

Generations

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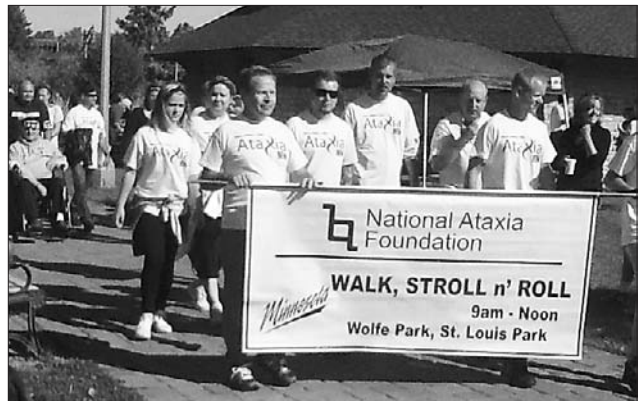
Summer 2014



International Ataxia Awareness Day (IAAD)

Creating Ataxia Awareness

The goal of International Ataxia Awareness Day (IAAD) is for everyone who is impacted by ataxia to participate in some activity, creating awareness about ataxia. Sharing your story with one other person who has never heard of ataxia, educating others by speaking at a school or civic group, getting in touch with your local media, or wearing ataxia awareness apparel on IAAD. Many have contacted city, county, or state government officials to receive a proclamation recognizing September 25 as IAAD. Others start or participate in an IAAD event, get involved or organize a Walk n' Roll for Ataxia, or participate in the Global Online Walk n' Roll.



Inside This Issue


- **International Ataxia Awareness Day** info is on pages 1-6
- Learn about **Coping with Depression and Anxiety** on pages 8-16
- Learn more about the **2015 AMM** and hotel reservations on page 23
- **Dealing with Denial** from Dr. James J. Messina appears on page 30
- The **Calendar of Events** on pages 51-55 will help you plan your summer and fall

Through IAAD, NAF Chapters, Support Groups, Ambassadors, and members have created ataxia awareness throughout the United States, better informing their communities about ataxia.

Make plans today to take part in IAAD activities and to make a difference in the lives of those with ataxia.



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The deadline for the Fall issue of Generations is Friday, August 15, 2014

International Ataxia Awareness Day (IAAD)

— Thursday, September 25, 2014 —

Chances are that if you had stopped 100 people on the street anywhere in the world 20 years ago and asked the question, “What is ataxia?” not one would have had an answer. From that question, a new initiative was born ... International Ataxia Awareness Day (IAAD). IAAD is an international effort from ataxia organizations around the world to dedicate September 25 as International Ataxia Awareness Day. The first IAAD occurred on September 25, 2000 and was the first time that ataxia organizations throughout the world declared and recognized September 25 as IAAD.

For Immediate Release

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FIFTEENTH ANNUAL INTERNATIONAL ATAXIA AWARENESS DAY

Chances are that you have never heard of ataxia. That is why the National Ataxia Foundation and other ataxia organizations throughout the world have declared September 25, 2014 as “International Ataxia Awareness Day” to help get the word out about ataxia.

Ataxia is a group of rare and often fatal degenerative neurological disorders. An estimated 150,000 people in the United States are affected by ataxia. Symptoms are progressive and often impact coordination, hearing, vision, and speech. Ataxia affects both genders and all ages, but too often ataxia strikes children and young adults. At this time, there is no effective treatment or cure for ataxia.

“The National Ataxia Foundation was established in 1957 and is dedicated in serving ataxia families through research, education, and support services,” says Michael Parent, the Executive Director of the National Ataxia Foundation. Parent continued, “Ataxia can affect anyone at any time and is caused by either a recessive or dominant gene. There are also sporadic forms of ataxia which have no known genetic link or family history.

In the dominant forms of ataxia, each child born has a 50/50 chance of developing the disorder. In the case of recessive forms, each child born has a 25% chance of being affected, a 50% chance of being a carrier, and only a 25% chance of not being affected or a carrier of the gene. In the recessive forms of ataxia, many times people do not know that they carry an ataxia gene until their child begins to display signs of in-coordination.

(Please share your personal story on how ataxia has impacted you and your family as part of this press release.)

To find out more about ataxia, visit the National Ataxia Foundation’s website at www.ataxia.org. You may also write the Foundation at 2600 Fernbrook Lane, Suite 119, Minneapolis, MN 55447-4752, email at naf@ataxia.org, or call (763) 553-0020.

-30-

Awareness Tools

The sample IAAD Press Release (left) and sample Proclamation (right) can aide you in contacting others and spreading the word about ataxia. These samples and other awareness tools can be found in the IAAD Kit available on NAF’s website at www.ataxia.org or by contacting the NAF office at (763) 553-0020.

Proclamation

International Ataxia Awareness Day
September 25, 2014

WHEREAS, the National Ataxia Foundation strives to meet the goals of:

- 1) Location of patients and persons at risk, NAF encourages a complete neurological examination to make early and correct diagnosis.
- 2) Increased awareness about ataxia. NAF assures that accurate information about ataxia will be available through a variety of educational programs for physicians, allied health professionals, and the public.
- 3) Prevention of the spread of these disorders. NAF encourages genetic counseling to help affected individuals and families make informed decisions about family planning.
- 4) Research. In addition to its own research efforts, the NAF supports those research projects that are designed to better understand the pathology and cause of the ataxia, or to institute new treatments based upon scientific data. The NAF helps to coordinate research efforts into the causes and early detection of ataxia through existing centers throughout the world.

WHEREAS, an estimated 150,000 individuals are affected by hereditary and sporadic ataxia in the United States.

WHEREAS, ataxia is an often fatal degenerative neurological disorder that affects balance, coordination, and speech.

WHEREAS, ataxia can strike anyone at any time, without regard to age, gender, race or creed.

WHEREAS, there is NO known cure, the only defense is research and prevention through education.

NOW THEREFORE, I _____ of the _____ hereby proclaim September 25, 2014 as INTERNATIONAL ATAXIA AWARENESS DAY in _____ and urge all citizens to honor and support those individuals with ataxia and their care givers, in the hope that a cure will soon be found.

IN WITNESS WHEREOF, I have hereunto set my hand and have caused the seal of the _____, 2014.

Get Involved

International Ataxia Awareness Day has grown over the years, with more ideas and more people getting involved. It will be celebrated on Wednesday, September 25. To find out how you can get involved, please download the IAAD Kit on NAF’s web site, www.ataxia.org, on the IAAD page under the Event Section. On NAF’s web site you will also find all the IAAD events near you on the Event Calendar under the Event Section.

How Did You Participate in IAAD?

Tell us how you recognized International Ataxia Awareness Day (IAAD) this year. Share a photo with us for a future issue of *Generations*. Please email your story/photo to joan@ataxia.org or mail to the National Ataxia Foundation, Attn: *Generations* Editor, 2600 Fernbrook Lane, Suite 119, Minneapolis, MN 55447-4752.

Sharing your stories on how the day was recognized could live on in a future issue of *Generations*. Please send us your articles, photos, and proclamations so the entire NAF community can relive this historic day.

Thank you.

Walk n' Roll for Ataxia

The ultimate finish line ... a cure for ataxia

In recognition of IAAD, NAF Walk n' Rolls for Ataxia began seven years ago to help create ataxia awareness and to raise funds to help support the important work of NAF. The first Walk n' Roll was hosted by the San Diego Ataxia Support Group, led by Earl McLaughlin, their Support Group Leader.

Over the past seven years, NAF Walk n' Rolls for Ataxia have been conducted throughout the United States and has raised more than \$900,000 to support research and programs. Participating, organizing, or donating to a local Walk n' Roll is now easier through a new web-based fund raising module called Friends Asking Friends (FAF). On NAF's website, www.ataxia.org, select your local support group who is conducting a Walk n' Roll and click to their site. You are able to participate, donate, create a team, register, or let others know about the event.

What is Walk n' Roll for Ataxia?

The Walk n' Roll for Ataxia program is the National Ataxia Foundation's largest national grass-roots fundraising event. Walk n' Roll for Ataxia currently takes place in cities across the U.S. Since its inception in 2007, Walk n' Roll for Ataxia has raised more than \$900,000 thanks to the support and tireless commitment of walkers, rollers, runners, volunteers, donors, and sponsors.

Why Walk or Roll?

Thousands of families, friends, co-workers, neighbors, and communities come together each year to support NAF's fight to improve the lives of people affected by ataxia and their families.

How Can I Participate?

For more information, or to start a Walk n' Roll in your community, please contact Lori Shogren, NAF Special Projects Coordinator, at (763) 553-0020 or lori@ataxia.org.

Now through September 25

- **Global Online Walk n' Roll** www.ataxia.org/walk/virtual

Upcoming Walk n' Roll Events & Locations

- Denver Walk n' Roll, Denver, CO – September 7
Contact: Charlotte DePew cldepew77@comcast.net
www.ataxia.org/walk/denver
- Minnesota Walk, Stroll n' Roll, St. Louis Park, MN – Sept. 13
Contact: Terry Sweeney mnataxiawalk@yahoo.com
www.ataxia.org/walk/minnesota
- Atlanta Walk n' Roll, Duluth, GA – September 20
Contact: Greg Rooks atlantaataxia@gmail.com
www.ataxia.org/walk/atlanta
- LA/OC Walk n' Roll, Long Beach, CA – September 20
Contact: Daniel Navar danieln27@gmail.com
www.ataxia.org/walk/longbeach ▶▶



- New England Walk n' Roll, Auburn, MA – September 20
Contact: John Mauro johnmauro62@me.com
www.ataxia.org/walk/auburn
- San Diego Walk n' Roll, San Diego, CA – September 27
Contact: Earl McLaughlin emclaugh@cox.net
www.ataxia.org/walk/sandiego
- Seattle Walk n' Roll, Seattle, WA – September 27
Contact: Milly Lewendon mmlewendon@comcast.net
www.ataxia.org/walk/seattle
- Michigan Walk n' Roll, Ann Arbor, MI – October 4
Contact: Elizabeth Sullivan elizsull@umich.edu
or Tanya Tunstull tinyt48221@yahoo.com
www.ataxia.org/walk/michigan



**For more information on
Walk n' Roll for Ataxia events
and locations, please visit
www.ataxia.org/events/walk_n_roll.aspx**



Global Online Walk n' Roll for Ataxia

If there is not a local NAF Walk n' Roll for Ataxia in your area ... we have some very exciting news ... NAF's Global Online Walk n' Roll. You can create your own team, have a friendly competition with a friend, family member or co-worker and begin creating ataxia awareness and raising funds to support the mission of NAF. On NAF's web site, www.ataxia.org, click "Global Online Walk n' Roll" and you will be able to enter NAF's "Global Online Walk n' Roll."

After you register through the event website you are automatically signed-up as a Global

Online Walk n' Roll participant. 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. If you wish to contribute without becoming a participant, please click "General Donation" to help out the Global Online Walk n' Roll in meeting our fundraising goal.

Continued on page 6

International Ataxia Awareness Day
Continued from page 5

International Reach

IAAD helps create ataxia awareness, but IAAD also creates a way to raise much needed funds. Funds raised through NAF Walk n' Rolls and other NAF IAAD events have helped support vital ataxia research studies not only here in the United States, but also has helped fund promising ataxia research in other countries. The International Ataxia Awareness Day impact is international. Without the involvement of NAF Chapters, Support Groups, Ambassadors, and members, many of these important ataxia research studies would have gone unfunded.

IAAD Events

Other exciting IAAD events planned include "Jeans Day" where on September 25 employees

are allowed by their employer to wear jeans at work on that day with a donation to NAF. Various restaurants are donating a percentage of sales to NAF during IAAD, group and family picnics, BINGO events, and many others. Bringing the word "Ataxia" to local communities throughout the country.

Many of the IAAD Events and fundraisers are printed in the Calendar of Events listing located in the back of this issue of *Generations*. (starting on page 51). For the most current event information, details and links, please visit the NAF event calendar at www.ataxia.org.

To purchase ataxia awareness apparel or items visit the NAF Merchandise at right, or visit NAF's online store at <http://tinyurl.com/nafstore>.

Thank You

Thank you to all who are creating ataxia awareness on IAAD and throughout the year. ❖

IAAD Apparel

Create ataxia awareness by wearing an "I am the Strength behind ataxia" T-shirt or other ataxia awareness apparel. You can order apparel online at www.ataxia.org (click "Store") or using the order form to the right.



International Ataxia Awareness Day (IAAD) on September 25 is just around the corner, so order your ataxia awareness apparel today!

Faces and Facts of Disability

The following article was published in the June Newsletter at <http://www.socialsecurity.gov/newsletter/>

Social Security touches the lives of many Americans, often during times of hardship, transition, or uncertainty. Our benefit programs – retirement, survivors, and disability – offer financial protection for people and families when they need it most.

Our new website and campaign – *The Faces and Facts of Disability* – provides facts about the Social Security Disability Insurance, or SSDI, program, as well as personal stories about the people helped by disability benefits.

The numbers and facts are important. But the inspiring stories of real people – our neighbors, family and friends – tell the real story of what Social Security disability benefits are all about.

Find out for yourself at www.socialsecurity.gov/disabilityfacts.

NAF Merchandise

BOOKS

Healing Wounded Doctor-Patient Relationships
by Linda Hanner with contributions by John J. Witek, MD \$10

Living with Ataxia: An Information and Resource Guide by Martha Nance, MD (2nd ed. 2003) \$14

Managing Speech and Swallowing Problems: A Guidebook for People with Ataxia
by G.N. Rangamani, PhD with contributions from Douglas E. Fox, MS (2nd ed. updated 2006) \$7.50

Ten Years to Live
by Henry J. Schut \$8.75

There's Nothing Wrong with Asking for a Little Help ... and Other Myths
by Dave Lewis \$15.95

Recipes and Recollections
by Kathryn Hoefler Smith \$10

Cooking for a Cause
by Julie Karjalanti for FRDA research \$12

VIDEO/CD

Ballads of a Family Man CD \$5
Together There is Understanding VHS \$20 **DVD** \$25

SHIRTS/MISCELLANEOUS

Original NAF IAAD T-Shirt S & XXXL only \$10
NAF Baseball Cap (White or Blue) \$10

IAAD T-Shirt Sizes S to XXXL \$10
Past Annual Membership Meeting (AMM) T-Shirts \$1 each while supplies last!
NAF Polo Shirts \$25
Mens – Royal blue w/ white NAF logo S, M, L & XXXL
Light blue w/ royal blue NAF logo in L to XXXL
Womens – Light blue w/ navy NAF logo in S to XXL
NAF Denim Shirt w/ white NAF logo \$27.50
“Ataxia is Not a Foreign Cab” T-Shirt \$10
White sizes S to XXXL
“Ataxia is Not a Foreign Cab” Long-Sleeve T-Shirt
Light blue sizes S to XXXL \$15
“Ataxia is Not a Foreign Cab” Sweatshirt
White sizes S to XXXL \$20
NAF 50th Anniversary Coffee Mug \$3
“Ataxia is Not a Foreign Cab” Magnet \$1
Window Cling or Bumper Sticker \$1 ea. or 6 for \$5
NAF Ataxia Awareness Band Blue
One size \$2 ea. or 3 for \$5
NAF Ataxia Awareness Ribbon Magnet \$4
Reusable Grocery Bag w/ NAF and Cab Logos \$5
“Know Ataxia” Backpack 20”x16” \$5
NAF Grip n’ Sip Water Mug \$5 **NAF Lapel Pin** \$5
Magnetic Power Clip \$3
NAF Shoulder Bag \$10

To place your order, call (763) 553-0020, fax (763) 553-0167, mail a copy of this form to National Ataxia Foundation, 2600 Fernbrook Lane, Suite 119, Minneapolis, MN 55447 or visit <http://tinyurl.com/nafstore>

ORDER FORM

Description	Qty.	Size	Each	Total
SUBTOTAL:				
Shipping within U.S.:			Add \$5.00	
Shipping outside U.S.:			Add \$15.00	
ORDER TOTAL:				

NAME: _____
ADDRESS: _____
CITY _____ **STATE:** _____ **ZIP:** _____
PHONE: _____
E-MAIL: _____

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

PLEASE CIRCLE ONE: Visa Mastercard Discover

NAME ON CARD: _____
CARD #: _____
EXP DATE: _____ **CVV #:** _____
SIGNATURE: _____

PLEASE ALLOW 4-6 WEEKS FOR DELIVERY

Coping Effectively with Depression and Anxiety: Considerations for People Living with Ataxia and their Family Members

By Roseanne D. Dobkin, PhD, Associate Professor of Psychiatry at the Rutgers-Robert Wood Johnson Medical School

The following was presented at the 2014 NAF Annual Membership Meeting in Las Vegas, NV and edited for publication in Generations.

