

Generations

The Official Publication of the National Ataxia Foundation
Volume 44, Number 4 — Winter 2016-17



 The National Ataxia Foundation

*Dedicated to improving the lives
of persons affected by Ataxia*

INSIDE THIS ISSUE

Highlights and photos from International Ataxia Awareness Day 2016 on pages 2-10



Annual Ataxia Conference information and registration forms begin on page 14

Calendar of upcoming events is on pages 44-46

Ambassador, Chapters and Support Group listings are on pages 36-40



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Table of Contents

Annual Ataxia Conference (AAC)

2017 AAC Announcement	14
2017 AAC Introduction	15
2017 AAC Schedule & Overview	16-20
2017 AAC Registration Instructions	21
'Birds of a Feather' FAQ	22-23
2017 AAC Registration Form	24-26
2017 AAC Conference Information and Resources	27-32
Explore San Antonio	28
2017 AAC Exhibitors, Sponsors Wanted	29
NAF 2017 AAC Travel Grant Program Needs Your Support	32
Applying for a Travel Grant	33
2017 AAC Silent Auction	33

Articles

Social Security Corner	11-12
2016 SHARE! Recovery Awards	13
Fundraisers	43

International Ataxia Awareness Day

Recognitions of IAAD	2-10
----------------------------	------

Membership Topics

From the Desk of Executive Director Joel Sutherland.....	1
---	---

Membership Topics (cont.)

Remembering the NAF in Your Will.....	10
Thrivent Choice Works	12
Chapter and Support Group News.....	34-35
NAF Directory of Chapters, Support Groups, Social Networks and Ambassadors	36-40
Calendar of Events	44-46
Memorials and In Your Honor	47

Personal Stories & Poems

Ataxia Awareness Ride	42
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Research/Research Opportunities

SCA Clinical Trial	12
Study of Cardiomyopathy in Friedreich's Ataxia Patients	12
Friedreich Ataxia Tissue Donation	13
Genes in Inherited Neurologic Disorders Study	23
Patients with MSA-C Needed for an MRI Study	40
Friedreich's Ataxia Clinical Trial at Mayo Clinic with Medication Epicatechin	41
SCA6 and SCA8 Study at the Kennedy Krieger Institute	48

The deadline to submit materials for the Spring issue of *Generations* is Friday, February 3, 2017.

From the Desk of Executive Director Joel Sutherland

Hey! So how do you like the new look AND feel of “Generations”? We think it looks great as it marks the first of a number of changes coming to the National Ataxia Foundation in the near future. Next up on our list of changes is a new addition, a monthly digital newsletter that we expect to launch in January. From there it’s a newly designed NAF website complete with a refreshed logo and new color scheme probably in April or May. Yes, changes are coming to the NAF.

Maybe the first change I should identify is, well, me. I come to the NAF after 28 years in sports marketing followed by four years in the non-profit sector serving as Executive Director of the Minnesota/Dakotas Chapter for the Cystic Fibrosis Foundation (CFF). I left the CFF in March of 2016 to join the NAF as its National Director of Development. When longtime NAF Executive Director Mike Parent announced his retirement in June, I sought-out the position of Executive Director believing I could begin taking the NAF to a new level. I was named the new Executive Director by the Board of Directors on August 25.

I am flanked by a committed staff in Minneapolis, and an experienced Board of Directors located around the country. We have aspirational goals to pursue and ultimately achieve. Our focus first needs to be finding a treatment for Ataxia and then a cure, while simultaneously working to improve the lives of those living with this “thief” we call Ataxia. But there is no mistake on what will be needed to achieve these goals. The answer is no difference in the Ataxia community as it is for any rare disease across this

country. The answer is money.

While working at the CFF I saw first-hand how “Money buys research and research finds answers.” This is a motto we all need to embrace here at the NAF and within our Ataxia community across this country. I have a focused commitment to raising our level of fundraising to support our researchers around the globe and I hope you’ll join me in this effort.

As you’ll see on page two in this publication of “Generations,” a friend of mine and I, along with our supportive wives, pulled together a 60-mile walk in September in support of the NAF mission. We walked 60 miles over three days, one mile for each year of the NAF existence (okay, it’s only been 59 years, so we rounded up). We were seeking \$60 donations and had a goal of \$9,000. After a four-week, on-line letter writing campaign, we raised a little more than

\$10,000. We were surprised and appreciative for all the support we received. For 2017 the NAF needs 60 more people to join us in this effort. If you would like to join me in supporting the NAF’s mission in 2017, please e-mail me at joel@ataxia.org. I will do I all I can to help you be successful.

As I mentioned earlier, I have a focused commitment to raising our level of fundraising at the NAF. But I hope that you, too, will raise your own level of commitment to fundraising for the mission of the NAF. We can all do “something” and if you need ideas, let us know. You see, the only thing that we can’t do is “nothing.” Yes, changes are coming, but one thing that will never change at the NAF is our commitment to find a cure for Ataxia. ❖



Recognitions of International Ataxia Awareness Day

— September 25, 2016 —

The National Ataxia Foundation (NAF) would like to thank all the individuals, support groups, ambassadors and chapters who recognized International Ataxia Awareness Day (IAAD) through various events, proclamations, resolutions, social media and press releases across the globe.

