase 10- to 20-fold (sometimes 100-fold) from other sources. Many times we learn from researchers that without the initial support from NAF they would not have received funding from NIH.

8) There would not be a worldwide tissue donation program.

9) There would not be a national patient registry.

10) More misdiagnoses would have occurred. Because of NAF publications written specifically for the medical community, sponsoring and staffing of information booths at various medical and scientific conferences, supporting a Continuing Medical Education course on ataxia at the AAN annual meeting and a full day symposium on “Children with Ataxia” at the Child Neurology Society Meeting, the medical community is better informed about diagnosing and treating ataxia.

Who Made This Happen?

The original founders had a vision to help ataxia families through research and programs. Their vision created the National Ataxia Foundation in 1957. Throughout NAF’s history, volunteers and donors have honored this...
vision and supported programs to help foster ataxia research, create better ataxia awareness, and connect ataxia families. There have been many champions throughout the years to further the mission of the National Ataxia Foundation. Generous donors, committed board members, unwavering support group leaders, determined members, tireless volunteers, devoted members of the medical research advisory board, dedicated staff, and others all working together, united in our cause.

People like Michael and Patricia Clementz, and a recent anonymous donor, who each committed more than a million dollars to help further our important ataxia research efforts. Our original founders, Dr. John W. Schut and Henry Schut, who pioneered the way to support research and programs for ataxia families. The long-term commitments of our members and volunteers, and board members like Dr. Larry Schut, Arnie Gruetzmacher, and Julie Schuur, who each have committed more than 40 years of their lives in helping those affected by ataxia. It is people like our Research Director, Dr. Harry T. Orr, who has made ataxia research his lifelong commitment to help end ataxia. We honor these champions and so many others.

What Can We Do To Help?

Through volunteerism and contributions, each of us is making a difference in the lives of ataxia families. The commitment of our members continues to make a profound impact on NAF’s ability to support important programs. Larger donations over the years from families, corporations, foundations, and estates have been the cornerstone in building a strong foundation of programs and initiatives. However, it is never more apparent than at the December Board of Directors Meeting when the final research funding decisions are made for the next fiscal year the importance of each research dollar. Each dollar donated makes a difference in NAF’s ability to fund the best science. Each dollar brings us one step closer in finding effective treatments and ultimately a cure. There are times that promising research goes unfunded due to limited funding. That is why each of us can make a difference in supporting the best science in the world by contributing to the NAF research drive this fall.

The same is true in supporting the annual NAF membership drive. Funds that support this drive help significantly in providing important programs and services. “Generations” and other important NAF publications, staffing information booths at various medical conferences, bringing ataxia families and scientists together at the annual membership meetings, developing support groups throughout the country, maintaining NAF’s web site, and much more are funded by funds from the membership drive.

Volunteering at an NAF event, leading a support group meeting, organizing a fund raising event, contacting your local media to tell your story about ataxia, telling others about ataxia, wearing an ataxia awareness shirt or cap to help create awareness, encouraging others to support NAF, registering on a patient registry, volunteers throughout the country are having a vast impact in support of programs and awareness.

Thank You!

The National Ataxia Foundation is truly grateful to all our members, supporters, volunteers, donors, sponsors and partners. Just like the film, “It’s A Wonderful Life,” it is your support that gives all of us hope and impacts ataxia families throughout the United States and beyond. Thank you.

CFC Number

The National Ataxia Foundation’s Combined Federal Campaign (CFC) number is 10752.

This program provides a convenient way to donate to the Foundation, and provides great benefit to those with ataxia. Please give as generously as you can.
Chapter and Support Group News from Around the Country

Alabama Support Group

The Alabama Ataxia Support Group met April 28th in Homewood, AL and enjoyed fellowship and a delicious luncheon with 23 members in attendance.

Our speaker of the day was Dr. Rita Cowell from the University of Alabama-Birmingham’s Department of Research. Rita is involved in research of neurodegenerative diseases, such as Parkinsons, multiple sclerosis and the ataxias. She is doing work with the cerebellum and purkinje cells which are greatly affected in ataxia.

Denise Higdon will run (actually roll) in the North Jefferson Women’s Center’s “Run for their Lives” event in Fultondale, AL on June 2 to celebrate ataxia awareness. Denise was sponsored by her father, Pat Guercio.