I am going to talk about coping effectively with depression and anxiety in ataxia. My presentation is geared towards coping strategies that are helpful for both people living with ataxia as well as their loved ones.

My three main objectives are to:

- Provide a brief overview of some of the non-motor or psychiatric complications that are frequently experienced by people with ataxia.
- Discuss the applications of Cognitive Behavioral Therapy (CBT) to the treatment of depression and anxiety in ataxia.
- Present some of my preliminary research data on the use of CBT for treating the depression and anxiety that commonly occurs with movement disorders.

Psychiatric Symptoms in Movement Disorders

This is a review of the more common non-motor or psychiatric complications that we may see in people with movement disorders.

Depression refers to any change in your mood that you are not so happy about, such as feeling a little bit down, or low, or blue, or not quite as good as you would like to feel. It doesn't have to be the severe type of major depression where someone is crying all day. Symptoms that are not that "severe" but are having an impact on your day-to-day functioning and your quality of life warrant attention.

If you get nothing else out of this presentation, I want to emphasize that you don't need to suffer

in silence. If your mood is not as good as you would like it to be, there is help available. Even if you are a little bit down, it is something that is worth addressing with your healthcare team.

Another symptom of depression that can be a clue that some intervention might be necessary, is when people are not interested in doing the things that they normally like to do. As an example:

I hate to clean my house. I've never liked cleaning my house. That really is not a sign of depression; that is just something I don't like doing. However, I love playing with my kids, I love going out to dinner with my husband, I love taking little weekend day trips; if I lost my interest in doing those kind of things then I should be concerned. Again, it's a loss of interest in the things that you normally like to do.

Those are the two key, cardinal symptoms of depression, to be mindful of:

- Your mood is not as good as you would like it to be
- Not having zest or enthusiasm for the things you normally like to do

Anxiety is another common symptom that comes up and people will ask:

"Doctor, what's the difference between depression and anxiety? They seem the same to me."

Depression is really about sadness, feeling low or blue, or not having the enthusiasm to pursue your goals in life; anxiety really focuses more on worry, fears about the future, fears about ►►

specific situations, or nervousness.

Sleep problems often come up for people with movement disorders. It could be trouble falling asleep or staying asleep. Sleep apnea is common. There is a condition called REM Behavior Disorder that sometimes comes up when people start to actually enact their dreams and they can end up hurting themselves.

Fatigue is feeling exhausted all of the time.

Psychosis is a fancy word that refers to having some beliefs that are extreme or unusual, such as believing that you have special powers or that people are out to get you. It can include unusual sensory experiences like seeing things that other people can't see, or hearing things that other people can't hear.

Impulse Control Disorders are changes in personality where people might start spending more money, gambling, or behaving in a way that is uncharacteristic for them.

Cognitive Changes is a category that falls under the umbrella of non-motor concerns that includes having more difficulties with planning, problem solving, memory and attention.

So what do we know about psychiatric problems in movement disorders?

They are very common and affect the majority of those diagnosed, with prevalence rates in ataxia that range anywhere from 20-75%. The numbers vary greatly depending on who did the study, where the study was done, the type of methodology that was used, as well as the specific type of ataxia that was being explored. They have a major impact on functioning. Many of the psychiatric complications are associated with a faster rate of physical and cognitive decline. They cause greater decrements in self-care and they also negatively affect quality of life and relationships. They are under-diagnosed and

sub-optimally treated, which is the subject of my research.

The good news is that these are all aspects of the medical condition over which you have control. Nobody in this room had any choice in the diagnosis but we all have a choice in the coping response. I will share some tips that might help facilitate coping as effectively as possible with a very difficult medical condition.

Cognitive-Behavioral Therapy

Cognitive-behavioral therapy (CBT) provides a comprehensive framework to facilitate adaptive coping with chronic medical conditions. CBT

is evidence-based psychotherapy with substantial empirical support for its use in other medical populations. It targets thoughts and behaviors and how they are related to the onset and the maintenance of depression and anxiety. It is very suitable for addressing psychiatric concerns in ataxia as well as other movement disorders.

This type of treatment is a structured and active approach. There are goals at every session and specific activities that will link up

to the goals that are a part of the broader treatment plan. It focuses on concrete coping skills, learning how to respond differently and how to apply different skills to the various challenges that you are confronted with on a daily basis. The frequency and the intensity of the practice matters. You can read about it, you can talk about it, you can understand it, but if you don't do it, it is not going to help you. The more you do it, the more you practice, the better you're going to feel.

Some examples of the concrete coping skills are breathing, relaxation training, and goal setting. It can be beneficial, if every day when you wake up, you set three concrete, specific, and realistic goals for yourself, and let the goals provide



Dr. Roseanne D. Dobkin

Coping Effectively with Depression and Anxiety...
Continued from page 9

structure for the day. I ask everyone to have an exercise goal, a social goal and a goal in one other area that are realistic, achievable and doable.

I suggest that when you get up in the morning and are starting your day, ask yourself: "What's my exercise goal for today? Do I want to try to do 15 minutes of yoga or stretching in the morning and another 15 minutes later in the day?"

Social goals might be: "Do I want to return that phone call? Do I want to go to Starbucks and be around other people?"

Other activity goals might include: "Do I want to spend 20 minutes organizing some of that paperwork that's been piling up on my desk because I've been too stressed to tackle it?"

We also talk about "Acting according to goals and not according to feelings." Many times somebody will say, "Dr. Dobkin, I really wanted to follow-up with that referral for speech therapy but I just didn't feel like it ... so I couldn't do it." My response is, "If I didn't do the things that I didn't feel like doing, especially on the administrative side of my job, I wouldn't have a job anymore."

So your feelings, especially if you are feeling depressed or anxious, are going to lead you down the wrong path. Appropriate goals won't. I suggest that you set your goals for the day and let your goals drive what you do or what you don't do, not your feelings. Because if you are coming from a place of high stress, or are down in the dumps, or are really worried or concerned, feelings can mislead you. Under normal circumstances our feelings are really good indicators as to what we should be doing or not doing. But high stress, depression, anxiety, these are not normal circumstances. So set your goals, and let your goals drive you.

Ataxia and other medical conditions are challenging enough to deal with in and of themselves. Excessive negative thinking makes it

that much harder to deal with a very difficult situation. So we want to try to keep our thoughts balanced and in perspective.

CBT is very amenable to family involvement. I like all of the family members, spouses, and close friends, who are interested and available, to be connected to the patient's treatment program. That is beneficial because it can facilitate the practice of new coping skills at home. When the support system learns the skills, not only can they help the patient to practice and reinforce the treatment material at home, they can also use the skills to help themselves.

There are multiple techniques and modules that fall under the umbrella of CBT. Everybody is different; all types of ataxia are different. Non-motor complications present differently for each person. CBT offers a way to address and target psychiatric complexities with an individualized and tailored approach. Importantly, there are several cognitive techniques that nicely target thoughts we might have about what it means to live with a chronic medical condition.

The last point I want to emphasize is that in movement disorders there is a very strong and direct relationship between mood and motor function. Optimizing your mood can make it easier to deal more effectively with the complications of motor disability. With ataxia, we know that there are structural and brain function changes that take place that may have an impact on mood responses. However, we also know that what people "do" or "don't do" in response to having the diagnosis and living with a medical condition, as well as how they think about themselves, their world and, their future, can have a direct impact on a person's mood and overall functioning.

The good news is that we don't have to worry about what came first, what set off the depressive or anxious cycle in motion. Was it the biology? Was it the behavioral coping response? Was it a person's thoughts? It doesn't really matter. Intervening anywhere in that cycle ►►

can help and I love intervening in those bottom two bubbles, (see Diagram 1) in the CBT diagram because our thoughts and behaviors are tangible, they are directly accessible to us, we can modify them and we can take control.

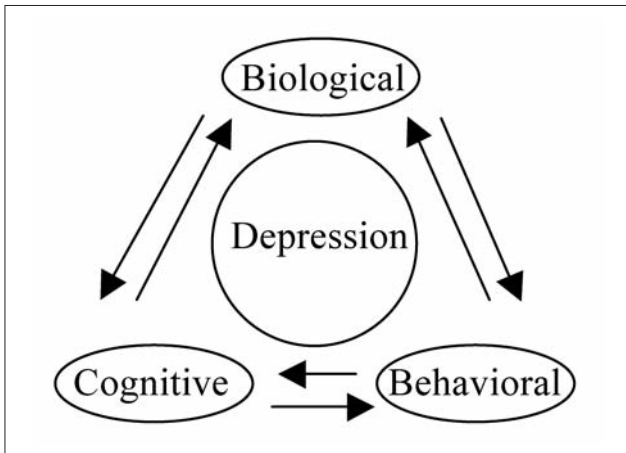


Diagram 1: This diagram shows that there are multiple, interacting causes in depression or anxiety. You can substitute any negative feeling or word that you might want to include the center bubble.

Examples of Patient Interventions

To start, I like to help people increase their involvement in meaningful and social activities. The more opportunities that we have to participate in things that provide us with reward or mastery or pleasure during our day-to-day life, the better. This is not about being busy for the sake of being busy. I don't want people to do things just for the sake of doing them. It is about how to incorporate meaningful things in our day-to-day life despite the physical limitations that ataxia causes which might give us an opportunity to feel good about ourselves.

Increasing meaningful and social activities

Old: Are there old things that you can 100% still do, but maybe you are not participating in those activities anymore because you are depressed or anxious or you just don't feel like doing them? Or, especially in newly diagnosed cases, it's not uncommon for people to overestimate the extent of their physical disability. As the movement disorder progresses, often people tend

to underestimate their ability to cope with whatever challenges come up. Both of those thinking errors can impact the person's involvement in meaningful and pleasurable activities. There might be old activities that we can experiment with and maybe they are very suitable to continue being a part of a person's repertoire.

New: Or maybe we need to find new activities to replace the things that physical limitations now render impossible. You can't replace something with nothing. You've got to replace something with something. And there are lots of options. I have seen people find their creative side and become interested in painting or poetry or even photography.

One example is a fireman whom I had worked with for years. As his movement disorder progressed, he was not in the physical shape that was necessary to fight fires. He became very depressed and cut himself off from all of his friends at his local fire station. We worked on a treatment: once a week he would go to the firehouse with his wife and bring coffee and sandwiches and they would just hang out and visit. That worked well and got him reconnected to an area in his life that was important to him. Once he became comfortable with that, he actually started to coordinate some of the fundraising activities for the volunteer fire department. So even though he was not able to go out and fight fires anymore, he could still be involved in a very meaningful and important way.

Modified: It doesn't have to be all or nothing. You might not be able to do something exactly the same as you used to do it, but it doesn't mean that you can't do it at all. So maybe you can't go for a five-mile run anymore, but that does not mean that you can't exercise; you can go for three 10-minute walks or practice yoga or some other activity.

Think of what old activities you can bring back in to your daily repertoire, what new activities

Coping Effectively with Depression and Anxiety...
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you might try to replace the things you are no longer able to do, and how can you modify some of the things you really love so that they are still feasible and workable given the limitations caused by the medical condition.

Anxiety management and relaxation training: Take five or ten minutes a day and try to focus in great detail on a scene or an image that is completely incompatible with anxiety. It doesn't matter what it is, and it is different for each person. It could be the beach, the mountains, it could be your favorite restaurant, even thinking about the smell of cinnamon buns baking in the oven. Whatever it is, give yourself that break to really focus on something that's calm and peaceful, and incompatible with feeling anxious.

Worry control technique: If you practice scheduling "worry time" every day for two weeks, you will start to see an effect. Instead of allowing the worries to take over your entire day, schedule a time for them. If they are that important, they should be on your agenda. Perhaps schedule 9-9:15 in the morning and when the buzzer goes off at 9:15 the time is over and you're done. If the worries come up, "kick the can" down the road until the next morning at 9:00 a.m. What happens is that if you consistently practice scheduling and postponing worries, they stop coming up. There is something about "kicking the can" down the road that decreases the importance and saliency of the worry.

Sleep hygiene is important: Follow a clear and consistent sleep schedule. Go to bed and get up at about the same time every day. Limit excessive time in bed. You shouldn't be hanging out in bed surfing the web or watching movies if you have sleep problems. If you sleep fine, this does not apply to you, but for people who are

struggling with sleep, limit time in the bed to sleep and sleep only.

Thought monitoring and restructuring: This is accomplished by rethinking the big picture which involves catching a negative thought, pressing pause on it, rewinding it, and replaying it in a more balanced way. It is important for people to have realistic views and perceptions of themselves, their world and their future. Not overly optimistic and unrealistic, but not so skewed to the negative that the thought is going to make coping even more difficult than it needs to be.

Thought Log: A tool that you can use to track your negative thoughts. Catching your negative thoughts is the first step to changing them. The illustration below shows how different thoughts about the same situation can lead to very different emotional responses.

Thought Log Example

<i>Situation</i>	<i>Emotion</i>	<i>Thought</i>
Newly diagnosed with Ataxia	Hopeless	My life is ruined. I have no control.
Newly diagnosed with Ataxia	More Hopeful	I wish this didn't happen, but I know I can still have a meaningful life.

We have two different people in this situation. The first person might have the initial thought, "My life is ruined and I have no control." They are probably going to feel pretty hopeless if they are going to think about it in that way. The second person might be thinking about it a little bit differently. Of course they are not happy about it, but if their thoughts are, "I wish this didn't happen but I know I can still have a meaningful life even with ataxia" they are probably going to be feeling a bit more hopeful than the person who thinks their life is ruined.