Individuals raised awareness about Ataxia and the activities for this year raised over \$405,000 to help support the important work of the National Ataxia Foundation.

Thank you to all who have organized, participated or sponsored an IAAD activity. Through IAAD, we honor those who are affected by Ataxia, those who we have lost, their families, friends and caregivers.

IAAD RECAPS Fundraisers

*International Walk n' Roll to Cure Ataxia**

Again this year individuals and groups participated in the Seventh Annual International Walk n' Roll to Cure Ataxia (previously the Global Walk n' Roll for Ataxia). Personal fundraising pages were available for each team or individual to upload a photo, write a personal text and set their own goal. It was another great initiative that raised almost \$11,000 to benefit the National Ataxia Foundation.

**International Walk n' Roll to Cure Ataxia Events*

- * **Cure Ataxia** – Organizer Sunny Prom
- * **Fitness in the Park** – See page 6
- * **Kansas City Ataxia Support Group IAAD Picnic** – See page 8

* **60 for 60** – On September 23, Vince Kelly and NAF's Executive Director Joel Sutherland

began their walk from Ely, MN down Highway 1 to the north shore of Lake Superior. Their goal was 20 miles per day, and ending on Sunday, September 25, IAAD. This event was part of the International Walk n' Roll to Cure Ataxia.



Left to right: Pam & Joel Sutherland, Vince & Jane Kelly

* **Team Tampa Bay** – Organizer Tampa Bay Ataxia Support Group

Atlanta Walk n' Roll to Cure Ataxia

Submitted by Dave, Greg, Diane and Lealan

The Greater Atlanta Support Group held their annual Walk n' Roll to Cure Ataxia at Shorty Howell Park in Duluth, GA on Saturday, September 24. The event was a 1.25 mile Walk or Roll around the Shorty Howell Park. Following the walk was refreshments, Ataxia information and team recognition for the most dollars raised.

There were about 100 participants in attendance this year with 10 teams participating. Team Jon raised over \$3,200, Team Olivia raised over \$3,300, the NacPac raised almost \$3,000 and Team HOPE raised almost \$4,500. Our top individual fundraiser was Marcie Anthone with \$3,300. ▶▶



The Atlanta Walk n' Roll to Cure Ataxia

Their sponsors this year were Athens Stonecasting and Workout Anytime (Buckhead location). Will Morris and Atlanta Soundworks provided their sound system and Marcie An-thone was able to get a water donation from the Coca-Cola Company. Costco provided snacks and gift cards for the raffle. Again this year, Rudy's New York Pizza donated 20% of lunch proceeds.

The event was a great success and the event raised more than \$25,000 to benefit the National Ataxia Foundation.

Concord Walk n' Roll and Swim to Cure Ataxia

The Concord California Walk n' Roll and Swim was held on Saturday, September 17 at the Newhall Community Park in Concord, CA for a walking or rolling around the path. After they headed over to the Montecito pool for pizza. The event raised more than \$4,000 to support the National Ataxia Foundation.

Sixth Annual Denver Run, Walk n' Roll to Cure Ataxia in Honor of Anne Killan

Submitted by Charlotte DePew

September 11th began with a peaceful and lovely Colorado sunrise at the scenic Denver City Park Pavilion. There was a scurry of activity in preparation for the Sixth Annual Denver Run, Walk n' Roll (RWnR) to Cure Ataxia. Led by our support group leader, RWnR chairperson and with the planning committee's hard work, these wonderful volunteers put on yet another successful and fun Ataxia awareness/fundraising event.

This year's event honored a passed support group member, Anne Killan (1965-2015). The family gave a compassionate account of her life and how Ataxia impacted the family. A poster-sized picture collage of precious moments in Karen's life was on display for all to view.

The day attracted a large group of over 230 participants. There were activities for everyone from the vendor fair to partaking of the generous donations from Dunkin Donuts as well as an amazing array of items donated for our drawing and silent auction. This year we had a superbly well-orchestrated sound system and music by Corey Banks, a member of our Planning Committee. I think it's safe to say a good time was had by all based on accolades as people departed.



The Denver Run, Walk n' Roll to Cure Ataxia

The Denver RWnR Committee, want to thank our gracious and dedicated members who attended, provided volunteers, and procured donations more than \$21,000 to benefit the National Ataxia Foundation. Since our event does not close the park to the public, we had a new and large start/finish overhead banner for all to see and two A-framed signs inviting passersby to join us and/or get Ataxia information. Each year we have a few inquirers. It is each and every one of our members who helped in various ways toward Ataxia research, awareness, and coping with a rare neurological progressive (I call it "nasty") disease.

Our group was once again thankful to have neurologists interested in Ataxia from The

International Ataxia Awareness Day *Continued from page 3*

University of Colorado Health Sciences (UCHS) at our event. Drs. Lauren Seeberger and Maureen Leehey participated in the walk and then spoke about research in Ataxia and UCHS becoming a designated site for Ataxia research by 2017.

The Seventh Annual Denver RWnR will be September 10, 2017 at Denver City Park at 8:00 a.m.