Jeff Cohn, leader for the summer social event, announced it will be held on Saturday, June 23 at 11:00 a.m. at Brio’s in Homewood, AL.

Cell Group Leaders were encouraged to stay in touch with members on their lists and offer encouragement.

The meeting ended with Ms. Juanita Dorroh giving an inspiring message on the boll weavel and its impact on society. She then gave an everyday example of life, challenging the group with her talk entitled, “Victim or Victor?” She told a real-life story of one who was suddenly challenged and is now an overcomer.

Greater Atlanta Support Group

By Greg Rooks

The Greater Atlanta Ataxia Support Group continues to be active during 2012 with a great group of members participating in our activities.

A meeting was held on February 4 with Kathi Geisler from the Dashaway company as our speaker. The Dashaway is a new innovative walker with an upright support system.

The group volunteered to work the NAF booth at the Atlanta Abilities Expo on February 17-19. At the Expo we distributed ataxia information, met new support group members, and met vendors which are potential guest speakers.

Our support group brochure was updated recently. The brochure is distributed to neurologists and at events like the Abilities Expo.

A meeting was held on May 19 with Carolyn Phillips from Tools for Life as our speaker. Tools for Life, Georgia’s Assistive Technology Act Program, gives more options for greater freedom by increasing access to and acquisition of assistive technology (AT) devices and services for Georgians of all ages and disabilities so they can live, learn, work, and play independently in communities of their choice.

Our spring picnic at Lake
Lanier will be held on June 9. We are also busy planning our second annual Walk n’ Roll on September 22. Our next meeting is scheduled for July 14.

**Delaware/Pennsylvania Support Group**

*By Christina Rakshys*

Our meeting on April 14 was very well-attended. Twenty-four people – 16 from PA, five from DE and three from NJ – attended the meeting.

Our Delaware co-leader, Joe DeCrescenzo, started out by telling us some information on the NAF annual meetings, this year’s in San Antonio and next year’s in Detroit. Next on the agenda, Mike Cammer, the Pennsylvania contact for our First Annual Walk, Roll n’ Run, spent some time talking about the tentative fundraiser event. And finally, Dr. Thyagarajan Subramanian from the Penn State Hershey Medical Center gave us a brief update of ataxia medical news/research over the past two years (some good, some bad). He also stuck around and fielded lots of questions from the group, related to and/or not related to his talk. It was very nice and greatly appreciated. Our fall meeting is TBA – please stay tuned.

**Central New York Support Group**

*By Mary Jane Damiano*

The Central New York Support Group met on April 21. Eight members were present.

We watched videos of service dogs in operation. Questions arose as to their effectiveness, and I responded as to their value. We shared our problems with each other and offered solutions. This is one of the main values of our little group. Afterward we enjoyed refreshments.

Cheryl, our support group member from Fort Drum announced that she was moving to San Antonio, TX.

Our next meeting will be on June 16.
Chapter and Support Group News  
Continued from page 33

Northeast Florida Support Group  
By Mac Kelso

The Northeast Florida Ataxia Support Group met at Baptist South Hospital on May 12 at 1 p.m. Our meeting had 18 attendees and five new members. John Richwine opened the meeting by introducing himself and welcoming the new members to the group. Then updates were given by Mac Kelso for the upcoming 2013 NAF Annual Membership Meeting in Detroit; and he discussed information just released from the NAF committee, they have decided to divide the Country into regions for future NAF Annual Membership meetings with a possibility of Florida being selected for 2014 or 2016. After the update, individual members introduced themselves to the new members and shared their ataxia stories. The time left was spent in roundtable discussions about resources available in the local area for new members, and what works and what doesn’t work. Steve Brown encouraged all new members and members to register on the National Ataxia Register to help with research and therapies.

In closing, all members who attended the “Clark’s Fish Camp” outing in April said they really enjoyed the great lunch and seeing each other. Our coordinator John Richwine said he would like to do another outing at Corky Bells in Palatka, FL. The next proposed meeting will be August 12 at 1 p.m. in the Camellia Room at Baptist South, unless we decide to have a meeting sooner offsite. All members were invited to come to Applebee’s after the meeting for supper and casual conversation.