Here is another situation: thinking about going to a party. Maybe the person's thought is that it will be horrible to have symptoms in public or ►►

it's terrible to have to go in a wheelchair. The person is feeling anxious or scared and will probably not go. Thoughts directly impact how we feel, and what we do. Most of the time we don't stop to think about what we are thinking about. But if you are feeling really stressed, depressed or anxious, it might be a good idea to stop and think about what you're thinking about to see if there is any room to balance it out. If we can balance out our thoughts, we can balance out our emotional responses and we can usually live in a healthier way.

Red Flag Thinking Patterns: This list is like a "cheat sheet" related to thoughts that we might want to examine closer. If you have a thought that matches one of these categories, it will be a good idea to "press pause."

Mindreading: "My symptoms make my friends uncomfortable."

Did you ask them? Unless we test things out and ask people, it's really hard to know that.

Fortune-telling: "I won't enjoy the ball game."

Thinking we have this crystal ball and we can predict the future.

Labeling: "I am useless."

Placing excessive negative labels on yourself.

Unfair Comparisons: "I can't work as efficiently as I used to, so my contributions are insignificant."

This one comes up often as we compare what we used to do with what we can do now and believing that because of the changes associated with ataxia, your current abilities are of little or no value.

What if: "What if I am unable to speak at the fundraiser?"

What if this? What if that? What if the other? Focus on "What is" not on "What might be," because "What is" IS all we know.

Catastrophizing: "I can't handle this. This is horrible, this is too much for me to bear."

It is challenging and difficult to deal with

ataxia, but telling yourself this over and over and over is only going to make the coping that much more difficult.

Emotional Reasoning: "I feel anxious so I need to stay home."

Making up reasons why you are not able to do things because of the way you are feeling.

Overgeneralizing: "Everybody in the restaurant is staring at me."

Everybody? All 150 people are specifically staring at you?

Shoulds: "I should be able to concentrate, and if I can't, I am a failure."

Don't "should" on yourself, don't "should" on your loved ones.

All or Nothing Thinking: "The seminar was a complete waste of time. I didn't learn anything that was important."

Blaming: "I can't exercise because I have ataxia."

So I am going to blame my lack of physical activity on my medical condition.

Personalizing: "My spouse was grumpy last night because my condition is too much for her/him to handle."

Maybe they had a bad day at work?

Discounting the Positive: "Exciting ataxia research is being funded, but that doesn't matter since there is still no cure."

So if you're having a thought that might fit into one of these categories, that's a sign that you want to pause the thought and look at it a more closely before you start living as if the thought is the absolute truth. When people are depressed or anxious, they tend to minimize the positive or neutral aspects of a situation and focus only on the negative. I am not saying to pretend the negative does not exist, but I am suggesting that we focus on balancing the negative and the positive.

Evidence For and Against: Is one technique to go about tackling thoughts that we want to balance.

Coping Effectively with Depression and Anxiety...
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Automatic Thought: “I am helpless.”

OK, let’s talk about the facts. What are the facts that would support this thought that would be believable to a jury of your peers that actually suggests that you are helpless?

Evidence For: I have a progressive neurological disorder for which there is no cure. The facts do show that you have this disorder and there is no cure.

Evidence Against: I have the power to follow through with all treatment recommendations, including PT, OT and speech therapy. I can participate in ataxia research and fundraising, and learn to effectively manage my mood.

So then the goal of this exercise would be to consider what is on both sides and come up with a better balanced, rational response. In this case it may sound like this:

Rational Response: “I am not helpless. There are many strategies that I can use to more effectively manage my symptoms and enhance my overall quality of life. Even when I can’t control physical symptoms as much as I would like to, I can control my emotional reactions to them.”

Cost-Benefit and Act “As If” are two more techniques that we can use to look at our thoughts.

Cost-Benefit Analysis: “I can’t handle this.”

If someone is always saying to themselves, “I can’t handle this,” we discuss how is it “beneficial” to give yourself that message every day? How might that message deter you from really enjoying your life and your day-to-day activities despite the limitations from your medical condition? So the benefit of doing a cost-benefit analysis around your thoughts is to recognize that a thought like that can come at a pretty high cost with very little benefit.

Act “As If”: “I am a worthwhile human being” (the opposite of “I am worthless”).

If someone has the thought that they are worthless, I suggest that they take an hour a day to act the complete opposite of what that negative thought might dictate. That might mean that the person may actually get up in time to get ready for the day, keep appointments and do any follow-ups for additional health-related services, like PT or speech. Because they have been thinking that they are worthless, they may not have been doing those things. To use this technique, act as if the opposite of your negative thought is true. And then monitor the impact of this on how you are feeling and functioning.

Behavioral Experiment

Negative Thought of Prediction: “Nobody (e.g., not one person) at the party will talk to me.”

Let’s test it out... Go to the party and see what happens. Do it once, it doesn’t mean you have ►►

CoRDS Registry
 Coordination of Rare Diseases
 at Sanford

 **National Ataxia
 Foundation**
www.ataxia.org

Everyone who has any form of ataxia or who is at risk for ataxia is encouraged to enroll in the CoRDS/NAF ataxia patient registry. To register in the CoRDS ataxia patient registry, go to www.ataxia.org and click on “**Ataxia Patient Registry**.” If you prefer to enroll by postal mail, please contact CoRDS personnel.

For more information on CoRDS and/or enrollment, visit www.sanfordresearch.org/cords or call (605) 312-6423. Thank you for participating in this important research tool.

to go to every party that you're invited to for the rest of your life. But, let's actually test out this belief that if you go to a party, not one person will talk to you.

Experiment: I will go to the block party on Saturday at 3 p.m. I will keep track of how many people I talk to and how I spend my time.

Outcome: I enjoyed getting out of the house. I said hello to 12 different people and every single one of them talked back. I had a more in-depth chat with three neighbors and sat among groups of people all afternoon, laughing with them, as they told their stories. I was never alone and felt welcome.

Summary: In this case, the person actually went to the party and kept track of how many people she spoke to. The outcome is that she enjoyed getting out of the house, she said hello to 12 different people, and guess what? Every single person talked back. Not one person ignored her. She actually had an in depth conversation with three neighbors and she felt really good about herself.

If you avoid situations, if you don't confront your fears, you never give yourself the opportunity to prove the fears wrong. We don't want the fears and insecurities to take on more power than they should have. If you avoid them, you can never crush them and we want to crush these things.

I have people keep track of their negative thoughts and replace them with more balanced responses (see "Summary Sheets" box below).

Caregiver Intervention

I also provide some education for friends and family members on how they can best help themselves and their loved ones cope effectively as possible with depression and anxiety.

An example of this might be role playing with the caregiver.

What might your loved one say about the meaning of this illness?

"I'm useless."

What might you say?

"I still depend on you for many things. You are my confidant and my best friend. You are a terrific artist and a creative thinker. You accomplish a great deal each day, despite the difficulties that the ataxia causes for you."

Often when someone is depressed or anxious, they will speak in a way that reflects their depression or anxiety. It can be really helpful for their loved ones to target those negative thoughts in their own verbal responses so they can help the person crush those negative thoughts.

Depression Outcomes in Movement Disorders

I recently completed a randomized trial using all of the techniques that were just discussed. This was a Parkinson Disease sample. The top line is people in the community who received treatment as usual for their depression. The bottom line is

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Summary Sheets

Negative Thought

I have no control over my symptoms.

My neurologist thinks I am a hopeless case.

I have nothing to look forward to.

Nobody at the party will talk to me.

Revised/Balanced Thought

There are many things I can do to manage my symptoms, even if I can't "cure" my condition.

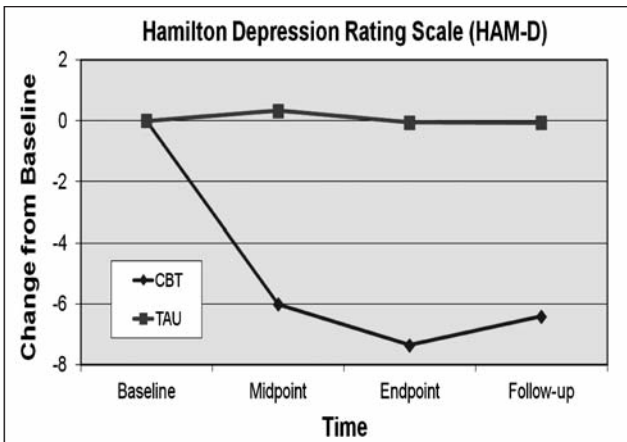
My neurologist makes very strategic treatment recommendations, as she knows there are ways I can improve my quality of life.

I can still have a meaningful life despite my symptoms.

At least some people at the party will talk to me. It is highly unlikely that I will be completely ignored.

*Coping Effectively with Depression and Anxiety...
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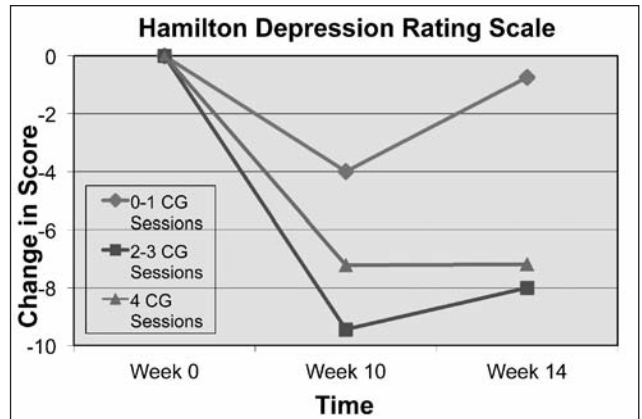
for the people who received this type of CBT. As you can see, those who really worked on the skills-based approach for dealing with the complications that the medical condition presented, fared much better than those who just continued to receive whatever the standard of care was in the community.



Co-Morbid Psychiatric and Functional Outcomes

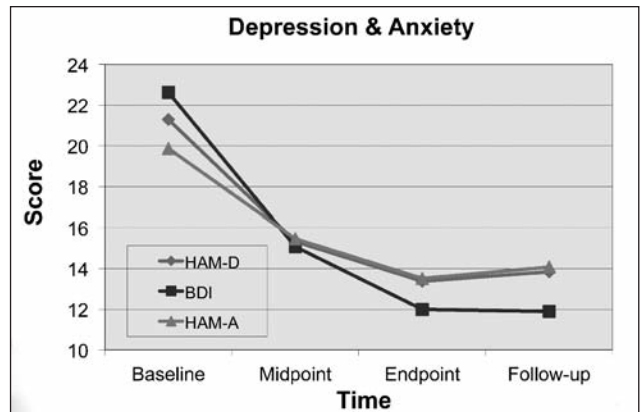
- Secondary Outcomes Improved
 - Anxiety
 - Coping-positive Reframing
 - Quality of Life – Social Functioning
 - Motor Function
 - Negative Thoughts

We also had notable improvements in anxiety, coping, quality of life, particularly to social functioning. We even had a small effect on motor function. This is not to say that motor functioning improved for those whose depression improved, but what happened was that, for those who had a good response in regards to depression, their motor functioning stayed about the same. For those who didn't have a good response in terms of treating their depression, they started to exhibit a more rapid decline in their motor functioning. As one might expect, we also found some good effects on negative thinking patterns.



Caregiver Participation Matters!

This diagram depicts that the more that friends and family members of the person with Parkinson were involved in the treatment the better the person with the movement disorder did. So caregiver participation matters!



Telephone-Based CBT

There were many folks who had a hard time getting to the office every week to do these sessions because of their physical disability. To remove that barrier, I designed a new protocol so that we can do this over the phone. They didn't have to actually travel to see me or someone on my team. The care was replicated over the phone and there were really good results.

Conclusions

Your mood is one critical aspect of your medical condition that you can control. Don't suffer in silence. Effective treatments are available. Initial data regarding CBT for depression and anxiety in movement disorders is promising. Explore telemedicine approaches as needed to improve access to care. Thank you very much. ❖

The Role of Antisense FMR1 in the Development of Fragile X-associated Tremor/Ataxia Syndrome

By Padmaja Vittal, MD, MS
Rush University Medical Center, Chicago, IL

The National Ataxia Foundation has partnered with the American Brain Foundation to fund a two-year Clinical Research Training Fellowship in Ataxia Award. The American Brain Foundation supports vital research and education to discover causes, improved treatments, and cures for brain and other nervous system diseases. The fellowship award is designed to train the next generation of clinical researchers. Clinical research is the fundamental transition stage between discovery and treatment.

Fragile X Associated Tremor/Ataxia Syndrome (FXTAS) is an inherited degenerative disorder causing tremor, ataxia and memory issues. FXTAS is caused by a 55–200 CGG repeat expansion (premutation) in the *fragile X mental retardation 1 (FMR1)* gene located on the X chromosome. This gene is essential for normal brain development. Elongated CGG repeats resulting from the repeat expansion renders the protein product of the *FMR1* gene toxic to the cell. The prevalence of premutation carriers in the population is 1 in 500 men and 1 in 250 women. It is estimated that 1.6/2,000 men in the United States are at risk for developing FXTAS and this number is lower for women.

Although there is an increased risk and severity at higher repeat lengths, CGG repeat size alone does not fully explain risk. Some men with a large premutation do not ever develop FXTAS, despite living past normal life expectancy and some men with a small premutation get FXTAS relatively early. It is probable that there are additional secondary gene or molecular effects related to the premutation expansion itself that contribute to risk for developing symptoms.

AGG trinucleotide interruptions (typically separated by 9–11 CGG repeats) within the CGG-repeat element of the *FMR1* gene are known to disrupt the otherwise pure CGG-repeat motif. Normal *FMR1* alleles typically possess 2–3 AGG interruptions; premutation alleles generally possess two or less interruptions, while larger premutation alleles tend to have fewer AGG interruptions. Loss of AGG interruptions may increase the likelihood of neurological symptoms in premutation carriers. In addition, a second gene, antisense fragile X mental retardation gene (*ASFMR*) represents a portion of the *FMR1* gene transcribed in the reverse direction from *FMR1*. We hypothesize that certain splice variants of this *ASFMR* transcript contribute to the etiology of FXTAS.

Thanks to the support of the American Brain Foundation and National Ataxia Foundation, we will conduct a study to determine splice patterns in *ASFMR* gene and assess level of symptomatology in patients with FXTAS. We will evaluate the role of CGG repeat size and AGG interruptions in the association between phenotype and *ASFMR* splice variants. The hope is that this research would allow us to predict if patients will develop symptoms of the disease or remain symptom free. There is a critical need for enhanced screening tools to help families of patients suffering from this disorder, so timely treatment can be implemented.



Dr. Padmaja Vittal



Coming to Terms

Make a Place for Your Illness and Put It in Its Place

By Pauline A. Salvucci

Pauline Salvucci, MA was a former licensed medical family therapist. She specialized in coaching men and women at midlife, particularly those living with chronic health conditions. She passed away at the age of 69 from her own chronic health condition.

“A place for everything, and everything in its place.” That may be a fine idea if you’re eyeing the clutter on the living room floor, or a pile or two of old magazines and catalogues collecting dust in a corner. But what has it got to do with chronic illness? A lot.