Minnesota Walk, Stroll n' Roll to Cure Ataxia

The Seventh Annual Minnesota Walk, Stroll n' Roll was held on Saturday, September 10 at Wolfe Park in St. Louis Park, MN. This year's Walk, Stroll n' Roll was in memory of Barbara Pogulis. It was another fabulous Minnesota fall day and a perfect day for the Twin Cities and Central Minnesota Ataxia Support groups and all those who participated in the event. Over 425 local supporters, friends and family attended.



The Minnesota Walk, Stroll n' Roll to Cure Ataxia

Again this year the Twin Cities Trumpet Ensemble played on the Wolfe Park amphitheater stage. It was another great event, with over 600 donations, and raising more than \$100,000 to benefit the National Ataxia Foundation. <https://www.youtube.com/watch?v=3YuOwZl6nhw>

Michigan Walk n' Roll and Symposium

The Michigan Walk n' Roll and Symposium was held on Saturday, August 27 at the University of Michigan Biological Sciences Research Building. This event raised more than \$7,000 to

benefit the National Ataxia Foundation.

New England Walk n' Roll to Cure Ataxia

The Ninth Annual New England Walk n Roll to Cure Ataxia was held at a new location this year on Saturday, September 10 at Bristol Town Beach in Bristol, RI. There was entertainment and a raffle following in the walk. The event raised more than \$45,000 to benefit the National Ataxia Foundation.



The New England Walk n' Roll to Cure Ataxia

Northeast Ohio Walk n' Roll to Cure Ataxia

This is the first 2K Walk n' Roll for Northeast Ohio and it was held on Sunday, August 14 at the Cleveland Metroparks West Creek Reservation Keystone Pavilion in Parma, OH. The event raised more than \$13,000 to benefit the National Ataxia Foundation.



The Northeast Ohio Walk n' Roll to Cure Ataxia

OC/LA Walk n' Roll to Cure Ataxia

On Saturday, September 17, the OC/LA chapter of the National Ataxia Foundation held ▶▶



The OC/LA Walk n’ Roll to Cure Ataxia

their Eighth Annual OC/LA Walk n’ Roll to Cure Ataxia. It was held again this year at the East Lake Village Community Association Clubhouse and parking lot in Yorba Linda. They had a DJ, opportunity drawings for participants, vendors showing their products/services, children’s activities which included face painting, balloon animals and games, and community with others affected by Ataxia.

After the Walk n’ Roll, Rudy’s Diner or Out of the Park Pizza offered a percentage of sales all day on the 17th, to be donated back to the NAF. The weather was beautiful and the event raised more than \$77,500 to benefit the National Ataxia Foundation.

Tri-State Walk n’ Roll to Cure Ataxia

The Tri-State Support Group held their first Walk n’ Roll to Cure Ataxia on Saturday, August 27 at the Liberty State Park in Jersey City, NY. Lead by support group leader, Kathy Gingerelli, they passed their original goal of \$10,000 and the event raised more than \$43,000 to benefit the National Ataxia Foundation.

Utah Walk n’ Roll to Cure Ataxia

On Saturday, October 1, the Utah Support Group hosted their Walk n’ Roll at the Layton Commons Park in Layton, UT. The event raised more than \$10,000 to benefit the National Ataxia Foundation.

Walk for Dave

The Walk for Dave was held on Saturday, August 6, at Onondaga Lake Park in Liverpool,



Walk for Dave

NY. This walk is dedicated to the memory of David Alessi, who passed away in October 2011 from complications of Spinocerebellar Ataxia Type 2. This event raised more than \$6,800 to benefit the National Ataxia Foundation.

Western PA Walk, Run n’ Roll

Submitted by Ed Schwartz

The Western PA Ataxia Support Group hosted their Second Annual Walk n’ Roll at the Allegheny County South Park in South Park Township on Saturday, September 24. This years Walk n’ Roll was in memory of Richard Reimond, Michael Friend and Larry Hillenbrand. More than 90 people attended the event.



Left to right: Donna Eiben, Ed Schwartz and John Mauro with the PA proclamation

A proclamation affirming support from the citizens of Pennsylvania for those with Ataxia was presented to John Mauro by Donna Eiben and Ed Schwartz. The event raised more than \$9,000 to benefit the National Ataxia Foundation.

<https://www.youtube.com/watch?v=LRXqFsWeRPY>

International Ataxia Awareness Day
Continued from page 5

Awareness Event

Submitted by Nancy Nelson

On Wednesday, September 21, my sister and I did an event at Winchester House Nursing Home in Libertyville, Illinois. My brother Craig was diagnosed with Ataxia about 17 years ago. He was 43 at that time. He is 62 now and resides in this nursing home. Many of the nursing staff did not know what Ataxia is. We had a slide presentation and used educational information provided by NAF. My brother spoke about his personal experiences. I made a photo board with photos from the past and present. I wanted people to see him as he was in his life before Ataxia.

The staff and administrator thanked us for helping them understand this condition.

Ataxia Awareness Extravaganza

The Arizona Ataxia Support group hosted the Ataxia Awareness Extravaganza on Saturday, September 24 at St. Xavier University in Gilbert, AZ. The event had local artists, health and wellness vendors, silent auction, raffle and children's activities. The event raised more than \$6,500 to benefit the National Ataxia Foundation.