Seek a Miracle Ataxia Group  
By Dr. Yasmin Sultana (SAMAG New Delhi Chapter President)

This goal of this lecture was to spread awareness about ataxia, as an initiative of SAMAG’s New Delhi chapter president Dr. Yasmin Sultana, Assistant Professor, Department of Pharmaceutics, Faculty of Pharmacy, Hamdard University, New Delhi.

Dr. Achal Srivastava, Additional Professor, Department of Neurology, All India Institute of Medical Sciences, New Delhi was invited to deliver a lecture on “ataxia” by Dr. Sultana and by Drs. Mohd. Aqil and Zeenat Iqbal, Assistant Professors in the Department of Pharmaceutics were the coordinators of that lecture.

Dr. Srivastava completed his DM Neurology Course from AIIMS in 1998 and worked as a Senior Scientist grade scientist fellow for about one year and then joined as assistant professor in the department of neurology in March 2001. He was selected as Associate Professor in September 2005. He runs the Ataxia Clinic and Intractable Epilepsy Clinic apart from seeing general neurology patients. He is in charge of the department’s Clinical Neurophysiology facility. He has a keen interest in epilepsy, ataxia, Parkinson’s disease and stroke. He is part of epilepsy surgery team. He has presented his research work in several national and international conferences. He was invited by Molecular Biology division at Johns Hopkins in the United States for »
presentation of his work on spinocerebellar ataxia type 12. He has received outstanding paper presentation award from AINA at American Academy of Neurology conference at San Francisco in 2004 and the best paper award at Neurological Society of India conference at Hyderabad in 1998. He has received many travel fellowships to attend international conferences. He has received a Young Investigator award for CAG triplet repeat disorder conference at USA and Italy. Dr. Srivastava has delivered several All India Radio talks and has done projects on epilepsy in rural areas in India.

Some of the key excerpts from his presentation:
- The most important goal in management of patients with ataxia is to identify treatable disease entities.
- The term ataxia denotes inability to make smooth, accurate and coordinated movements.
- The main cause of ataxia is failure of the cerebellum to modify muscle tone and contractions to achieve coordination.
- Hereditary ataxias are inherited by either autosomal dominant, autosomal recessive or maternal (mitochondrial) modes.
- Autosomal recessive ataxias are most common form of inherited ataxia (50%).
- Spinocerebellar ataxia type 2 (SCA2) is the most predominant type of ataxia in northern India, whereas, SCA1 is the most predominant type in southern India.
- To cope up with the disease, physical therapy, speech therapy, and emotional therapy and support are required.

Pictures of the event are available at https://picasaweb.google.com/samataxiagroup/SAMAG NEWDELHICCHAPTERMay102012?authuser=0&feat=directlink.

Members of the Louisiana Chapter

Louisiana Chapter

By Elizabeth Tanner

On April 29, the Louisiana Chapter met at the home of Vicky and Andrea Fantacci in Baton Rouge, LA for a spring picnic and informal meeting.

The Fantacci’s had just finished their new, very-accessible house on the lake, and it was a perfect day for a gathering. We enjoyed great food and company.

The group talked about ideas for future functions, in which part of the state events should be held in order to have the most participants, and the best time of day for events. Possible events that were mentioned were a trip to the aquarium in New Orleans, a wild life tour, and a Fourth of July party.

The Louisiana Chapter recently staffed a booth at the American Academy of Neurology annual meeting in New Orleans, and information from the event was given to members. We thank Joan and Mark Lawrence, Denise Drake, Susan Hammett, Elizabeth Tanner, and Bill and Sue Avery for helping out with the booth.

It was a great day, and the Chapter thanks Pete Martinez of PhRMA for providing the food for the event as well as Vicky and Andrea for the use of their home.
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 family member or friend 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 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. Thank you.

Social Networks

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Moderator – Atilla
www.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 7, 2012 —**

**Central Texas Ataxia Support Group Meeting**

**Time:** 11 a.m. – 1:30 p.m.

**Location:** Dell Children’s Medical Center, 4900 Mueller Blvd., Austin, TX 78723

**Details:** Meets on the first Saturday of every other month. 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 calesbnana2@msn.com. [http://www.ataxia.org/chapters/Linda/default.aspx](http://www.ataxia.org/chapters/Linda/default.aspx)