Chronic illness is never a welcomed guest in anyone’s life. However, when it becomes a visitor in yours, in many cases, it’s there to stay. How you cope with your illness will determine, in great part, how well you live your life. Of the three primary factors which measure your ability to cope: your attitude, the social context of your life, and the quality of resources available to you, your attitude becomes the foundation upon

which the others build. Making a place in your life for your illness may sound like a strange thing to do, but it’s a crucial step in learning how to cope with illness and putting it in its place.

Here are some suggestions:

Acceptance and denial are normal steps toward making a place for illness

When you begin to accept your illness, you open yourself up to see what’s on your plate. Then you can begin to interact with it and make a place for it. When you deny your illness, you close yourself off to yourself, and you shut down. Feeling both acceptance and denial are normal responses to chronic illness. Being sick makes you different from healthy people. And, if your ►►

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 donates 50 percent of its revenue to the charities designated by its users. Simply go to the site and follow the easy steps to make NAF your charity of choice. Then use GoodSearch as you would any other search engine.

By doing something as simple as using *GoodSearch.com*, you’ll make a difference in the lives of those with ataxia!

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.

illness isn't visible, you may deny it more than if it were. Accepting illness is a process. It doesn't happen all at once. Don't be harsh on yourself when you fluctuate between accepting your illness and denying it. Acceptance isn't something you do once and for all. Acceptance lives in the present moment. Little by little as you accept your illness, you make room for it in your life.

Adapting to change takes time and patience

Like an onion, you peel off one layer of change at a time. The changes you often are faced with will stretch and challenge your ability to adapt. You may have to let go of, or even say goodbye to some parts of your life, either for a time, or perhaps permanently. Grieve this loss. Perhaps create a ritual to say goodbye, but don't deny those parts of your life which you enjoyed and which were important to you. They are a very real part of your history and deserve your respect. Your life is different than it was before you became ill, but don't treat your past and the things you enjoyed as if they never existed. As you make the changes your illness requires, you can become more flexible and creative in adapting to change. An idea that may help you is to keep a journal of the changes you've already made and how you made them. This can serve as a reminder of your accomplishments, and as a guide for making other changes. As you develop a greater degree of flexibility in adapting to change, the easier change becomes.

Befriend your illness as a part of your life

Chronic illness is your daily companion. You already know how it affects your body. Now get to know what you feel and think about it, and especially how you treat it. If you consider your illness an enemy to be crushed, or an unwelcome guest which you refuse to tolerate, or even an interloper you must annihilate, how will

you allow your illness to be what it is, a part of your life which you can learn to befriend? Do you remember what Lincoln said about a house being divided against itself unable to stand? If you're divided against yourself by refusing to know your illness, or by waging war against it, how will you come to befriend it? Consider giving your illness a name and talking with it. Speak from your heart and your passion. Write down everything you think and feel about it. Don't keep your thoughts running around in your mind creating havoc. Then, listen to what your illness says to you in return. If you find this difficult to do, don't be discouraged. It is

difficult, but there are rewards. An uneasy alliance is better than none at all.

Do you feel as if you're losing yourself?

Do you feel as if your blue moods are turning into dark depression? Is inertia increasingly becoming more a part of your life? Do you do less for yourself on the days when you could be doing more? Do you isolate yourself from your loved ones and friends? If over a period of time, you are regularly experi-

encing these feelings and can't shake them, don't hesitate to find professional help. Ask your doctor to refer you to a therapist whose specialty is working with people with chronic illness. These therapists can help you to make your way through difficult times. Yes, it's important to talk with your friends and family, but talking with a professional can be very freeing. They are available to help you sort out your experiences and the many feelings and thoughts you have about yourself and your illness. This isn't the time to "tough it out," or attempt to dismiss your feelings with a mind over matter mentality. Allow yourself to get whatever help you need. It can

“
**Making a place for
 illness in your life
 may sound like a
 strange thing to do
 but it's a crucial
 step in learning
 how to cope...**
 ”

Make a Place for Your Illness
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make a real difference in your life.

How often during the course of a day do you talk about your illness or refer to it?

Do you feel it's taking more of your time and energy than you would like it to? That can happen, especially when you are initially diagnosed and you're learning about your illness and trying to figure out your relationship with it. If it becomes a habit, and you feel as if you're losing perspective, here's a way to regain your balance. Create "talk space." Choose a comfortable place in a room in your home and make time to talk about your illness with your partner and your family. Let them know what you're experiencing and thinking. This is a time for honest sharing, for you and for your loved ones. Allow this "talk space" to be the place and time where you discuss your illness. Keep the rest of your home an "illness-free talk zone." This will allow you and your family to enjoy one another's company and conversation without reverting to the topic of illness.

Seeing with new eyes doesn't mean looking through rose colored glasses

When it comes to putting your illness in its place, you might try seeing with new eyes. When

it takes you more time to do just about everything, when simple tasks frustrate you because they're not so simple to do anymore, when the familiar becomes foreign, when you can not do the many things you once loved doing, maybe seeing with new eyes can help. If you were an artist and can no longer paint, you can still go to museums or art galleries. If you can't do that, you can enjoy art on the Internet since it offers you access to the world's best museums, galleries and art exhibits. If you worked with your hands and can no longer use tools to do a job or hobby, teach someone else to do what you know how to do so well. Share your knowledge and lend your expertise. If you loved nature and the outdoors, but can no longer hike, drive along some of the scenic roadways and enjoy the beauty and majesty of nature. Find a way to keep what you have been passionate about in your life. It takes time, work, patience, spirit and heart to make a place for illness in your life. Seeing with new eyes is both a tribute to courage and the ability to put illness in its place.

This was a free article that was offered by Pauline Salvucci on her website, www.self-care-online.com, and was also available at www.SelfGrowth.com. Since her passing, the site is no longer available. She believed that you could learn to cope with chronic illness because you are more than what ails you. ❖

CFC Number

The mission of the Combined Federal Campaign (CFC) is to promote and support philanthropy by providing federal employees with an effective workplace giving program.

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

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

E-mail Blasts

E-mail blasts from the National Ataxia Foundation are sent out periodically with updates on ataxia research, events and other timely issues of interest to those with ataxia and their families.

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

Be sure to add naf-eblast@ataxia.org to your address book or "safe sender list" to make sure you get the e-mails, or check your "spam" folder.

Brain Health Fair Held in Philadelphia

Submitted by Mike Cammer

I had the pleasure of volunteering and representing the NAF at the 2014 Brain Health Fair in Philadelphia along with my Central PA Support Group co-leader, Chris Rakshys, and Sue Hagen from the NAF on April 26. Also showing up to volunteer were Bob and Caroline St. George from the Philadelphia area and Joe and Cathy DeCrescenzo from the Delaware ASG, as well as my wife Larissa.

There were exhibitor booths representing just about every organization involved with brain health as well as several hands-on exhibits in conjunction with the American Academy of Neurology's Annual Meeting. There were many interesting things to see and do throughout the day with classes for child development, concussions and several other neurological disorders.

There were also many hands-on displays, such as the "Lobe"-ratory where you could learn all about each section of the brain and each of its functions. There was a large interactive screen to play "mind" games on that was a big hit (think iPad on steroids!). The games on it were interesting and challenging.

Another station that was a big hit was the exhibit by "the Brain Dude," a former co-worker of mine at the VA hospital at which I work. Dr. Buono is now researching and teaching at Cooper Medical School and had a display of real human brains! Visitors put on gloves and got to hold brains and learn about them. My wife, Larissa, was fascinated by it, but I found it better to walk away, if you know what I mean! Can you say "Clean up on aisle 5!" We even earned new bike helmets to protect our twins' brains by visiting several exhibits and getting our program stamped.

Visitors at the NAF table included neurologists who arrived early for the AAN conference, a number of nursing students and many people

curious about what ataxia is. We had a visit from Mike, Karen and Jennifer Leader from Hershey and Joan and her daughter from NJ who have all been involved in the NAF for many years. We also got to meet Ed and Thomas who are ataxians and to see their faces light up to know they are not alone and there is information out there for them. Ed is from the Pittsburgh area and he and his wife Linda traveled to Philadelphia for the health fair seeking information. I have introduced him to Jake, who I met at this year's conference in Las Vegas. Jake is also from the Pittsburgh area and they live only about eight



(Left to right) Caroline St. George, Mike Cammer, Chris Rakshys and Bob St. George at the Brain Health Fair

miles apart, Small world! This was by far the most rewarding part of the day, knowing we reached someone makes it all worth it.

The AAN conference continued throughout the week and I was able to take off work to volunteer along with Chris, Caroline and Sue on Tuesday and Wednesday at the NAF booth during the neurology conference. Their annual meeting is attended by over 12,000 neurologists, yes 12,000! We got visits from neurologists from

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Brain Health Fair
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around the world and a lot of them were just as curious about cerebellar ataxias as someone who was just diagnosed. It was also very nice to get to meet a few well known ataxia neurologists, Dr. Subramony from the University of Florida and

Dr. Bird from Seattle as well as Dr. Chen, who is one of this year's NAF research grant recipients!

Overall, the three days I got to spend at the Brain Health Fair and American Academy of Neurology Conference was very rewarding and I highly encourage anyone who gets the chance to "man" the booth for the NAF to do so. I had an awesome time! ❖

Remembering NAF in Your Will

Each year we are reminded by the kindness of others who have named the National Ataxia Foundation as a beneficiary in their wills. These planned gifts have made a profound impact on NAF's ability to fund important research and programs and are felt for years after they are gone.

Please know that gifts through wills and estates have enabled NAF to support a number of crucial research studies, along with important programs and operational support.

We are truly grateful to all who have named NAF in their Wills. Your kindness has a lasting impact in giving all of us hope. Thank you!

Brain Donation Pre-Plan

If you have a diagnosis of hereditary ataxia, other than Friedreich Ataxia, and you are interested in donating your brain after death for ataxia research, you may contact the National Ataxia Foundation at susan@ataxia.org to have a "Brain Donation Pre-Plan Form" sent to you.

This form will guide you in the necessary decisions that need to be made to have your wishes known regarding a brain donation. It is very important that plans are made well in advance and that you involve your next-of-kin in the planning process.

Thank you for considering this precious gift of a brain donation in furthering vital ataxia research.



SEEKING PATIENTS WITH SCA (ANY TYPE)

FOR A CLINICAL TRIAL USING TRANSCRANIAL MAGNETIC STIMULATION TO IMPROVE GAIT, POSTURE, AND MOBILITY

at the Berenson-Allen Center for Non-invasive Brain Stimulation at
Beth Israel Deaconess Medical Center, Boston MA

You will be asked to come in for daily treatments (M-F) for 4 weeks, 30 minutes a session.

You will be compensated for your time.

If you are interested or would like more information, please contact
Seth Wakefield at 617-667-0209 or email swakefie@bidmc.harvard.edu



*The NAF Board of Directors along with the
NAF North Central Region would like to invite you to attend the*

National Ataxia Foundation 58th Annual Membership Meeting

★★★★ New Date: March 6-8, 2015 ★★★★★



Join us in Denver for the Annual Membership Meeting!

Sheraton Downtown Denver is pleased to provide the facilities for the 2015 AMM.

Standard Room Reservations

Standard room reservations at the Sheraton can be made online at

<https://www.starwoodmeeting.com/StarGroupsWeb/booking/reservation?id=1404149168&key=1BDAEAC6#>

For guests who prefer to phone in their reservation can call Hotel Reservations at

1-888-627-8405 and ask for the National Ataxia Foundation's group rate,

which is under the group name "Natl Ataxia Foundation 2015."

ADA Room Reservations

**Please note all ADA rooms must be reserved through the NAF office starting on
October 1 at noon CDT by contacting (763) 553-0020 or lori@ataxia.org. Calls or e-mails
prior to noon CDT on October 1 to reserve an ADA room cannot be honored.**

The NAF special discounted group rate is \$159 + tax. Please note there is limited availability on discounted rate rooms.

Meeting Registration

Registration for the 2015 NAF AMM will open in mid-December. Please make sure you take advantage of the early registration discount rate. In addition, members of the NAF pay a lower registration fee to attend the annual membership meeting. If you are not currently a member of the

Foundation go online at www.ataxia.org or call the NAF office at (763) 553-0020 to become a member or renew your membership. The meeting registration fee includes attendance at all the sessions, light appetizers at the Welcome Reception and a delicious plated meal at the Banquet.

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

2015 NAF Annual Membership Meeting "Support Our Conference" Campaign

<https://naf.myetap.org/fundraiser/15AMM/>

For more information on Denver visit <http://www.denver.org>.

My Las Vegas Annual Meeting Experience

Submitted by Mary Hutchings

The weekend of March 20–23 was certainly a milestone for me in my 25-year-long experience as a care giver of family members with ataxia. It was the first time I took the opportunity to attend the NAF annual conference in Las Vegas. Though I was skeptical at first about how I might feel while being in company with so many people whose suffering with this disease hits so close to home, I quickly realized that the instant I fell into the company of all these wonderful people, I suddenly felt more at home than ever. I am grateful to the many people who have worked continuously to make it possible for such a gathering to occur.

Presentations were made by speakers working in a wide variety of fields related to ataxia. We heard from research scientists whose efforts are yielding promising results in genetic therapies. We saw the results people are achieving by working with the balance wear vest. There was a presentation explaining how cognitive behavioral therapy can give us practical strategies for dealing with anxiety and depression, a seemingly common duet of emotions that accompany our movement disorders. We experienced how yoga breathing and stretching can lift our spirits even when we are seated in an audience for several hours at a time, and that physical therapy is an essential part of every person's life, every day. Most importantly, we heard repeatedly how available these therapies are to all of us, and the presenters' contact information was repeatedly displayed, emphasizing their determination to help however they possibly can.

Before attending this conference I had heard

from past attendees that the “Birds of a Feather” sessions were often the highlight of the conference. I have to agree with those who urged me not to miss this experience. Participants were sorted according to life experiences. Non-ataxian family members of different ages were grouped in one room, while their ataxian counterparts met separately. From this meeting I took home something concrete and lasting: friendship with others in my same situation. When living with ataxia, there is nothing more soothing and healing than a friend whose understanding is

based on shared experience. Because the conference is much more than a series of lectures, my life has been enriched in the most important way possible, the knowledge of shared experience with others, our mutual understanding, compassion, and encouragement. Not to feel alone is what I hope most for my daughter as her ataxia takes her down life's road. And that is what the conference has done for me. I feel

so much more connected to others than I did before the conference.

In conclusion, let me encourage any reader who has not attended a conference to do so. Let me encourage any reader who has attended one to encourage others, and to contribute to fundraising efforts which target expenses of the conference in order to make it more affordable to everyone. Let me encourage all of us to find ways to overcome the many barriers that make it difficult to find each other, and to enjoy the lives we have been given to live. I hope to be an annual returnee to the conference, and hope to see many of you again as we travel this road together. ❖



**Mary Hutchings and her husband
Terry Snider**

Behind the Bench: One Student's Mission to Fight Ataxia

Written by Jackie Ward

NAF would like to thank Jackie Ward for allowing us to reprint her most recent experience at the Ataxia Investigator Meeting. Occasionally she is a guest blogger and posts for the California Institute for Regenerative Medicine (CIRM). She is a graduate student at the University of California, San Diego (UCSD), and former CIRM trainee. At UCSD Jackie studies rare neurodegenerative diseases in the lab of Dr. Albert La Spada.