Ataxia Presentation

Submitted by Ron Smith

I gave a presentation on September 21 to the local Rotary club for IAAD. It included information about Ataxia and how it affects those who have it. He also showed a video about Ataxia.

Bosco's friends Helping Friends

Bosco's Friends Helping Friends shopping event was held on October 18. Mike Cammer and Kathy Schmidt sold over 130 shopping passes which raised more than \$650 for the National Ataxia Foundation.

Delaware Park Trophy Race

Submitted by Cathy & Joe DeCrescenzo

Delaware Park held its Third Annual Trophy



Delaware Park Trophy Race trophy presentation

Race on September 24 in honor of IAAD. Cathy and Joe DeCrescenzo, with friends and family, presented the trophy plate to the winning jockey in the winners' circle after the race. Delaware Park also printed a full page in their program explaining Ataxia and the mission of the NAF. The programs are used by almost everyone attending the races.

All this happened by accident. Joe was writing to the person in charge at the races, asking them if they would donate a race and waive the normal \$150 fee. He wasn't asking for any money, just a chance to make people aware of Ataxia. Then, because of their generosity, it "snowballed" and this year is our third race. It is my hope that this will inspire others to just take a moment to connect with someone or an event in their community that may also be able to help them share awareness about Ataxia in some unexpected way. You will never know unless you ask!

If you want more information please e-mail Joe at jdecr26@verizon.net or Cathy at cdecres@verizon.net.

***Fitness in the Park**

Submitted by Jalean Retzlaff

It was a foggy start to the day. We arrived at Hap McLean Park around 8 a.m. to get everything set up. The event started at 9 a.m. There were five Zumba instructors at the event that taught routines. There were silent auctions ►►



Fitness in the Park

going on and we held a raffle for a Patriotic Quilt. The winner of the Patriotic Quilt was Kay Banks. We had about 30 people in attendance. The event raised \$950.

Every Day is IAAD – Change for Change Fundraiser

Submitted by Sandy Stein

Every day is International Ataxia Awareness Day because I have promised to raise \$10,000 in honor of my son, Dave Stein. Dave, 61, served in the Peace Corps in the South Pacific and taught people how to make water drinkable. I am a very proud mom to have a son who has given so much. I have collected \$9,077 so far. To everyone I ask for a donation, I give information on Ataxia.



Dave Stein

Go on 3! Tour de Shunk

This year Mike Cammer entered the “Tour de Shunk” for the third year in a row! The event was on Sunday, September 18, and he entered to ride his trike the entire 102 miles! This event raised more than \$2,700 to benefit the National Ataxia Foundation.

IAAD T-shirt Helps Spread Awareness

Submitted by Margaret “Peggy” Swanson

I have had diagnosed SCA7 since 2009; it forced my medical retirement early in 2011. I went to my first NAF Annual Ataxia Conference last year in Orlando and realized we need to raise Ataxia awareness. I have been telling people I have MS just because it was easier for them to relate. Most people think that I will get better with exercise. This year I had the humbling experience of being part of a five-year family history research study (no treatment) at the NIH/NEI (National Institutes of Health and National Eye Institute) in Bethesda, MD (we live in Tampa, FL). I had purchased my IAAD t-shirts before we left. My husband and I wore them at NIH. I stopped anyone who would

listen in the hallway to be a spokesman (walker and all). I told everyone at the NIH campus family lodge we were staying at. The one thing I wanted to do while in Maryland was to eat Maryland crab cakes; so my husband and I wore the t-shirts to the local restaurant and bar. When we got back to Florida, we wore them at home and told our friends. I am not strong enough to be in an event, but together my husband and I are "the strength behind Ataxia."



Margaret and Howard Swanson

I have also worn my t-shirt to the gym for my Silver Sneakers class and told them about Ataxia. I am not old enough to be in silver sneakers but I have done it as a club member since I retired. I am fighting to remain walking and keep muscle tone.

Madi Runs Over Ataxia

In recognition of IAAD and in Honor of Madi Ford, a 5K fun run to raise Ataxia awareness was held on October 2 at Norio Park in Fayetteville, PA. The event raised more than \$1,500.

Participating in the Michigan WnR

Submitted by Cheri Bearman

This year, my husband Gil and I participated in the Michigan Walk 'n' Roll event, held in recognition of IAAD. The event took place on the University of Michigan campus in Ann Arbor on August 27.



Cheri Bearman

We enjoyed an excellent seminar featuring key personnel from the University of Michigan Ataxia Clinic, followed by a wonderful Italian lunch catered by Olive Garden. The weather was quite

International Ataxia Awareness Day Continued from page 7

warm and stormy, but we chose to walk outdoors on the track. We were joined by a few other brave walkers/rollers. A thunder and lightning storm blew in, so we had to cut our walk short and hurry back to the car!

With the loving support of many faithful friends and family members, I raised more than \$1,900 for the National Ataxia Foundation!

Race for a Cure

Submitted by Cindy De Mint

Saturday's Race for a Cure was a very busy but fun event for our family. We were able to meet with Trevor Huddleston and Dylan Garner, drivers with TEAM 97. Trevor won California State Champion and Dylan won Rookie of the Year for late model cars ... a very exciting night.