**West Central FL Ataxia Support Group Meeting**

**Time:** Noon – 3 p.m.

**Location:** USF Morsani Center, 13330 USF Laurel Dr., Tampa, FL

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

**— Thursday, July 12, 2012 —**

**Tri-State Ataxia Support Group Meeting**

**Time:** 6 – 8 p.m.

**Location:** Beth Israel, Phillips Ambulatory Care Center (PACC), 2nd Floor, 10 Union Square, New York, NY

**Details:** For more information contact Denise Mitchell at (212) 844-8711 or markmegan2@gmail.com. [http://www.ataxia.org/chapters/Tri-State/default.aspx](http://www.ataxia.org/chapters/Tri-State/default.aspx)

**— Saturday, July 14, 2012 —**

**1st Annual Tarheel Ataxia Support Group Picnic**

**Time:** Noon – 3 p.m.

**Location:** White Deer Park, Nature Center, 2400 Aversboro Rd., Garner, NC

**Details:** The park is entirely handicapped accessible featuring numerous paved walking/wheelchair trails. Hot dogs/hamburgers/drinks/paper products will be provided. Attendees are encouraged to bring a side dish/dessert. A donation of $5 per adult is encouraged to cover expenses. Please RSVP to Donna Smith at dsmith@sa-pr.com or call (919) 779-0414. [http://www.ataxia.org/chapters/Tarheel/default.aspx](http://www.ataxia.org/chapters/Tarheel/default.aspx)

**Central MN Ataxia Support Group Meeting**

**Time:** 10 a.m. – noon

**Location:** Liberty Bank (1st Floor Conference Room), 111 7th Ave. S., St. Cloud, MN

**Details:** Entrance in rear of building. Please park toward Fitzharris Sports or street side on 7th. For more information please contact Marsha Binnebose at marshabinnebose@yahoo.com or (320) 248-9851. [http://www.ataxia.org/chapters/StCloud/default.aspx](http://www.ataxia.org/chapters/StCloud/default.aspx)

**Greater Atlanta Ataxia Support Group Meeting**

**Time:** 1 – 3 p.m.

**Location:** Emory Center for Rehabilitative Medicine (Room 101), 1441 Clifton Rd., Atlanta, GA 30322

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

**Los Angeles Area Ataxia Support Group Annual Barbecue**

**Time:** 2 – 4 p.m.

**Location:** Home of Jim and Selina Fritz, 2210 Penmar Ave., Venice, CA 90291

**Details:** For more information contact Sherry McLaughlin at (626) 791-1558 or ccherilynmc@yahoo.com.

**North Texas Ataxia Support Group Meeting**

**Time:** 10 a.m. – noon

**Location:** Las Colinas Cancer Center, 7415 Las Colinas Blvd., Irving, TX 75039

**Details:** The group meets the second Saturday of every month. Parking is free and the building is handicap accessible. We meet in the front lobby of the Las Colinas Cancer Center, a one-story building behind the “Regions Bank.” There is a map on their website, [www.LasColinasCancerCenter.com](http://www.LasColinasCancerCenter.com). Most of the meeting time is for sharing and asking questions about the difficulties and successes we have in our everyday life with ataxia. From time to time we do have an outside speaker address some of our concerns from the caregivers, patients and families. For additional information please contact David Henry Jr. at cheve11e@sbcglobal.net. [http://www.ataxia.org/chapters/NorthTexas/default.aspx](http://www.ataxia.org/chapters/NorthTexas/default.aspx)

**Northern CA Ataxia Support Group Meeting**

**Time:** 11:30 a.m. – 2 p.m.
Calendar of Events
Continued from page 41

Location: Our Savior’s Lutheran Church (Recreation Hall), 1035 Carol Lane, Lafayette, CA
Details: The cost to attend is $7 per person with lunch or $4 per person without lunch. RSVP by July 5. For more information please contact Joanne Loveland at joanneloveland@gmail.com. http://www.ataxia.org/chapters/NorthernCalifornia/default.aspx

Tarheel NC Ataxia Support Group Meeting
Time: 1 – 3 p.m.
Location: BestHealth in Hans Mall, 3320 Silas Creek Pkwy, Winston-Salem, NC
Details: Call (336) 713-2378 to RSVP. For more information contact Jerry Hauser at (336) 998-2942 or deaconwfu@msn.com. http://www.ataxia.org/chapters/Tarheel/default.aspx

— Sunday, July 15, 2012 —

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. http://www.ataxia.org/chapters/Chicago/default.aspx