My work as a PhD student focuses on a rare form of inherited neurodegeneration called spinocerebellar ataxia. Previous to grad school, I can't remember if I'd ever heard the word "ataxia" before. It's an affliction that you don't come across often, so even those of us who study this disease rarely encounter anyone who has it.

This all changed when I had the opportunity to attend the annual meeting of the National Ataxia Foundation. This conference is quite unique in that it combines a gathering for patients with a science conference for ataxia investigators. There is a dedicated poster session specifically for patients to interact one-on-one with the scientists actually doing the work, as well as small group meetings for patients to ask

questions of the scientists and clinicians in attendance.

My thesis project focuses on generating a disease-in-a-dish model of spinocerebellar ataxia. To do this, I have reprogrammed skin cells obtained from ataxic individuals into pluripotent stem cells. We are now trying to learn more about the disease by morphing these stem cells into the type of cells that are sick and dying in ataxia. Inherently, my work relies on consent, information, and tissue donations from patients. I was looking forward to interacting with the people who make work like mine possible, but I was not expecting an entirely different outlook

Continued on page 26



Attendees of the 2014 Ataxia Investigators Meeting

*Behind the Bench...**Continued from page 25*

on my own work.

The patients and families with whom I interacted were so interested and responsive and eager to hear about my research. After spending many, many hours in the lab focusing on the technical details and minutiae of daily experiments, it was eye opening to take a step back and meet the people who I am actually doing this research for. It is so easy to get caught up in classes and committee meetings and the next set of deadlines, that sometimes I



Jackie Ward

forget about the big picture.

It was important to see that behind my work are real people with faces and names and senses of humor and affinities for the same TV shows as me. It's not just coded cell lines and tubes of DNA. I feel a renewed interest and perspective in the work I'm doing. I encourage any stem cell researcher to jump at the opportunity to interact with the individuals who will ultimately be affected by your work. It is not just these patients' consent and tissue samples I am grateful for now, but also a new excitement in my own research. ❖

www.Ataxia.org

A Closer Look at the NAF Website

One of the resources of the National Ataxia Foundation is its robust website, www.ataxia.org, which is continually updated with pertinent information about ataxia.

While the NAF continues to be a world-leader and trusted source of information on the various forms of ataxia, the genetics of ataxia, and ataxia research, we recognize that there are other organizations that focus on a specific area which may provide additional assistance to those who are living with ataxia and their families and caregivers. NAF provides listings and links to relevant organizations on our website that may be of value to you.

We recognize that caregiving for a person with ataxia can be challenging and so in this issue of

Generations, the Caregiver Resource page is highlighted. The link to this page on our website is www.ataxia.org/resources/caregivers.aspx. On

this page organizations that provide caregivers with support and valuable information on all aspects of caregiving are listed. There are organizations specific for spouses who serve as caregivers, for caregivers of a person with a rare disease, for caregivers of children with disabilities and many more. There is also information on how to prevent caregiver burnout and palliative care.

We encourage you to review the website of the National Ataxia Foundation often as we continually update its pages to provide current and meaningful information on ataxia.





Why You Should Be Seen at an Ataxia Clinic



The following is part of a presentation given at the 2014 Annual Membership Meeting in Las Vegas by Christopher M. Gomez, MD, PhD, University of Chicago.

- 10.) More complete access to diagnostic tests.
 - Proper tests for common and rare diagnoses
 - Ideal imaging studies
 - Most up-to-date genetic testing
- 9.) Better understanding of disease causes and progression.
- 8.) Better experience with risks and complications.
- 7.) Better experience with symptomatic treatment.
- 6.) Team approach with ancillary providers and other specialists.
- 5.) Function with a “Center of Excellence” mentality with regard to patient care.
- 4.) Better access to ongoing research.
 - Ideal imaging studies
 - Latest news on clinical trials
 - Access to participate in local research projects
 - Connected to lab developments
 - Easier access to brain donation program
- 3.) Complete integration with ataxia physician community
- 2.) Function within teaching centers to further ataxia awareness.



Dr. Christopher M. Gomez

And the top reason you should be seen at an Ataxia Clinic is:

- 1.) Are you kidding?

“With this rare, complicated disease that is so hard for other neurologists to understand and manage, would you not want to be seen at a place where the specialists dedicate their careers to studying and caring for similar patients?”

“Why Should I be seen at an Ataxia Clinic?” was the title of Dr. Christopher Gomez’ presentation at the National Ataxia Foundation’s 2014 Annual Membership Meeting in March. His slide presentation is synced with his oral presentation and is available as a “free view” selection at this link: http://www.dcpvidersonline.com/naf/?event_id=NAF104

In Dr. Gomez presentation he encourages everyone who has ataxia to be seen at an ataxia clinic at least once. This link – <http://www.ataxia.org/links/ataxia-clinics.aspx> – will take you to a listing of ataxia clinics in the United States.

A listing of the Ataxia Clinics in the U.S. can be found on pages 38–40.



THE NATIONAL AT
57th Annual Mem

“*Betting on Ata*”

Las Vegas, Nevada



A Las Vegas theme
graced the banquet

Cammie Ayers
and Rocy Wu
(Photo by Rocy Wu)



Mike &
Alena
Wolfson



Izzy and
Zoe
Penston

Denise Drake
and Nette
Westley

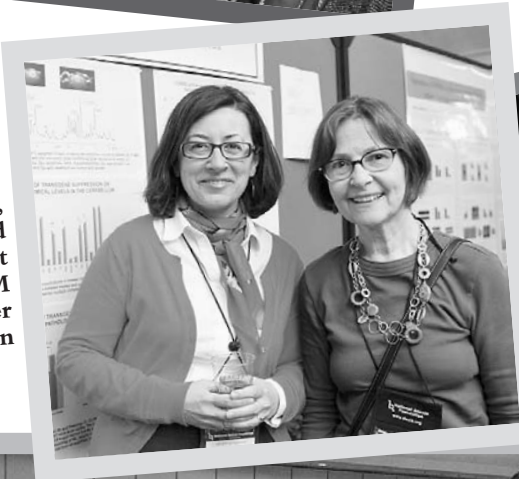


Special thanks
to photographer
David Garcia
for taking the
photographs
you see on
these pages



AMM presenters (Lyn
Swingle, PT; Ha
and Rosanne D)

Gülin Öz,
PhD, and
Lyn Culbert
at the AIM
poster
session



Rita & David Garcia



AMM presenters (Lyn
Gibson-Horn; Carolin
and Franziska Hoche)



A great time was had by all at the Reception

ATAXIA FOUNDATION
 Membership Meeting
 "Ataxia Research"

— March 21-23, 2014 —



(Left to right) Margaret Hoag, Lyn Tippett, and Cathy DeCrescenzo



(Left to right) Ray & Clarence Ching and Cindy & Gerry De Mint



Dancing the night away at the Saturday night banquet are Karen & Michael Leader



(Left to right): Polly Murray Orr, PhD; Bobkins, PhD



George Corns & Corey with Adam Avery at the Poster Session



Peter DeMint and Heather Evans



(Back, left to right): Cynthia Coffield, PhD; Ralph Miller, MD; and (front) Kyle Bryant



(Left to right) Lori Shogren, Arnie Gruetzmacher, Greg Rooks, and Renae & Mike Parent

Dealing with Denial

The following suggestions are from James J. Messina, PhD, a licensed psychologist with more than 35 years of experience counseling individuals and families. Messina, who specializes in adult and children psychotherapy, serves as Director of Psychological services at St. Joseph's Children Hospital in Tampa, FL. He has a private practice in Tampa and is a member of the American Psychological association.

The information and medical advice expressed here are not a substitute for conventional medical service.

What is denial?

Denial is:

- Being unwilling to face problems on either a conscious or subconscious level.
- Acting as if there are no problems to face.
- A defensive response; protection from pain, hurt or suffering.
- A mask to hide feeling or emotions behind.
- A way to avoid conflict, disagreements, or disapproval from others.
- A way to avoid facing the negative consequences of reality.
- A way to retaining our sanity when experiencing unbearable pain.
- A way to repress the truth of our loss, a way to continue to function "normally."
- A way to avoid the risk of change as a result of problems or loss.

How does denial look to others?

Persons in denial:

- Appear to be irrational to those who know the problems and losses they have suffered.
- Appear to be calm and relaxed to those who do not know the problems and losses they have suffered.
- Are a cause of frustration to those who want them to confront the truth of the problem or loss honestly.
- Appear to be unemotional, apathetic, or indifferent in the face of loss.
- Are considered pathetic and pitiable by those who have tried to confront them with the denial and have failed.
- Appear to be caught up in magical thinking about the loss involved.
- Appear to be childlike, very dependent on ►►

Membership Matters

Become a NAF Member Today!

Have you ever been frustrated by the fact that most people do not know what "ataxia" is, or worse yet, have never even heard of the word?

As a community, we must come together to raise awareness of ataxia. The best place to start is by becoming a member of the National Ataxia Foundation, a leading non-profit organization that is committed to improving the lives of those living with ataxia.

The Foundation not only funds ataxia research, but provides ongoing support to families by connecting them to local resources and the most up-to-date information. By becoming a

member, you will become a part of an extensive community that will support you through this journey. Become a member today!

2014 NAF Membership Drive

Thank you to all who supported the 2014 National Ataxia Foundation Annual Membership Drive. We warmly welcome our new and renewing members. Thank you also to our current members who gave a Gift Membership or a donation towards the drive.

There is still time to contribute by going on-line to NAF's website, www.ataxia.org, and clicking on "Donate Now."

others to nurture them and reassure them that everything will be all right.

- Appear to be running away from the truth concerning their problems or loss.
- Appear to be avoiding or rejecting those who are intent on confronting them with their problems.

How can we cope with denial in others?

In coping with denial in others we need to:

- Have a great deal of patience in order to allow them the time it takes to finally confront their loss or problems.
- Be accepting of the denial as a psychological defense that is a vehicle for them to retain their sanity.
- Be careful in confronting them, so that they don't run away or withdraw from reality even more.
- Be ready for their resistance in dealing with the truth about their loss or problems.
- Freely offer them out support and understanding.

- Accept them as they are, waiting to deal with the loss or problem until they are ready.
- Be ready with a rational perspective to help them refute their current irrational beliefs.
- Resist solving their loss or problems.
- Continue to let them know that there is support for them in dealing with the loss or problems. Let them face the existence of the loss or problem gently but continuously.
- Provide them with subtle means to face the problem by giving them magazine or newspaper articles, pamphlets, or books on the subject; suggesting TV, and radio programs on the subject, or proposing professional help.
- Recognize that if they are locked into a chronic state of denial, which is debilitating to their mental health, that a denial intervention may be necessary.

“Dealing with Denial” can be found on James J. Messina’s website by following this link: <http://www.jamesjmessina.com/toolsforhandlingloss/dealingwithdenial.html>. ❖

Importance of Supporting National Ataxia Foundation Research

From a Question and Answer session at the 2014 NAF Annual Membership Meeting

Question: When I ask family members to support NAF research their initial response is that the real money for supporting gene-based therapeutics and drug development is with the pharmaceutical companies, so why bother supporting such a little foundation money-wise when it's the drug companies where the real money that can make a difference is going to come. What do I say to them?

Answer: Finding answers to address any disease or disorder, particularly for rare disorders like ataxia, requires a partnership of nonprofits, government, industry, patients/families and others. Nonprofits foster areas to aid in clinical trials by championing natural history studies, patient registries, rallying patients to register in

patient registries, tissue donation programs, as well as supporting basic and translational research. These are all important steps to further our understanding of the disease, but also brings forward an opportunity for researchers to be better armed in securing additional funding from the federal government to further their important research efforts.

Without the lead from nonprofits, like the National Ataxia Foundation, and ataxia scientists bringing research forward, pharma and biotech companies would not be in a position to focus on disorders like ataxia. It is through these connecting partnerships that we will piece the puzzle together in bringing effective treatments for ataxia forward.

From the Desk of the **Executive Director**

The National Ataxia Foundation Annual Membership Drive began in mid-May and we are truly grateful to those who renewed or became members of the National Ataxia Foundation. Your support is very important to us in enabling the Foundation to continue its mission in serving ataxia families. Thank you also to those who became NAF Recurring Gift Members, your monthly or quarterly contributions significantly help in the National Ataxia Foundation's vital efforts in maintaining important programs and services.

We warmly welcome our new members, as well as our renewing and recurring gift members. For those who have not yet renewed their memberships, there is still time. Please also encourage others to become an NAF member today.

It has now been one year since the National Ataxia Foundation formed a partnership with the Coordination of Rare Diseases (CoRDS) at Sanford Research to establish an ataxia patient registry. One year later, more than 1,000 people have entered the CoRDS screening process and there are now registrants from 14 countries including Australia, Belgium, Canada, Croatia, Germany, India, Malaysia, Mexico, Netherlands, New Zealand, Portugal, South Africa, the United Kingdom and the United States. Within the United States, there are 43 states represented.

To help further and accelerate vital ataxia research, we encourage you to register in the CoRDS ataxia patient registry. To register, you may contact CoRDS personnel at (605) 312-6423, e-mail CoRDS@sanfordhealth.org or go directly to the CoRDS website at <http://www.sanfordresearch.org/cords/enroll/>. A very

special thank you to all who have registered in the CoRDS ataxia patient registry. Your involvement with the CoRDS ataxia patient registry helps scientists in finding answers for effective treatments and ultimately a cure.

International Ataxia Awareness Day (IAAD) is September 25. Please help recognize this very special day by participating or hosting an ataxia awareness event, getting involved with an NAF Walk n' Roll for Ataxia, supporting the Global On-Line Walk n' Roll, or telling a friend, neighbor, or co-worker about ataxia. To learn

more about how you can get involved with IAAD, please visit NAF's web site at www.ataxia.org and click on "Events" and then "International Ataxia Awareness Day" on the left side of the page.

Plans are underway for the 2015 National Ataxia Foundation's 58th Annual Membership Meeting (AMM) which will be held at the Sheraton Denver Downtown Hotel in Denver, Colorado on March 6-8, 2015. The 2015 AMM will be hosted by the

North Central Region.

If you are interested in making a reservation for an accessible ADA room at the Sheraton Denver Downtown Hotel during the conference, please contact the National Ataxia Foundation directly. NAF will be accepting accessible ADA room reservations beginning on October 1 at 12 p.m. noon (CDT). You may either e-mail lori@ataxia.org or call (763) 553-0020 beginning on October 1 at noon (CDT) for an accessible ADA room reservation. Information for standard room reservations at the reduced meeting rate can be found on page 23 in this issue of *Generations*.

We look forward in seeing you in Denver! ❖



Michael Parent

Sweating the Small Stuff

Submitted by Jason Wolfer

Let me first begin by stating that I have full knowledge of what the saying “don’t sweat the small stuff” means. It’s just that for me the saying is a bit more literal than to simply worry over minute details. Sweating is not just a fancy term for something else, it’s actually the physical act of sweating, like I’m sitting in a sauna with my clothes on (which would be a strange thing to do). I’m finding that it is the little things that are leading me to feel as if I have just participated in an Iron-Man competition, (in reality my speed would be more of a Wet-Paper-Bag competition).