We were introduced at the autograph session and photos were taken with first responders. It really was all about them this night, which it should be, on 9-11 weekend. We did get a shout out from Dylan, and he was able to tell the few fans about Ataxia.

I had a big community event on October 1st where I handed out the 2,000 cards I had made. Since there wasn't a date on the flyers, they could be used at any time.

I want to thank everyone involved with getting

the new NAF Pushpay app approved, and Julie for all her time and effort to make this happen. Apps like Pushpay are the way of the future here in CA.

The good news is we were chosen for the Celebrity Charity Race for the 2017 season! They have more than 5,000 people attend. All the celebrities tweet and Instagram out all night. We will be interviewed in the Winner's Circle.

Signs, Signs, Everywhere a Sign

Submitted by Lisa Cole

A few things that I did for the month of September through September 25 are:

Several IAAD signs were posted up at the St. Lucie West Gold's Gym, Cowboy's restaurant, St. Lucie West Campus of IRSC (Indian River State College), several eye doctor offices and an eye surgery center and two Dunkin Donut locations. All of this was done near the beginning of September.

I wore my IAAD t-shirt several times and on September 25, I wore my t-shirt to a busy breakfast place and took pics.

I asked the KVJ Radio show, via e-mail, if they could mention IAAD. They did on September 26. <http://livestream.com/KVJShow/events/3742291/videos/136983236>

Lastly, I did sign up on the Atlanta Walk N' Roll, created a nice e-mail and had several donations. This went to at least 100 people. I told several of my clients and they donated as well.



Lisa Cole

New NAF App

You can now connect and engage with the Ataxia community through the new National Ataxia Foundation App, available for iOS, Android and for your desktop or laptop computer.

Please see the inside back cover of this issue for more information and links to download the app.



Tea Time for Ataxia

This year's Tea Time for Ataxia was held in the Aubrey Rose Tea Room on September 24. We really do have a lot of followers who look forward to the event each year. This year our event raised more than \$9,250.

*Kansas City Ataxia Support Group Picnic

Kansas City Ataxia Support Group planned their first annual fund and awareness raising event at the Shawnee Mission Park in Shawnee ►►

Mission, KS, raising more than \$3,500 and exceeding their group goal of \$1,000.

North Texas Area Support Group Annual Picnic
Submitted by David Henry, Jr.

The North Texas Area Support Group held their annual picnic on Saturday, September 24, in Trophy Club, TX, with 17 members attending. It was a great social event for the group to enjoy time with each other, share great food and recognize IAAD.



The North Texas Ataxia Support Group

Walk n' Roll Tour 2016

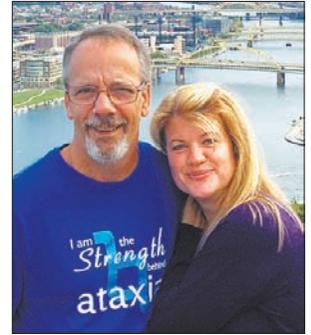
Submitted by Susan Kresnye

On Sunday, August 14, John Mauro and I started the Walk n' Roll tour with the the Greater Cleveland Area Support Group inaugural Northeastern Ohio Walk n' Roll. "Cleveland Rocks" was our theme and we did just that. We are so proud of how it turned out. There were so many variables, but somehow everything came together. I think it all started to come together when John Mauro and Ed and Linda Schwartz arrived. Even the weather worked out. Our first event raised more than \$13,000! Amazing!

Next was the 9th Annual New England Walk n' Roll held on Saturday, September 10, in a new location. John Mauro originally organized this event and for 2016 handed over the reins to the Rhode Island group. The backdrop was Bristol Town Beach and they were organized! Kudos to Jeanette. This was her first effort at hosting a Walk n' Roll. It was a huge success! They raised more than \$44,000. Absolutely amazing!

Last stop was on Saturday, September 24, at the Western Pennsylvania Walk n' Roll. John Mauro and I traveled together, missing the first flight. Once we got to the site everything went like clockwork.

We were greeted by Ed and Linda Schwartz.



Susan Kresny and John Mauro

Ed's a person that has a funny story or joke that will always make you smile. This was their second annual Walk n' Roll and you could tell that they applied what they learned from the first walk. Another big success! They raised more than \$9,000!

The main lesson I took away from this tour is the importance of cooperation. We all have one goal and the more people helping, makes reaching that goal more of a reality. I like to believe that a cure is just around the corner. Turning that corner is where research comes into play and raising funds has never been more important.

IAAD in Pakistan

Submitted by Ashim Shah

IAAD was recognized in Gujat, Pakistan on September 25 and dedicated to Syeda Nigar Hassan, who passed away on October 17, 2016.