— Saturday, July 21, 2012 —

Denver Area Ataxia Support Group Meeting
Time: 1 – 4 p.m.
Location: Swedish Medical Center, 501 E. Hampden Ave., Englewood, CO 80113
Details: We meet in meeting room Spruce A & B. For more information contact Charlotte DePew at (720) 783-3190 or cldepew77@comcast.net. http://www.ataxia.org/chapters/Denver/default.aspx

Twin Cities Ataxia Support Group Meeting
Time: 10 a.m.
Location: Langton Place, 1910 W. County Rd. D, Roseville, MN 55112
Details: The Twin Cities Ataxia Support Group meets once a month. Family and friends of an afflicted individual are always welcome! We meet on the third Saturday of every month in a meeting room at Langton Place which is located on the south side of the road on County Road D roughly four-tenths of a mile east of I35W in Roseville. We wanted to provide a central location that it easy to access which is why we picked this place. Please join us and make new connections! For more information contact Lenore Healey Schultz at (612) 724-3784 or cshultz.lenore@yahoo.com. http://www.ataxia.org/chapters/TwinCities/default.aspx

— Saturday, July 28, 2012 —

Detroit Area Ataxia Support Group Meeting
Time: 1 – 4 p.m.
Location: Harper Hospital (Wertz Classroom 1237)
Details: Near the main entrance off of John R (3990 John R). For more information contact Tanya Tunstull at (313) 397-7858 or tinyt48221@yahoo.com. http://www.ataxia.org/chapters/Detroit/default.aspx

— Saturday, August 11, 2012 —

Arizona Ataxia Support Group Meeting
Time: 1:30 – 3:30 p.m.
Location: Disability Empowerment Center (DEC), Arizona Bridge to Independent Living (ABIL), 5025 E. Washington St., Suite 200, Phoenix, AZ 85034
Details: For more information contact Rita Garcia at (480) 726-3579 or rtg22@cox.net, or Mary Fuchs at (480) 883-7633 or mary11115@msn.com. http://www.ataxia.org/chapters/Phoenix/default.aspx

Central MN Ataxia Support Group Meeting
Time: 10 a.m. – noon
Location: Liberty Bank (1st Floor Conference Room), 111 7th Ave. S., St. Cloud, MN
Details: Entrance in rear of building. Please park toward Fitzharris Sports or street side on 7th. For more information please contact Marsha Binnebose at marsha.binnebose@yahoo.com or (320) 248-9851. http://www.ataxia.org/chapters/StCloud/default.aspx

Kansas City Area Ataxia Support Group Meeting
Time: 2 – 4 p.m.
Location: Northeast Library, 6000 Wilson Rd., Kansas City, MO.
Details: We meet on the second Saturday every other month. For more information contact Lois Goodman at (816) 257-2428 or Jim Clark at (816) 468-7260 or clarkstone9348@sbcglobal.net. http://www.ataxia.org/chapters/KansasCity/default.aspx

NE Florida Ataxia Support Group Meeting
Time: 1 p.m.
Location: Baptist South Hospital
Details: 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 one-half mile off of the interstate. Directions to
the conference rooms from main entrance: Come in the main entrance and make a right. Go past the first hallway on left and the Azalea, Begonia and Camellia conference rooms will be next doors. The August 12 meeting will be held in the Camellia conference room. For more information please contact John Richwine at sirichwine@aol.com or Steve Brown at bike4brown@aol.com. http://www.ataxia.org/chapters/NortheastFlorida/default.aspx

North Texas Ataxia Support Group Meeting
Time: 10 a.m. – noon
Location: Las Colinas Cancer Center, 7415 Las Colinas Blvd., Irving, TX 75039
Details: The group meets the second Saturday of every month. Parking is free and the building is handicap accessible. We meet in the front lobby of the Las Colinas Cancer Center, a one-story building behind the “Regions Bank.” There is a map on their website, www.LasColinasCancerCenter.com. Most of the meeting time is for sharing and asking questions about the difficulties and successes we have in our everyday life with ataxia. From time to time we do have an outside speaker address some of our concerns from the caregivers, patients and families. For additional information please contact David Henry Jr. at cheve11e@sbcglobal.net. http://www.ataxia.org/chapters/NorthTexas/default.aspx