If you are old enough to remember the pay-phone then you will, of course, also remember the phone book. Years and years ago, back in the 80’s, it became a trend to show your strength by ripping a 500-page phone book in half (this also served as a form of intimidation and was a warning to all phone books that you weren’t beneath tearing them apart in case any of them happened to be thinking of attacking you when your attention was averted). Now I don’t want to brag here, but once I was actually able to tear a 10-page document in half.

Currently, I feel I am carrying on in that very important tradition whenever I try to remove the paper cover off of the straw that comes with the drink that I’ve purchased. Most people can grasp that little flap at the top of the straw and tear that paper off in about half a second. I feel like I need one of those industrial-size grabbers, you know, the ones you see guys on the side of the freeway picking up trash with. It feels like I need to order one every time I order a drink. It’s either that or a new brain so that I have the fine motor skills needed to grasp the quarter-inch flap of paper on the end. “Sir, would you care for any fries with your iced tea? No thank you...but would you happen to have the ability I’m going to need to

remove my straw from it’s Fort Knox-like paper encasing?” Seems to me that if one of these fast food chains wanted to really make a great Happy Meal that they should include a new cerebellum with each order instead of a toy. At least make it an option!

For those of us who take more than 30 seconds to unwrap a piece of chewing gum, again, I don’t mean to brag but I have come up with an idea for gum manufacturers. They really should start making the foiled wrapper chewable and the same artificially enhanced flavor as the gum, or



Jason Wolfer

some strangely complimentary flavor, like broccoli, so that we could just pop the whole thing in our mouth. I’d chew sugar-free gum but I don’t have to when I lose 35 calories just trying to wrestle the gum out of the wrapper. At times I’ve found myself wondering why there is not a hotline number you can call for assistance and helpful tips on how to unwrap a single stick of gum.

This next one I am actually not sure could be done, but it would make my life a lot easier, is if

Continued on page 34

Sweating the Small Stuff *Continued from page 33*

there were a television remote available that did everything but just had one button. You might think it's simple (and for my kids it is), and you might wonder why, after using the same remote for the last 10 years, it is so difficult, but by the time I figure it out the season premiere of the new show we want to check out is now through its second season and showing reruns. And on top of that, I am still trying to figure out where to point the thing and the perfect angle for maximum efficiency. Do I aim it straight at the

television? Would it work better if I bounce the signal off a wall or the dog? Should I just skip the middle man and go outside, aim up, and hope I hit a satellite? At this point, a game of charades is looking like a strong alternative.

Why is it that the small stuff, the things that should be easy, and easily done in five minutes or less, are the things that end up consuming the whole day? I don't know the answer but as I continue to struggle with the things that should come easily and as I am wiping the sweat out of my eyes from wrestling with one of those simple tasks, I am reminded to not sweat the small stuff. ❖

Friedreich Ataxia Tissue Donation

If you have Friedreich Ataxia and you are interested in the Tissue Donation Program, please contact Dr. Arnulf Koeppen at (518) 626-6377 or arnulf.koeppen@va.gov.

Stay in Touch

Please send stories, events, and reports about your chapter and support group activities to joan@ataxia.org or by mail to National Ataxia Foundation, 2600 Fernbrook Lane, Suite 119, Minneapolis, MN 55447.

The deadline for the upcoming fall issue is August 15.

**PATIENTS with EARLY SYMPTOMS of
FRIEDREICH'S ATAXIA**
age 10 and above needed for an MRI study to
evaluate the chemistry and connectivity of the
brain and spinal cord in Friedreich's ataxia
at the Center for Magnetic Resonance Research
at University of Minnesota

You will lie in the scanner for ~1.5 hour while listening to the music of your choice. Reimbursement for travel expenses is available and you will be compensated for your time.

Please note that we cannot scan you if you have Harrington rods, and we cannot scan people with diabetes at this time.

If you are interested or have questions, please call Diane Hutter @ (612) 625-2350 or e-mail hutte019@umn.edu.



Macy's 'Shop for a Cause'

Purchase a Macy's "Shop for a Cause" discount card today for \$5 and help the National Ataxia Foundation. Your special Macy's "Shop for a Cause" discount card gives you access to a special one-day-only sales event at Macy's stores nationwide on Saturday, August 23. Card holders receive a 25% discount on regular, sale, and clearance items, including home. Even save on most brands usually excluded! Card holders 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 cards until August 15.



To purchase your discount card today you can order online through NAF's online store or mail a check made payable to the National Ataxia Foundation to 2600 Fernbrook Lane, Suite 119 Minneapolis, MN 55447. Please write "Macy's Card" in the memo line. You may also call the NAF office to place an order or to request more information at (763) 553-0020. <https://www.ataxia.org/macyscard> ❖

Delaware 'Fun at the Pub' Fundraiser

Submitted by Cathy and Joe DeCrescenzo

Our unconventional approach at our major fundraiser this year proved to be a great success! "Fun at the Pub" on Sunday, May 18, truly lived up to its name. It was a fun afternoon with friends and family, many coming from out-of-state to support us. We enjoyed a delicious meal, dancing to the tunes DJ Jim provided, and the country line dancing was a big hit. Our Silent Auction was fabulous, raising \$1,500. Our pastor and dear friend, Fr. Roger DiBuo, who is blessed with the gift of gab, shared a few stories about Joe.

A special thank you to our friends and several of our DE Support Group members for their help in making the event a success! We chose to throw a big party to celebrate life, along with raising awareness and funds for NAF. A heartfelt thank you to our sponsors who ensured all aspects of the event were funded, therefore, every penny raised was donated to NAF. We thank ALL for celebrating with us and for supporting the NAF with their generous donations. We also thank those unable to attend but so graciously donated through our on-line NAF event website.



Dancing fun at the "Fun at the Pub" fundraiser

We are pleased to announce our 2014 "Fun At The Pub" event raised \$6,000 for NAF.

When planning your next fundraiser, think outside the box – you may be pleasantly surprised with the outcome! ❖

The Penny Harvest

Submitted by Daisy Bachofen

The Penny Harvest has been a tradition since 2010 for the Roxborough Intermediate School in Roxborough, Colorado (southwest of Denver). Our school and many other schools collect as much money as possible from collecting spare change from around the house or by going door-to-door spreading the word about the Penny Harvest. The Penny Harvest has changed so many people's lives because of the donations given.

I was one of the seven student leaders who got to decide to whom the money would be donated this year. We call ourselves the Penny Harvest Roundtable Leadership Group. Each member of the group



Daisy Bachofen

got to choose an organization that they would like to donate to. I chose the National Ataxia Foundation because my grandma, Sharie Lindberg, passed away in 2013 from ataxia just five years after she got it. I thought it would be nice if we, as a school, could donate and give some money to help find a cure.

Our school raised over \$5,000 and decided to divide the money among all the charities that the Roundtable Leaders chose. To decide how much to give, we had someone from each charity speak to the seven students and our faculty advisors. They told us about



Sharie Lindberg

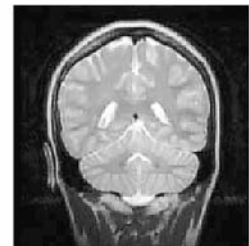
their charity and then we asked them questions. Charlotte DePew, Denver Ataxia Support Group Leader, represented the National Ataxia Foundation.

We gave \$500 to the Denver Hospice and Soles 4 Souls, \$2,000 to the Animal Sanctuary, and \$2,025 to the National Ataxia Foundation. Our hope is that this money will help other families going through the same thing that my grandfather, family and I did with my grandmother's ataxia.

Thank you for letting me share my story. ❖



**PATIENTS with
SCA1, SCA2, SCA3, SCA6 and
MSA-C
needed for an MRI study
at the University of Minnesota, Minneapolis**



Travel expenses reimbursed.

Contact: Diane Hutter
(612) 625-2350
hutte019@umn.edu

Chuck and Duck Dodgeball Tourney

Submitted by Andrew Haluska

Charlton Heights Elementary School held their Fifth Annual Chuck and Duck Dodgeball Tournament on May 2. The event raised over \$3,600 in honor of past student Jacob Van Buren.

Jacob, who has since moved to Florida, was able to Skype with the entire group to “kick off” the event. Students, staff members, and the community look forward to the event. It has become a tradition at Charlton Heights. They are already thinking of ways to make the event even better next year!



It was all action at the Fifth Annual Chuck and Duck Dodgeball Tournament

success. They asked businesses in the community to sponsor the event. They had 13 businesses sponsor the event and their donations essentially paid for the t-shirts each student received. This also allowed them to make a sizable donation to Jacob to help him purchase a new wheelchair. ❖

STRIKE Out Ataxia

Submitted by Neddroy “DJ HeadBussa” Bent

DJ HeadBussa partnered with the National Ataxia Foundation to host his 3rd Annual Charity Celebrity Bowling Event, STRIKE Out Ataxia, in Tampa, Florida, on May 4.



DJ HeadBussa (wearing hat) and friends at the STRIKE Out Ataxia event

DJ HeadBussa knows very well the effects of ataxia.

“Ataxia really hits close to home for me. In 1998, my mother was diagnosed with Spinal Cerebral Ataxia. My uncle and grandmother died of the same disease. The sole propose of this event is to build awareness and prepare individuals that are at risk for this devastating disease. It hits people randomly and as early as childbirth. I’m here to shed some light and hope to all the individuals with this disease,” he said.

The awareness is growing. They are already looking forward to the event again next year. ❖

Ataxia Clinics

Ataxia clinics are specialty clinics committed to providing specialized medical care for people affected with cerebellar ataxia. Clinics are devoted to the diagnosis, treatment and management of ataxias as well as prevention and management of complications affecting this group of patients. Patients with the many types of rare ataxias can benefit from multidisciplinary specialists, which often include genetic counselors, speech therapist, physical therapists, and other specialists who are devoted to their care and treatment,

For more information on Ataxia Clinics please visit www.ataxia.org/links/ataxia-clinics.aspx.

— ARIZONA —

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Phoenix, AZ 85013
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Phone: (602) 406-6281

Aurora, CO 80045-7106
Phone: (720) 777-5513
Fax: (720) 777-7285

University of Colorado Hospitals, Neurology

(Sees adults on Friday a.m.)
1635 Aurora Court, Suite 4500
Aurora, CO 80045
Phone: (720) 848-2080
Fax: (720) 848-2106

— CALIFORNIA —

UCLA Ataxia Clinic

Dr. Susan Perlman, Dr. Brent Fogel
300 UCLA Medical Plaza, Suite B200
Los Angeles, CA 90095
Phone: (310) 794-1195
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Stanford Movement Disorders Center

Dr. Rosalind Chuang
Stanford Hospital and Clinics, Boswell Building
300 Pasteur Dr., A301
Stanford, CA 94305

New Patient Coordinator: (650) 725-5792

Fax: (650) 723-6002

Movement Disorders Center Information:
(650) 736-0514

UCSF Neurogenetics Cognitive & Movement Disorder Clinic – UCSF Memory and Aging Center

1500 Owens St., Suite 320
San Francisco, CA 94158
Phone: (415) 353-2057
Fax: (415) 353-8292

— COLORADO —

Children's Hospital Colorado

Dr. Abigail Collins
Children's Hospital Aurora NEU
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USF Ataxia Research Center

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University of Chicago Ataxia Center

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 Phone: (773) 702-6222 to make an appointment

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 601 N. Caroline St., 5th Floor
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**Friedreich Ataxia Clinic, Department of
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Mayo Clinic
 200 1st St. SW
 Rochester, MN 55905
 Appointments: (507) 284-8198

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**Albany Medical College Department
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 (A referral is required to schedule an appointment.)
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 Ataxia Clinic**

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*Ataxia Clinics**Continued from page 39*

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Children's Hospital of Philadelphia

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Philadelphia, PA 19404-4399

CHOP Specialty Care Center

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Clinical Program for Movement Disorders at UT Southwestern

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— UTAH —

University of Utah Healthcare Movement Disorders Clinic

Dr. Stefan Pulst

Clinical Neurosciences Center

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Salt Lake City, UT 84132

Appointments: (801) 585-7575

Fax: (801) 585-2746



Studies of Brain and Behavior in Individuals with Premutations of the Fragile X gene (FMR1)

We currently are seeking individuals who carry a premutation allele of the Fragile X gene, FMR1. Some individuals with this premutation allele may show signs of Fragile X-associated Tremor/Ataxia Syndrome (FXTAS) which is characterized by motor and cognitive issues. This study aims to better understand these issues and their bases in the brain in individuals with FXTAS.

Eligible participants will be asked to complete the following:

- questions about family medical history and behavior
- tests of thinking abilities
- testing of sensory processing and movement control
- brain activity recording and imaging
- genetics testing

Testing will be conducted at the Center for Autism and Developmental Disabilities at UT Southwestern. Participants will be compensated for their time.

For more information, please contact us by phone at **214-648-5155** or by e-mail at **fragilex@utsouthwestern.edu**

Chapter and Support Group News
from Around the Country

Delaware Ataxia Support Group

Submitted by Joe DeCrescenzo

The Delaware Support Group held a meeting on April 5 at the Easter Seals Disability Services facility in New Castle, DE. We enjoyed a tour through their Assistive Technology Room, where many assistive devices were set up for hands-on demonstrations. These devices can sometimes mean the difference between struggling to perform everyday tasks and living a full and independent life! We were surprised to learn that Easter Seals has many resources available for adults with disabilities, including an adult day-care center as well as a caregiver support group. They can also direct those with questions about assistive technologies financing to resources from both public and state-offered programs.

For more information, please contact Joe DeCrescenzo at jdecr@comcast.net.

Tar Heel Ataxia Support Group

Submitted by Ron Smith

We had our picnic on Saturday, April 26. We had a great turnout, about 37 people, and had a

great time. Our guest speaker, physical therapist Sabine Hanamean, did a good job talking about balance problems and provided some helpful tips for all of us.

Denver Ataxia Support Group

Submitted by Charlotte DePew

We thank Ellen Belle, Physical Therapy Director at the Colorado Neurological Institute (CNI), for graciously hosting our May 3 meeting. About 30 attended and we were able to accommodate all within CNI’s waiting area.

The meeting started with updates by Charlotte on the 2015 NAF AMM at Denver’s downtown Sheraton and our fourth annual fundraising Run, Walk ‘n Roll (RWnR) September 7.

Charlotte introduced three new Support Group members and their spouses. Attendees had the opportunity to introduced themselves plus relate how ataxia has impacted their lives and their families. There were moments of humor and laughter as well as, “Ah, I experience

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Members of the Tar Heel Ataxia Support Group

Chapter and Support Group News
Continued from page 41

the same and thought I was alone.”

Harlan Lindquist, whose wife Sharie died of ataxia last summer, proudly spoke about his granddaughter Daisy’s Roxborough Intermediate Penny Harvest. Because of her efforts, \$2,025 will go to NAF (the largest donation of five). Harlan shared his grief regarding the losses that ataxia caused Sharie, the family, and himself. Everyone heartedly applauded after his bitter-sweet story. Sharie is one of two honorees at our 2014 WRnR.