Media/Video Coverage

Eaglenews online on July 27, 2016 – Walk for Dave is Aug. 6 – <http://tinyurl.com/Walk4Dave2016>

NeurologyNow, August/September 2016 – Saving Grace: For Kathleen Gingerelli, 48, a diagnosis of Friedreich's ataxia finally explained her lifelong clumsiness – <http://tinyurl.com/KathyGingerelli>

NeurologyNow, September 12, 2016 – Videos of You: Kathleen Gingerelli Doesn't Let Friedreich's Ataxia Slow Her Down – <http://tinyurl.com/hekqnnw>

Continued on page 10

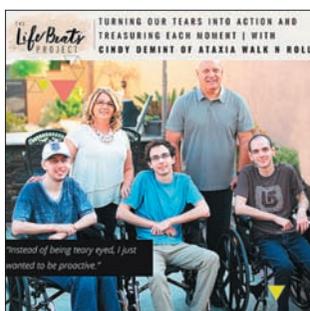
International Ataxia Awareness Day Continued from page 9

prweb on September 13, 2016 – International Ataxia Awareness Day Shines Spotlight on Neurological Diseases – <http://tinyurl.com/LAAD-ShinesSpotlight>

OC Register on September 16, 2016 – These three brothers stumble with a rare genetic condition, now they'll walk to let others know about it – <http://tinyurl.com/hpbryj3>

Public Opinion on October 11, 2016 – Local Student Hosts Ataxia Fundraiser – <http://tinyurl.com/AtaxiaFundraiser>

Cindy DeMint
The Life Beats Project Podcast: “Turning our Tears into Action and Treasuring Each Moment” – <http://www.thelifebeatsproject.com/cindy/>



Dana Mauro has **The Life Beats Project** continued her “Did you Know” daily videos and a Facebook Live session. Some of these can be found on the NAF’s You Tube Channel: <https://www.youtube.com/user/NatlAtaxiaFound?feature=mhum>

Ed Schwartz Ataxia Awareness Sessions

Session 1: What Your Family Needs to Know About Ataxia – <http://tinyurl.com/h2r3egc>

Session II: The Classifications of Different Types of Ataxia and the Most Significant Impacts – <http://tinyurl.com/hm5um2p>

Session III: The Impact on Ed Schwartz’s Life and Other Ataxia Issues – <http://tinyurl.com/zkufgqu>

Proclamations

On September 25, 2014, a bill was passed recognizing September 25 as International Ataxia Awareness Day (IAAD) in the State of Massachusetts every year.

On September 25, a proclamation was signed by the Governor of Pennsylvania, Tom Wolf, on behalf of all citizens of the Commonwealth of Pennsylvania, to support September 25, 2016 as Ataxia Awareness Day.



The PA Proclamation

— Thank you to everyone who participated in IAAD 2016! — ❖

Remembering the NAF in Your Will

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

Most of the time the Foundation is unaware of the kind acts of these champions until after they are gone, but each time we are deeply touched and honored by their selfless commitment in helping others.

Over the years these individuals, who have chosen NAF as a beneficiary, have given any-

where from a few thousand dollars to nearly one million dollars. Their forethought and benevolence has enabled the Foundation to support promising Ataxia research and provide meaningful programs and services to Ataxia families. We are thankful for their compassionate acts and we will be eternally grateful for the impact they have made in helping Ataxia families.

Perhaps this is the time to consider adding the Foundation in your will. For more information, please call (763) 553-0020 or e-mail joel@ataxia.org.

Social Security Corner

By Jon Rodis

Since becoming disabled in 2001, I have been a disability and medical advocate for people who have to face (in addition to their day to day health struggles) the many challenges and hardships of the decision-making process to file for disability and the navigation of the Social Security system to reaching the ultimate and extremely important goal of getting approved.

It is important to know what the two Social Security programs are and which one you would be filing under. Here is a great description from the Social Security Administrations's site:

What is the difference between Social Security Disability Income (SSDI) and Supplemental Security Income (SSI)?

Answer: The Social Security Administration is responsible for two major programs that provide benefits based on disability: Social Security Disability Insurance (SSDI), which is based on prior work under Social Security, and Supplemental Security Income (SSI). Under SSI, payments are made on the basis of financial need.

SSDI is financed with Social Security taxes paid by workers, employers, and self-employed persons. To be eligible for a Social Security benefit, the worker must earn sufficient credits based on taxable work to be "insured" for Social Security purposes. Disability benefits are payable to blind or disabled workers, widow(er)s, or adults disabled since childhood, who are otherwise eligible. The amount of the monthly disability benefit is based on the Social Security earnings record of the insured worker.

SSI is a program financed through general revenues. SSI disability benefits are payable to

adults or children who are disabled or blind, have limited income and resources, meet the living arrangement requirements, and are otherwise eligible. The monthly payment varies up to the maximum federal benefit rate, which may be supplemented by the State or decreased by countable income and resources. Please see <https://www.ssa.gov/ssi/text-notice-ussi.htm> for more information.

In this series, I will be addressing many of the questions and concerns that I have received from Ataxia patients through the years on the entire social security process/program.

One of the first areas/questions that everyone faces is:

Q: When should I file for social security disability?

A: It will all depend on several factors. One major one is if you are at the point that you cannot work 30-40 hours a week. No matter how much you want to, how much you try, it just isn't physically possible. Another consideration is financial or better said, what will I be living on while I am going

through the process. This would encompass what your present income is, what your current budget looks like and what other income generating programs are available.