South FL Ataxia Support Group Meeting
Time: Noon – 3 p.m.
Location: TBA
Details: For more information contact Cindy Steever-Ziegler at (239) 878-3092 or csteever@mson.com. http://www.ataxia.org/chapters/TampaBay/default.aspx

Greater Cincinnati Area
Ataxia Support Group Meeting
Time: 1 – 3 p.m.
Location: Groesbeck Public Library, 2994 W. Galbraith Rd., Cincinnati, OH
Details: For more information contact Jennifer Mueller at (513) 834-7002 or jenmu@yahoo.com. http://www.ataxia.org/chapters/JenniferM/default.aspx

Orange County Ataxia Support Group Meeting
Time: 4 – 5 p.m.
Location: Orange Coast Memorial Medical Center, Breast Cancer Building, Classroom 1A (building nearest Talbort Ave. and Foster St.), 9900 Talbort Ave., Fountain Valley, CA 92708
Details: For more information please contact Daniel Navar at (323) 788-7751 or danieln27@gmail.com. http://www.ataxia.org/chapters/OrangeCounty/default.aspx

Twin Cities Ataxia Support Group Meeting
Time: 10 a.m.
Location: Langton Place, 1910 W. County Rd. D, Roseville, MN 55112
Details: The Twin Cities Ataxia Support Group meets once a month. Family and friends of an afflicted individual are always welcome! We meet on the third Saturday of every month in a meeting room at Langton Place which is located on the south side of the road on County Road D roughly four-tenths of a mile east of I35W in Roseville. We wanted to provide a central location that it easy to access which is why we picked this place. Please join us and make new connections! For more information contact Lenore Healey Schultz at (612) 724-3784 or cschultz.lenore@yahoo.com. http://www.ataxia.org/chapters/TwinCities/default.aspx

Metro Chicago Ataxia Support Group Meeting
Time: 1 p.m.
Location: Ravenwood Chiropractic & Wellness Center, 5215 N. Ravenswood Ave., Suite 105, Chicago, IL
Details: For more information contact Christopher Marsh at (312) 662-1127 or cmarshal34@ameritech.net. http://www.ataxia.org/chapters/ChrisMarsh/default.aspx

Central Texas Ataxia Support Group Meeting
Time: 11 a.m. – 1:30 p.m.
Location: 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. http://www.ataxia.org/chapters/Linda/default.aspx

North Texas Ataxia Support Group Meeting
Time: 10 a.m. – noon
Location: Las Colinas Cancer Center, 7415 Las Colinas Blvd., Irving, TX 75039
Details: The group meets the second Saturday of
Calendar of Events
Continued from page 43

every month. Parking is free and the building is handicap accessible. We meet in the front lobby of the Las Colinas Cancer Center, a one-story building behind the “Regions Bank.” There is a map on their website, www.LasColinasCancerCenter.com. Most of the meeting time is for sharing and asking questions about the difficulties and successes we have in our everyday life with ataxia. From time to time we do have an outside speaker address some of our concerns from the caregivers, patients and families. For additional information please contact David Henry Jr. at cheve11e@sbcglobal.net. http://www.ataxia.org/chapters/NorthTexas/default.aspx

— Saturday, September 8, 2012 —
Central MN Ataxia Support Group Meeting
Time: 10 a.m. – noon
Location: Liberty Bank (1st Floor Conference Room), 111 7th Ave. S., St. Cloud, MN
Details: Entrance in rear of building. Please park toward Fitzharris Sports or street side on 7th. For more information please contact Marsha Binnebose at marshabinnebose@yahoo.com or (320) 248-9851. http://www.ataxia.org/chapters/StCloud/default.aspx

Los Angeles Area Ataxia Support Group Meeting
Time: 2 – 4 p.m.
Location: TBA
Details: For more information contact Sherry McLaughlin at (626) 791-1558 or cherilynmc@yahoo.com.