Dr. Abbie Collins, a movement-disorder neurologist at CU Children’s and Ataxia Clinic Director in CU’s Adult Neurology Department, was our guest speaker. She spoke on what she felt we needed to hear from the March Las Vegas AMM Investigators and member meetings. It was very informative and easy-to-understand. Many commented on how they appreciated learning the research process that starts with basic understanding of disease cellular pathology and progression to drug development and drug trials. Abbie reported on recent progress in some of the SCA’s, FA, and spent time on sporadic ataxia where many of our “unknowns” are classified.

Central New York Ataxia Support Group

Submitted by Ed Lueck for Mary Jane Damiano

The Central New York Ataxia Support Group met on Saturday, April 26. We discussed important lists that we need to carry with us in case of emergencies. These included a list of all current physicians, list of medications currently taking, and a list of equipment vendors in case our equipment breaks down when we are out of the house.

The wallet identification cards (from NAF) were distributed at the meeting. We also talked about the upcoming fundraiser for NAF at the North Syracuse Family Festival on May 24. We

will have “Pet a Service Dog” for \$1, and two gift baskets to raffle. All proceeds will be donated to NAF.

Central PA Ataxia Support Group

Submitted by Chris Rakshys

Our spring meeting took place on Saturday, May 10. We didn’t have a speaker on hand – rather, it was a very nice and casual gathering – a perfect opportunity for us to chit-chat among ourselves. We brainstormed about future fundraisers, meeting locations, and exercise info. We also swapped notes about ataxia clinics and research happenings.

Utah Ataxia Support Group

Submitted by Jenny Durrant

The Utah Ataxia Support Group or UASG has had a great year so far! We started the year with a new co-leader, Jenny Durrant, who also has ataxia. We are excited to have her be a part of the UASG! We started the year receiving welcome packets, which included a letter from the leaders, a UASG brochure, a questionnaire and the current issue of *Generations*. Our first meeting of the year was in February and we had 15 members in attendance. The meeting was a planning and open mic session, where members were able to share their ideas for the UASG. The meeting in April was a recap of the NAFAM by Ryan and Jenny Durrant. The presentation can be found on the new UASG website, www.utahataxia.org. A new Facebook page has also been created at www.facebook.com/utahataxia. Thanks to Ryan Durrant for creating these! We are looking forward to a great rest of the year for the UASG!

Arizona Ataxia Support Group

Submitted by Mary Fuchs & Angela Li

On Saturday, April 12, the Arizona Ataxia Support group organized an outing to the Desert Botanical Garden. We experienced the ►►

“Chihuly Exhibit” featuring beautiful, world-famous glass art sculptures. We also enjoyed the butterfly exhibit and had a lovely time admiring the desert landscape.

Our spring meeting was held on Saturday, May 17. Our guest speaker, Leanne Murrillo, a Therapeutic Recreational Therapist from ABIL (Arizona Bridge to Independent Living), shared wonderful recreation ideas as well as opportunities in the community.

We also had a surprise potluck and tribute for Rita Garcia, who has been our fearless group leader for 19 years! She has stepped down and will be GREATLY missed. Angela Li is our new co-leader with Mary Fuchs.

We plan to have a social outing in June and our next support group meeting is August 16 at the Disability Empowerment Center. Join our Facebook group “Arizona Ataxia Support Group” or contact Angela or Mary for more information.



Members of the Arizona Ataxia Support Group at the Desert Botanical Garden (photo by David Garcia)

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Northern California Ataxia Support Group

Submitted by Joanne Loveland

We have had two meetings this year. On January 11 we had 20 people attend.

After lunch we broke into three groups: men,

women, and caregivers. Some suggested topics were discussed, and each group discussed issues that were relevant to them.

It was nice to devote some time to sharing with each other. It means a lot when you realize you are not alone in this journey. This meeting was very well received by those who attended.

Our second meeting was on April 12. Lunch was brought by Shirley and Barry Hanks. We opened our business meeting with discussion about Fundraising. These ideas were discussed:

- Dining for Ataxia – Asking restaurants to donate a percentage of sales on an agreed upon date. Several people have been to fundraising events at restaurants and were supportive of the idea.
- Online auction
- Have a picnic in a park with a few large raffle items
- Use the Virtual ‘Walk n’ Roll’ site to make donations for research
- All of the above

Joanne shared the need to have a better format to respond to Support Group inquiries and general email inquiries about help in the area.

We agreed upon some new objectives:

- Reformat our membership roster by areas
- Assign a leader in each area
- Enlarge our active membership
- Launch a newsletter to increase information and local resources
- Develop our own website for NCASG.

Reports from the AMM Conference in Las Vegas were given by five people who attended.

Potential speakers for upcoming meetings were discussed.

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New Hampshire Ataxia Support Group

Submitted by John Mauro

We had nine in attendance at our last NH monthly support group meeting. Jack Gallant

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Chapter and Support Group News
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joined us for the first time. We were happy to welcome him and learn about how he handles his ataxia. We were also happy to have Peter and his brother Matt for their second meeting.

Old Business

Balance-wear: We continued our previous discussion on where those with balance wear vests are with their vest. Donna and Jack are wearing their vests some part of most every day and still feel it gives them balance benefit. Kathy had hers tweaked at the AMM but would like to have it tweaked again.

The live auction for “Coffee with the Governor of NH” is up and running. The opening bid has been set for \$100 with a “buy it” bid set at \$300.

Here is the link location for anyone interested: <http://ataxia.kintera.org/faf/auction/auction/Index.asp?ievent=1102762&lis=1&kntae1102762=FEE83F72B99C4EC19B3FA5165298CA0C>

Status of the NH bill for IAAD: Senator Boutin has promised to submit a bill late December pending his re-election. At some point we will address a proclamation for 2014. This may not be as easy to achieve as last year being an election year.

New Business

Walk 'n Roll 2014: The date is set for the morning of September 20 in Auburn, MA. Those interested in using a trike or needing a room to stay Friday or Saturday night (note if the room needs to be an ADA room), please contact John Mauro at johnmauro62@gmail.com.

We had an open discussion as to what folks are doing with their physical therapy/exercise and speech programs.

Christine Boucher, a yoga teacher volunteer from Yoga Caps joined us to share some yoga practices with the group. She invited our group to attend a class at any of the Yoga Caps locations where classes are held mentioning, Manchester,

Merrimack, and Nashua. Her chair yoga practice was well received and Christine indicated she would gladly volunteer to lead us at another meeting.

If you would like more information please contact me at jilleporter@comcast.net.

Update from the Mid-Atlantic Ataxia Social Group

Submitted by Bailey Vernon

Since 2012, the Johns Hopkins Ataxia Center has expanded outreach and education programs to support those living with ataxia. The center sponsors the support group that meets quarterly in Baltimore County, Maryland. In 2013, the group officially named itself the Mid-Atlantic Ataxia Social Group and has grown its membership to over 115 individuals. The group has developed into a community by creating a Facebook page and an extensive contact list of members to support one another outside of the meetings.

In addition to serving the Maryland community, the group reaches individuals living in Virginia, Pennsylvania, West Virginia, Delaware, and New Jersey. The meetings allow for those with ataxia and their families to connect and hear from professionals with extensive experience in the ataxia field. In 2013, the group discussed topics on exercise, genetics, medical treatment and maximizing independence and even had the opportunity to practice Qigong, which is a health care practice that focuses on the integration of breathing techniques, physical postures, and more. At each meeting the group eats lunch together and engages in discussion, often separating between those with ataxia and the care partners.

In early 2014, the center also added a new program specifically designed to address the needs of care partners. The Ataxia Care Partner Conference took place in February of 2014 and featured lectures on various topics such as understanding an ataxia diagnosis, navigating ►►



Members of the Mid-Atlantic Ataxia Support Group

community resources and defining behaviors in ataxia. With over 50 in attendance, care partners were able to connect with one another and develop a network of support.

In 2014 and beyond, the center looks forward to continuing its commitment to the ataxia community through support groups, exercise initiatives and educational conferences. The group is planning an Ataxia Wellness Day on September 6 that will focus on helping families live well with ataxia and include member-led discussions, exercise demonstrations and relaxation activities. Ataxia Ambassadors is an undergraduate student club at Johns Hopkins University that raises awareness of ataxia and will be holding an Arts for Ataxia Picnic for the ataxia community on September 28. Those with

ataxia are also invited to the Johns Hopkins Movement Disorders Symposium on November 8 that will feature educational presentations and a special lunch for those with ataxia. To learn more about the group or these events, please contact Bailey Vernon at (410) 616-2811 or bvernon1@jhmi.edu.

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Central New York Support Group

*Submitted by
Mary Jane Domiano*

The North Syracuse Family Festival fundraiser on May 24 and “Pet Pawday” on June 8 was a big success. We raised \$75 for NAF through the “Petting a Service Dog” effort.



Emma

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Alabama Ataxia Support Group

Submitted by Becky Donnelly

The Alabama Ataxia Support Group enjoyed a social event in May at B@A Warehouse in downtown Birmingham. A delicious luncheon buffet was enjoyed by the group, followed by social interaction. Sandee Mackinaw coordinated the event, along with Susan Mason of B@A Warehouse. ❖



Members of the Alabama Ataxia Support Group

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

NAF BULLETIN BOARD

Moderator – Atilla and Bear

www.ataxia.org/forum/toast.asp

NAF CHAT ROOM

Moderator – Della (ddpokernut@yahoo.com)

www.ataxia.org/connect/chat-rooms.aspx

NAF FACEBOOK GROUP

www.facebook.com/group.php?gid=93226257641

NAF FACEBOOK FANS

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

NAF YOUTUBE CHANNEL

www.youtube.com/user/NatlAtaxiaFound?feature=mhum

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NAF Directory

Continued from page 47

— IOWA —

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— NEW YORK —**CENTRAL NEW YORK SUPPORT GROUP LEADER****Mary Jane Damiano**

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— OREGON —**WILLAMETTE VALLEY SUPPORT GROUP LEADER****Jason Wolfer**

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NAF Directory

Continued from page 49

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www.ataxia.org/chapters/Chandu/default.aspxPlease visit our website: www.ataxia.in<http://seekamiracleataxiagroupindia-samagindia.webs.com> ❖

Calendar of Events

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

SUPPORT GROUP MEETINGS

Tuesday, August 12, 2014

Utah Ataxia Support Group Meeting

Time: 6 p.m.

Location: John A. Moran Eye Center, SLC, UT

Details: For additional information contact Jenny Durrant at (801) 721-7140 or jenny@utahataxia.org.

– Wednesday, August 13, 2014 –

Willamette Valley Ataxia Support Group Meeting

Time: 11:30 a.m. – 1 p.m. on the second Wednesday of every month

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

Details: For more information contact Jason Wolfer at (503) 502-2633 or at wolfer.jason@gmail.com.

– Saturday, August 16, 2014 –

Arizona Ataxia Support Group Meeting

Time: 1-3 p.m.

Location: Disability Empowerment Center, Suite 214, 5025 E. Washington St., Phoenix, AZ 85034

Details: For more information contact Angela Li at (847) 505-4325 or angelali1010@gmail.com or Mary Fuchs at (480) 883-7633 or mary11115@msn.com.

Tarheel Ataxia Support Group Meeting

Time: 1 – 4 p.m.

Location: Piedmont Plaza One in the Kitty Hawk Room, 1920 W. First St., Winston-Salem, NC 27104

Details: Guest speaker is Page Mikol from North Carolina Assistive Technology Program (www.ncatp.org). For more information contact Jerry or Tammy Hauser at (336) 998-2942 or deaconwfu@msn.com.

Twin Cities Ataxia Support Group Meeting

Time: 10 a.m. on the third Saturday of every month

Location: Langton Place in Roseville at 1910 W. County Rd. D, Roseville, MN 55112

Details: For additional information contact Lenore Healey Schultz at (612) 724-3784 or cschultz.lenore@yahoo.com.

– Sunday, August 17, 2014 –

Iowa Ataxia Support Group Meeting

Time: 1 – 2:30 p.m.

Location: Urbandale Public Library, 3520 86th St, Urbandale, IA 50322

Details: Our guest speaker will be Mike Boone from Adaptive Sports. For more information contact Emily Medina at (515) 727-8713 or emily061578@yahoo.com.

– Saturday, August 23, 2014 –

New Hampshire Ataxia Support Group Meeting

Time: 10 a.m. – noon

Location: Hannafords at the Bedford Shopping Mall, 5 Colby Ct., Bedford, NH 03110, (603) 625-5431

Details: For more information contact Jill & Ken Porter at (603) 626-0129 or jilleporter@comcast.net.

Northeast Florida

Ataxia Support Group Meeting

Time: 2 – 4 p.m.

Location: Baptist South Hospital, Jacksonville, FL. Azelea/Begonia/Camelia meeting rooms.

Details: For more information contact Cory Hannan at (904) 314-2061 or coryhannan@hotmail.com.

Ottawa Ataxia Support Group Meeting

Time: 1 – 5 p.m.

Location: Emerald Plaza branch of the Ottawa Public Library. 1547 Merivale Rd., Ottawa

Details: For more information contact Prentis Clairmont at (613) 864-8545 or prentis.clairmont@gmail.com.

– Saturday, September 6, 2014 –

Mid-Atlantic Social Group Ataxia Wellness Day

Time: 10 a.m. – 3 p.m.

Location: North Baltimore Plaza Hotel, 2006 Greenspring Dr., Lutherville-Timonium, MD 21093.

Details: For additional information or to RSVP contact Bailey Vernon, Health Educator, at (410) 616-2811 or bvernon@jhmi.edu.

– Sunday, September 7, 2014 –

Mississippi Chapter Annual Picnic

Time: 1 – 3 p.m.