Example: If you have a short and long term disability policy through work. If so, evaluating both programs are important before making your decision to file. Another consideration that is just as important as the first two I have mentioned, is emotional considerations. It is very hard for someone who wants to work and has done everything they can to continue to work to make



Jon Rodis

Social Security Corner
Continued from page 11

the decision to stop. I know because I struggled with it for years. Looking back, I wish I filed many more years before I did because of the damage I did to my body struggling with working full-time, battling my pride and stubbornness (because no one wants to give up their career)

and not realizing the impact of all this on my future. I would advise everyone to take time and evaluate all the factors I have mentioned and know that I am always available to discuss this important first step in the disability process.

If you have a question the you would like to have Jon answer in an upcoming issue of *Generations*, you can e-mail him at wsalmgcdjm@aol.com. ❖

SCA Clinical Trial

The NAF would like to make you aware that Biohaven Pharmaceuticals will soon be starting a clinical trial for an agent to treat Spinocerebellar Ataxia. There will be approximately 15 sites, all in the United States.

If you are interested in learning more or considering to volunteer for this study, you can find the most up-to-date information on the following link: <https://clinicaltrials.gov/ct2/show/NCT02960893?term=Biohaven&rank=1>.

Thrivent Choice Works

The National Ataxia Foundation is a participating organization of the Thrivent Choice Works program of Thrivent Financial. If you are an eligible member of Thrivent Financial, please consider directing your Thrivent Choice Dollars to the NAF.

For more information, please visit www.thrivent.com/making-a-difference/living-generously/thrivent-choice/.

Study of Cardiomyopathy in Friedreich's Ataxia Patients

The Department of Genetic Medicine at Weill Cornell Medical College is looking for patients with Friedreich's Ataxia for a research study to compare and evaluate different tests in assessing the cardiac dysfunction that can occur with the disease.

The study involves a single two-day visit, with an overnight stay.

Who can participate?

Patients age 18-30 years old who have genetic confirmation of diagnosis and are capable of

completing all study tests and procedures.

What are the study tests and procedures?

Blood and urine tests, cardiac magnetic resonance imaging (CMR), chest x-ray, echocardiogram (ECHO), lectrocardiogram (ECG), exercise-stress test, neurological assessment, eye exam with local anesthetic, and physical and medical history.

If you would like more information, please contact Michelle at (646) 962-2672 or miy2006@med.cornell.edu.

Like us on FACEBOOK – www.facebook.com/ataxiafoundation/timeline/

Follow us on TWITTER – https://twitter.com/NAF_Ataxia

2016 SHARE! Recovery Awards

The National Ataxia Foundation is proud to share word that Cindy De Mint, Orange County Support Group Leader, OC/LA Walk n' Roll Organizer, wife and mother, was recently an honoree for the Frances E. Jemmott Award at the 2016 SHARE! Recovery Awards.

The mission of SHARE! is to help people in Los Angeles pursue personal growth and change. SHARE! empowers people to change their own lives and provides them a loving, safe, non-judgmental place where they can find community, information and support.

The idea for SHARE! grew out of the frustrations people attending self-help support groups faced, repeatedly encountering operational problems that interfered with the healing process. Under the Emotional Health Association, a California 501(c)(3) corporation, a group of meeting-goers formed a board and working committees. SHARE! is a peer-run contractor with the Los Angeles County Department of Mental Health.

The 2016 SHARE! Recovery Awards were held October 16 at the DoubleTree Hotel in Culver City, California. There were seven awards given out that evening.



Cindy and Gerry De Mint

Frances E. Jemmott Award – Cindy De Mint (Ataxia Support Groups)

Frances E. Jemmott is a pioneer in self-help clearing houses and was Director of the California Self-Help Center at UCLA.

“I always wanted to be the best Mom I could be and thought that was my purpose. God had other plans for my life, bringing awareness to Ataxia and helping other families navigate this disorder.”

– Cindy De Mint

Other SHARE! Recovery Award Honorees were:

- **Ruth Hollman Award – Martin R. Smith** (Self-help Group Researcher)
- **James Christopher Award – Yolonda Young Simmons** (Tough Love Christian Family Support)
- **Elizabeth Hartigan Award – Stephen Brown** (Chronic Fatigue and Fibromyalgia Support Group)
- **Mareen Brugh Award – Christopher Lawford** (Author/Speaker)
- **Ken Schonlau Award – Ed Storti** (Interventionist)
- **Susan Laufer Award – Candy Finnigan** (Interventionist, A&E's Intervention) ❖

Friedreich Ataxia Tissue Donations

If you have been diagnosed with Friedreich ataxia and wish to contribute to its eradication by helping research, please consider donating your tissues after death. To do so, contact Dr. Arnulf H Koeppen for detailed information. Tissues affected by Friedreich ataxia are brain, eyes, spinal cord, dorsal root ganglia, sensory peripheral nerves, heart, and the insulin-producing beta-cells of the pancreas.

Arnulf H. Koeppen, MD
Professor of Neurology and Pathology
Research Service (151)
VA Medical Center
113 Holland Ave, Albany, NY 12208
Tel. 518-626-6377 FAX 518-626-5628
E-mail: arnulf.koeppen@va.gov or akoeppen@mail.amc.edu.