West Central FL Ataxia Support Group Meeting
Time: Noon – 3 p.m.
Location: USF Morsani Center, 13330 USF Laurel Dr., Tampa, FL
Details: For more information contact Cindy Steever-Ziegler at (239) 878-3092 or csteever@msn.com. http://www.ataxia.org/chapters/TampaBay/default.aspx

— Wednesday, September 12, 2012 —
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. http://www.ataxia.org/chapters/Willamette/default.aspx

— Thursday, September 13, 2012 —
Tri-State Ataxia Support Group Meeting
Time: 6 – 8 p.m.
Location: Beth Israel, Phillips Ambulatory Care Center (PACC), 2nd Floor, 10 Union Square, New York, NY
Details: For more information contact Denise Mitchell at (212) 844-8711 or markmeghan2@gmail.com. http://www.ataxia.org/chapters/Tri-State/default.aspx

— Saturday, September 15, 2012 —
Detroit Area Ataxia Support Group Meeting
Time: 1 – 4 p.m.
Location: Harper Hospital (Wertz Classroom 1237)
Details: Near the main entrance off of John R (3990 John R). For more information contact Tanya Tunstill at (313) 397-7858 or tinyt48221@yahoo.com. http://www.ataxia.org/chapters/Detroit/default.aspx

Twin Cities Ataxia Support Group Meeting
Time: 10 a.m.
Location: Langton Place, 1910 W. County Rd. D, Roseville, MN 55112
Details: The Twin Cities Ataxia Support Group meets once a month. Family and friends of an afflicted individual are always welcome! We meet on the third Saturday of every month in a meeting room at Langton Place which is located on the south side of the road on County Road D roughly four-tenths of a mile east of I35W in Roseville. We wanted to provide a central location that it easy to access which is why we picked this place. Please join us and make new connections! For more information contact Lenore Healey Schultz at (612) 724-3784 or cshultz.lenore@yahoo.com. http://www.ataxia.org/chapters/TwinCities/default.aspx

— Sunday, September 16, 2012 —
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. http://www.ataxia.org/chapters/Chicago/default.aspx

— Saturday, September 22, 2012 —
Central New York Ataxia Support Group Meeting
Time: 1 – 3 p.m.
Location: North Syracuse Community Center,
700 South Bay Rd., North Syracuse, NY 13212
Details: For more information contact Judy Tarrants at jtarrants@aol.com or (315) 683-9486. http://www.ataxia.org/chapters/CentralNewYork/default.aspx

INFORMATIONAL AND AWARENESS EVENTS

— Sunday, September 9, 2012 —

Denver Run, Walk n’ Roll for Ataxia
Time: 8 – 11 a.m.
Location: Denver City Park, 17th St. & York St., Denver, CO
Details: All participants are requested to donate or raise a minimum of $30. To volunteer or for more information please contact Keri Naccarato at kfragola@yahoo.com or (720) 982-9562. All proceeds benefit NAF. www.denverataxiawalk.org

— Saturday, September 15, 2012 —

Auburn Walk N’ Roll for Ataxia
Time: 10 a.m.
Location: Pappas Recreation Complex, Auburn, MA
Details: To volunteer or for more information contact John Mauro at johnmauro@verizon.net or (508) 736-6084. All proceeds benefit NAF.

Bowling Green Park & Recreation
IAAD Pull Up Competition
Time: 10 a.m.
Location: City of Bowling Green Fitness Center, 225 E. Third St., Bowling Green, KY
Details: For more information contact Michael Carter at cartermw@yahoo.com.

Concord Walk, Roll n’ Swim for Ataxia
Time: 9:30 a.m. – 2 p.m.
Location: Montecito Oakmont Senior Living & Newhall Park, 4756 Clayton Rd. & 5000 Newhall Pkwy, Concord, CA.
Details: For more information contact Brian Petersen at (925) 953-3733 or smileypetersen@yahoo.com. All proceeds benefit NAF.

Minnesota Walk, Stroll N’ Roll for Ataxia
Time: 9 a.m. registration (refreshments and social), 10 a.m. walk begins, 10:45 a.m. program (speakers and drawing)
Location: Wolfe Park in St. Louis Park, MN
Details: To volunteer or for more information please contact Terry Sweeney at mnataxiawalk@yahoo.com. All proceeds benefit NAF. https://naf.myetap.org/12MNWNR/

— Saturday, September 22, 2012 —

Atlanta Walk n’ Roll for Ataxia
Time: 9:30 a.m. registration, 10 a.m. walk begins
Location: Shorty Howell Park, 2750 Pleasant Hill Rd., Duluth, GA
Details: All proceeds benefit NAF. For more information contact the Atlanta Ataxia Support Group at atlantaatxia@gmail.com. https://naf.myetap.org/12atlantawnr/