Location: Peter and Susan Hank's house, 103 Timberton Dr., Hattiesburg, MS

Details: For additional information contact Camille

Continued on page 52

*Calendar of Events**Continued from page 51*Daglio at daglio1@bellsouth.net.**– Wednesday, September 10, 2014 –****Willamette Valley Ataxia Support Group Meeting****Time:** 11:30 a.m. – 1 p.m. on the second Wednesday of every month**Location:** Albany General Hospital, 1046 6th Ave. SW, Albany, OR 97321**Details:** For more information contact Jason Wolfer at (503) 502-2633 or wolfer.jason@gmail.com.**– Thursday, September 11, 2014 –****Tri-State Ataxia Support Group Meeting****Time:** 6:30 – 8:30 p.m.**Location:** Bethel Israel Medical Center, Phillips Ambulatory Care Center (PACC), Second Floor Conference Room, 10 Union Square East, New York, NY 10003**Details:** For more information contact Denise Mitchell at markmeghan2@gmail.com or Kathy Gingerelli at kgingerelli@msn.com.**– Saturday, September 13, 2014 –****North Texas Ataxia Support Group Picnic****Time:** 10 a.m. – noon**Location:** Las Colinas cancer Center, 7415 Las Colinas Blvd., Irving, TX**Details:** RISE will provide free lunch and drinks. For additional information contact David Henry, Jr. at (817) 739-2886 or cheve11e@sbcglobal.net.**– Saturday, September 20, 2014 –****Happy Hoosiers Indiana****Ataxia Support Group Meeting****Time:** 10:30 a.m.**Location:** McDonald's, 1024 E. Main St., Gas City, IN 46933**Details:** For additional information contact Cheri Bearman at (260) 452-6231 or cheribearman@gmail.com.**Louisiana Chapter Meeting****Time:** 11:30 a.m. – 2:30 p.m.**Location:** TBA**Details:** Guest speaker Dr. Copeland. For additional information contact Elizabeth Tanner (225) 241-3745 or hammett_e@hotmail.com.**Twin Cities Ataxia Support Group Meeting****Time:** 10 a.m. on the third Saturday of every month**Location:** Langton Place in Roseville at 1910 W. County Rd. D, Roseville, MN 55112**Details:** For additional information contact Lenore Healey Schultz at (612) 724-3784 or cshultz.lenore@yahoo.com.**– Sunday, September 21, 2014 –****Chi-town Area Ataxia Friendship Group Meeting****Time:** 1 p.m. Meetings on the third Sunday of odd numbered months.**Location:** Good Samaritan Hospital, 3815 Highland Ave., Downers Grover, IL 60515**Details:** For more information contact Jonas Cepkauskas at (708) 381-5555 or jonas@chitownataxia.org.**– Saturday, September 27, 2014 –****Alabama Ataxia Support Group Social****Time:** To be announced**Location:** To be announced**Details:** For more information contact Becky Donnelly at (205) 987-2883 or donnelly6132b@aol.com.**– Saturday, October 4, 2014 –****Rhode Island Ataxia Support group Meeting****Time:** 11 a.m. – 2 p.m.**Location:** Franklin Court, 150-160 Franklin St., Bristol, RI**Details:** For more information contact Anabela Azevedo at (401) 297-8627 or azevedo_anabela@yahoo.com.**– Wednesday, October 8, 2014 –****Willamette Valley Ataxia Support Group Meeting****Time:** 11:30 a.m. – 1 p.m. on the second Wednesday of every month**Location:** Albany General Hospital, 1046 6th Ave. SW, Albany, OR 97321**Details:** For more information contact Jason Wolfer at (503) 502-2633 or wolfer.jason@gmail.com.**– Saturday, October 11, 2014 –****Central MN Ataxia Support Group Meeting****Time:** 9:45 – 11:45 a.m.

If you are an 80+ year old member of an ataxia support group and are concerned how you can support your group. Simple, JUST SHOW UP!

— Peter Meyeirhoff

▶▶

Location: Kimball State Bank of St. Augusta, in the Board Room, 24952 County Rd. 7, St. Cloud, MN 56301

Details: For more information contact Marsha Binnebose at (320) 248-9851 or mbinnebose@hotmail.com.

North Texas Ataxia Support Group Picnic

Time: 10 a.m.- noon

Location: Las Colinas cancer Center, 7415 Las Colinas Blvd., Irving, TX

Details: RISE will provide free lunch and drinks. For additional information contact David Henry, Jr. at (817) 739-2886 or cheve11e@sbcglobal.net.

Tampa Bay Ataxia Support Group Meeting

Time: 12:30 - 3 p.m.

Location: Morsani Center, 13330 USF Laurel Dr. #1013, Tampa, FL

Details: For more information contact Nygel Lenz at (727) 451-9165 or nygellenz@gmail.com.

INFORMATIONAL, AWARENESS, AND IAAD EVENTS AND FUNDRAISERS

Global Online Walk n' Roll 2014

IAAD Event and Fundraiser

Details: You can create your own team, have a friendly competition, and begin creating ataxia awareness and raising funds to support the mission of NAF. For more information please visit the event website, www.ataxia.org/walk/virtual.

– Saturday, August 23, 2014 –

Macy's "Shop for a Cause"

Details: Just in time for "Back to School" shopping! One-day-only sales event at Macy's stores nationwide. Card holders receive a 25% discount on regular, sale, and clearance items, including home. Even save on most brands usually excluded. Card holders 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. All Macy's card orders must be received by August 16. For more information please contact NAF at (763) 553-0020. All proceeds benefit the National Ataxia Foundation. <https://www.ataxia.org/macyscard>

– Friday, September 5-7, 2014 –

Boston Abilities Expo

Time: Friday and Saturday 11 a.m. – 5 p.m., Sunday 11 a.m. – 4 p.m.

Location: Boston Convention and Exhibition Center, Hall C, Boston, MA

Details: Admission is free. <http://www.abilitiesexpo.com/boston/index.html>

– Sunday, September 7, 2014 –

Denver Fourth Annual Walk n' Roll for Ataxia IAAD Event and Fundraiser

Time: Registration begins at 8 a.m.

Location: Denver City Park Pavilion, Denver, CO

Details: The event includes non-competitive 1, 3 and 5K run/walk/roll routes. All proceeds benefit the National Ataxia Foundation. For more information please visit the event website or contact Charlotte DePew at (720) 379-6887 or cldepew77@comcast.net. www.ataxia.org/walk/denver

– Saturday, September 13, 2014 –

Concord California Walk 'n Roll for Ataxia IAAD Event and Fundraiser

Time: 10 a.m. – 1 p.m.

Location: Newhall Park, Concord, CA

Details: All proceeds benefit the National Ataxia Foundation. For more information please visit the event website <http://ataxia.kintera.org/faf/search/searchTeamPart.asp?ievent=1104992&lis=1&kntae1104992=DCA6810210F046F89461461EA0393AD9&team=6017927>.

Lowndes County Alabama Walk 'n Roll for Ataxia IAAD Event and Fundraiser

Time: 10 – 11:30 a.m.

Location: Catoma Park, Mitchell-Young Rd., Montgomery, AL

Details: All proceeds benefit the National Ataxia Foundation. For more information contact Carly Hill at (334) 651-1196 or chill12482@gmail.com. <http://www.kintera.org/faf/search/searchTeamPart.asp?ievent=1104992&team=6027941>

Minnesota Fourth Annual Walk Stroll n' Roll for Ataxia IAAD Event and Fundraiser

Time: Registration and Social Hour 9 – 10 a.m., Walk and Program at 10 a.m.

Location: Wolfe Park, 3700 Monterey Dr., St. Louis Park, MN 55416

Details: Wolfe Park is kid and pet friendly. No registration fee – donations only. All proceeds benefit the National Ataxia Foundation. For more information or to volunteer please visit the event website or contact Terry Sweeney at (612) 763-9320 or mnataxiawalk@yahoo.com. www.ataxia.org/walk/minnesota

*Calendar of Events**Continued from page 53***– Sunday, September 14, 2014 –****Tour de Shunk – Go On 3! For Ataxia Awareness IAAD Event and Fundraiser**

Details: Michael Cammer is attempting a 50-mile bike ride to raise ataxia awareness. All proceeds benefit the National Ataxia Foundation. For more information please visit the event website <https://naf.myetap.org/fundraiser/GoOn3/>.

– Saturday, September 20, 2014 –**Atlanta Fourth Annual Walk n' Roll for Ataxia IAAD Event and Fundraiser**

Time: Registration 9:30 a.m., Walk 10 a.m.

Location: Shorty Howell Park, 2750 Pleasant Hill Road, Duluth, GA 30096

Details: All proceeds benefit the National Ataxia Foundation. For more information visit the event website or contact Greg Rooks at (404) 822-7451 or atlantaataxia@gmail.com. www.ataxia.org/walk/atlanta

LA/OC Sixth Annual Walk n' Roll for Ataxia IAAD Event and Fundraiser

Time: 8 – 11 a.m.

Location: Aquarium area in Long Beach, CA. Starts at 340 S. Pine Ave.

Details: All proceeds benefit the National Ataxia Foundation. For more information visit the event website or contact Daniel Navar at (323) 788-7751 or danieln27@gmail.com, Cindy DeMint at (714) 329-4437 or chatsdots@sbcglobal.net or Sherry McLaughlin at (626) 791-1558 ccherilynmc@yahoo.com. www.ataxia.org/walk/longbeach

New England Fourth Annual Walk n' Roll for Ataxia IAAD Event and Fundraiser

Time: 9 a.m. – 1 p.m.

Location: Lamanski Park, 400 Oxford St. N., Auburn, MA 01501

Details: All proceeds benefit the National Ataxia Foundation. To volunteer or for more information visit the event website or contact John Mauro at (508) 736-6084 or ngataxia@outlook.com. www.ataxia.org/walk/auburn

– Thursday, September 25, 2014 –**International Ataxia Awareness Day (IAAD)**

Details: International Ataxia Awareness Day (IAAD) 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.

For more information on organizing an event in recognition of IAAD, please visit www.ataxia.org/events/international-ataxia-awareness-day.aspx. Tell us how you recognized International Ataxia Awareness Day (IAAD) and share a photo with us for a future issue of *Generations*.

Please e-mail your story/photo to joan@ataxia.org or mail to National Ataxia Foundation, Attn: *Generations* Editor, 2600 Fernbrook Lane, Suite 119, Minneapolis, MN 55447-4752. Your stories on how that day was recognized could live on in a future issue of *Generations*. Please send us your articles, photos, and proclamations so the entire NAF community can relive this historic day.

– Saturday, September 27, 2014 –**BINGO for Ataxia IAAD Event and Fundraiser**

Time: 5:30 p.m.

Location: Berlin Fire House, 214 N. Main St., Berlin, MD 21811

Details: All proceeds benefit the National Ataxia Foundation. For more information contact JoAnn or Dana Simpson at (410) 251-2478 dsimpson2478@yahoo.com.

Fort4Fitness – Happy Hoosiers Team

Location: Parkview Field, Fort Wayne, IN

Details: The Bearman Family is participating in this year's Fort4Fitness event to raise ataxia awareness and funds. All proceeds benefit the National Ataxia Foundation. <http://ataxia.kintera.org/faf/search/searchTeamPart.asp?ievent=1104992&lis=1&kntae1104992=CB1CABF0E373424A83576CCB11D64307&team=6028499>

San Diego Eighth Annual Walk n' Roll for Ataxia IAAD Event and Fundraiser

Time: Registration 7 a.m., Walk begins 8 a.m.

Location: Tuna Harbor Park, Downtown San Diego, CA

Details: Free t-shirt for the first 200 participants. All proceeds benefit the National Ataxia Foundation. To volunteer or for more information visit the event website or contact Earl McLaughlin at (619) 840-3753 oremclaugh@cox.net. www.ataxia.org/walk/sandiego

Seattle Walk n' Roll for Ataxia IAAD Event and Fundraiser

Time: 9 a.m. – 1 p.m.

Location: Alki Beach, 1702 Alki Ave. S.W., Seattle, WA 98116



Details: All proceeds benefit the National Ataxia Foundation. For more information contact Milly Lewendon at (425) 823-6239 or [mmllewendon@comcast.net](mailto:mmlewendon@comcast.net). www.ataxia.org/walk/seattle

– **Sunday, September 28, 2014** –

Arts for Ataxia Picnic

IAAD Event

Time: Noon – 3 p.m.

Location: Johns Hopkins University, Homewood Campus, 3400 N. Charles St., Baltimore, MD 21218

Details: The picnic will be a social event for the ataxia community full of entertainment, arts and food. For more information contact Bailey Vernon at (410) 616-2811 or bvernon1@jhmi.edu.

– **Saturday, October 4, 2014** –

Michigan Walk n' Roll for Ataxia

IAAD Event and Fundraiser

Time: Registration 8:30 – 9:00 a.m., Symposium 9 a.m., Luncheon 11:30 a.m., Walk 1 p.m.

Location: University of Michigan Biomedical Science Research Building (BSRB), 109 Zina Place, 5031 BSRB, Ann Arbor, MI 48109

Details: All proceeds benefit the National Ataxia Foundation. For more information contact Elizabeth Sullivan at (734) 232-6247 or elizsull@umich.edu or Tanya Tunstull at (313) 736-2827 or tinyt48221@yahoo.com. www.ataxia.org/walk/michigan

– **Sunday, October 5, 2014** –

Jack's Run

Details: Ann Nuese is training for the Medtronic Marathon. She will be running for her dad, Jack Moore. All proceeds benefit the National Ataxia Foundation. For more information visit the event website, <https://naf.myetap.org/fundraiser/14jacksrun/>.

– **Sunday, October 11, 2014** –

Tea Time for Ataxia

IAAD Event and Fundraiser

Time: 11 a.m. – 1 p.m. or 1:30 – 3:30 p.m.

Location: Aubrey Rose Tea Room, La Mesa, CA

Details: Cost is \$35/person. All proceeds benefit the National Ataxia Foundation. For more information contact Jane Jaffe at (619) 286-9745 or sicilianmother@cox.net. ❖

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 through May 2014. 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.

Ray Agostini	Dr. Robert Currier	Mary Lou Hinman	Gary Peterson	Stafford Family
Dave Alessi	John Cwiok	Dr. Paul Humes	Debra Peterson-Adair	Carol St. George
Diane Anderson	Melissa Davis	Krista Humes	Nelda Pogulis	Janette St. George
Jeffery Barberi	Dawn Dizon	Kar Kee-Ng	Amanda Poon	Robert St. George
Betty Beck	Marsha Donaldson	Linda Kleen	Elsie Poon	St. George Family
Clair Beck	Naomi Droz	Jamie Kosieracki	Jill Porter	Joseph Stamer
Cora Bell	Robert Dudzik	John Lane Sr.	Ken Porter	Nina Strong
Nathan Bell	Lorraine Emanuel	Jennifer Leader	Rolando Ramos	William Sullivan
Mathew Berens Sr.	Dan Eustache	Kathryn Leicht	Charity Ranger	John Surabian
Carol Brackett	Rick Eustache	William Lytle III	Elizabeth Riley	Merlyn Swedberg
Ruth Buckley	Trinity Falk	Keith Mizutani	Janet Riley	Cynthia Swift
Paul Cerbatos	Mrs. Eugenie Fauver	Jack Moore	Aneglina Ritschel	Patricia Tobias
Kai Chau	Richard Green	Carol Mullen	Samantha Ritschel	Margaret Tseng
William Chwee	Carol Greenblatt	Charles Murphy	Eileen Roscoe	Bill Vande Brake
Debra Clementz	Mary Kay Hartmann	Hubert Myers	Lydia Santos	David Westrick
Karen Cocquyt	Paul Heimann	Frances Na	Derek Semler	Steven Wiens
Joseph Coffey	JoAnn Henderson	Trent Pavelec	Popi Sideris	Raymond Wong
Russell Crystal		Tyrell Pavelec	Kathryn Smithers	Jesse York
		Norma Payne		





National Ataxia Foundation

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GIFT – HONOR – MEMORIAL

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

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

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

My contribution is:

- In Memory In Honor Gift Membership

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Occasion _____

Send Acknowledgment Card to:

Name _____

Address _____

City/State/Zip _____

From:

Name _____

Address _____

City/State/Zip _____

MEMBERSHIP

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

- Lifetime membership \$500

Annual memberships:

- Patron membership \$100-\$499

- Professional membership \$55

- Individual \$35

- Household \$55

- Addresses outside the U.S. please add \$15

Name _____

Address _____

City/State/Zip _____

Phone _____

E-Mail _____

- Yes, sign me up for NAF e-mails

PAYMENT INFORMATION

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

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

Total Amount Enclosed \$ _____

Credit Card: Visa MasterCard Discover

Name on Card _____

Card # _____

Exp. Date _____ CVV # _____

Signature _____

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