Detroit Walk N’ Roll for Ataxia
Time: On-site registration 9 – 11 a.m. Walk begins at 11 a.m. followed by raffle and picnic.
Location: William G. Miiken State Park, 1900 Atwater (between Orlean and St. Aubin), Detroit, MI
Details: To volunteer or for more information, contact Tanya Tunstull at tinyt48221@yahoo.com or (313) 736-2827. All proceeds benefit NAF. https://naf.myetap.org/12DetroitWnR/

Kansas Walk n’ Roll for Ataxia
Time and Location: TBA
Details: For more information contact Jalean Retzlaff at (316) 303-2351 or jlrtrolls@yahoo.com.

LA/OC Walk N’ Roll for Ataxia
Time: Registration begins at 8:00 a.m. Walk N’ Roll starts at 9:00 a.m.
Location: Shoreline Aquatic Park, Long Beach, CA.
Details: Reserve your Walk N’ Roll T-shirt by registering early. For more information please contact Daniel Navar at danielin27@gmail.com or (323) 788-7751, Cindy DeMint at (714) 329-4437 or chatdots@sbcglobal.net, or Sherry McLaughlin at (626) 791-1558 or ccherilynmc@yahoo.com. All proceeds benefit NAF. https://naf.myetap.org/12LAOCWNR/

— Saturday, September 29, 2012 —

International Ataxia Awareness Day
Details: 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

BINGO for Ataxia
Time: 5:30 p.m.
National Ataxia Registry Update

We are excited to report that a scientific poster on the National Ataxia Registry was featured at the Ataxia Investigators Meeting and the Academy of Neurology Meeting.

We encourage you to enroll in the Registry at www.NationalAtaxiaRegistry.org.

If you have begun the process, and received the Informed Consent Form, you must sign the form, scan it and e-mail it to nationalataxiaregistry@neurology.ufl.edu, fax it to (352) 392-8058 or mail it back to complete the enrollment. We encourage those of you who have not completed this important step to do so soon.

If you have questions please contact the Ataxia Research Coordinator at (352) 273-9194.

Those attending the Faire will be invited to participate. We will have an instructor teaching yoga and chair yoga, a physical therapist, a chiropractor, and a strength trainer, all whom have worked with individuals who have movement disorders.

The Walk n’ Roll will be part of the Faire. Registration for the day will be $25. Lunch will be included in the registration. There will be raffle items to win. The winner of a drawing to win an Apple iPad will be announced. Mark your calendar and plan to attend. For more information contact Joanne Loveland at joaneloveland@gmail.com. https://naf.myetap.org/12NCAWnR/

San Diego Walk N’ Roll for Ataxia
Time: Registration from 7 – 8 a.m.; walk starts at 8:00 a.m.
Location: Tuna Harbor Park (next to the Midway Museum), San Diego, CA
Details: To volunteer or for more information, please contact the event committee by phone at (619) 442-0415, fax at (619) 442-0592, or by email at sdwnr@ataxia.org. All proceeds benefit NAF.

Central Texas Walk N’ Roll for Ataxia
Time: 9:00 a.m.
Location: San Gabriel Park (Area A), 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. All proceeds benefit NAF. https://naf.myetap.org/12TXWnR/

Dewayne’s Walk, Run N’ Roll for Ataxia
Time: 7:30 a.m.
Location: First Baptist Church, 441 Lewie St., Gilbert, SC 29054
Details: For more information or to volunteer please contact Anna Hite at (803) 532-2447 or doca35@att.net. All proceeds benefit NAF.
Memorials and In Your Honor

The National Ataxia Foundation is grateful to those who have made contributions in memory or in honor of their friends and families whose names are listed below. This list reflects contributions made in March 2012 through May 2012. 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.


**Remembering NAF in Your Will**

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

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

Please consider remembering NAF in your will, and making a difference in the lives of ataxia families.

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

### GIFT – HONOR – MEMORIAL

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

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

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

My contribution is:
- [ ] In Memory
- [ ] In Honor
- [ ] Gift Membership

Name ________________________________
Occasion ________________________________

Send Acknowledgment Card to:
Name ________________________________
Address ________________________________
City/State/Zip ____________________________

### 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 ________________ CVV # ________________
Signature ________________________________
Phone Number ________________________________