THE NAF BOARD OF DIRECTORS ALONG WITH THE NAF
SOUTHCENTRAL REGION WOULD LIKE TO INVITE YOU TO ATTEND THE

National Ataxia Foundation 60th Annual Ataxia Conference

March 10-11, 2017



The Grand Hyatt San Antonio is pleased to provide the facilities for the 2017 Annual Ataxia Conference (AAC)

Join us in San Antonio, TX for the Annual Ataxia Conference!

Room Reservations-Available Now

Room reservations for all room types at the Grand Hyatt available now.

Reservations at group rate will be available until February 13, 2017.

The NAF group rate starts at only \$169 + tax for Standard Rooms.

ADA room reservations must be reserved through the NAF office

by contacting (763) 553-0020 or lori@ataxia.org.

Standard room reservations at the Grand Hyatt can be made at

<https://resweb.passkey.com/go/2017AnnualConference>

For guests who prefer to phone in their reservation call Hotel Reservations at 888-421-1442 and ask for the National Ataxia Foundation's group rate which is under the group name, "2017 Annual Ataxia Conference."

Meeting Registration-Open

Registration for the 2017 NAF AAC is open. You are encouraged to register before January 30, 2017 to receive the early registration discount rate. In addition, members of the NAF pay a lower registration fee to attend the Annual Ataxia Conference. 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. For the latest information on conference registration, program schedule, and area information keep checking the NAF's website www.ataxia.org. **Note:** The conference will end with the banquet on Saturday night.

2017 NAF Annual Ataxia Conference "Support Our Conference" Campaign

<http://ataxia.donorpages.com/2017AACLetterWritingCampaign/>



For more information on San Antonio visit <http://visitsanantonio.com/>.



The National Ataxia Foundation 60th Anniversary Annual Ataxia Conference (AAC)

March 10-11, 2017

San Antonio, TX

The National Ataxia Foundation (NAF) Board of Directors and the National Ataxia Foundation Southcentral Region invite you to join us for the NAF's 60th Anniversary at the **NAF 2017 Annual Ataxia Conference (AAC)**. The AAC is being held at the Grand Hyatt in San Antonio, TX.

The 2017 AAC will bring together the Ataxia community to not only meet and learn from world-leading Ataxia researchers and clinicians, but also to build new friendships and reunite with old friends. Come and be part of the largest Ataxia gathering in the world to learn, share, network, have fun, and observe the **NAF's 60th Anniversary!**

The complete conference schedule, events and registration forms are available in this issue of *Generations* on pages 16-26 and on the NAF's website, www.ataxia.org. **General Sessions** and **Birds of a Feather Sessions (BOF)** will be held on both Friday, March 10 (BOF–Group A) and Saturday, March 11 (BOF–Group B). See pages 22-23 for more information about these BOF sessions. You will still only select one BOF session to attend on either Friday or Saturday with an option to also attend additional **Small Group Sessions**: Safe Mobility Strategies; Proper Lifting/Transfer/Fall Prevention on Friday, March 10, from 1 – 2 p.m.; Healing Through Writing on Friday, March 10, from 4-5 p.m.; General Exercise Recommendations on Saturday, March 11, from 1 – 2 p.m.; or Demystifying Feeding Tubes also on Saturday, March 11, from 4-5 p.m.

The **Southwestern Meet and Greet Reception** will be held on Friday at 5 p.m. Attendees will have the chance to meet others attending from their region and will also have the opportunity to connect and meet attendees who are members of the NAF's Bulletin Board and Facebook Group.

The conference will conclude with the **Diamond Jubilee Banquet** on Saturday at 7 p.m. This is a ticketed event. Be sure to get your banquet ticket, which is included with your registration, prior to Saturday.

2017 NAF Annual Ataxia Conference Schedule & Overview



Please Note: Due to circumstances beyond our control, this conference agenda is subject to change. The most current version of the schedule can be found at <http://www.tinyulr.com/schedule2017>

THURSDAY, MARCH 9TH

EVENT	LOCATION	TIMES
NAF Registration	2nd Floor Foyer	9:00 a.m. – 5:00 p.m.
Come by and get your conference program, name badge, Saturday banquet tickets, and welcome bag. Check in your Silent Auction items and say, “Hi” to the NAF Staff and volunteers.		
Silent Auction Item Drop Off	Lone Star C	9:00 a.m. – 5:00 p.m.
All items being donated for the Silent Auction are due in the Silent Auction room by Friday, March 10 at 4 p.m. Auction items range from something that represents your state or country, art work, sports memorabilia, theme baskets, hand-crafted items, hotel stays and weekend getaways. Bring an item to donate and then have fun bidding on the items of your choice. Thank you for supporting this event and sharing items from your local area.		
Leadership Meeting	Lonestar F	1:00 – 3:00 p.m.
Designed to provide information and support to the NAF’s Chapter Presidents, Support Group Leaders and Ambassadors. The meeting is a valuable resource for volunteers who serve in these appreciated positions. If you are interested in becoming a NAF Support Group Leader or Ambassador, contact Lori Shogren at lori@ataxia.org prior to the meeting.		
Fundraising Meeting	Lonestar F	4:00 – 5:00 p.m.
Anyone who is interested in learning more about organizing a fundraising event or getting involved in an Ataxia event to support the important work of the National Ataxia Foundation is encouraged to attend.		

FRIDAY, MARCH 10TH

EVENT	LOCATION	TIMES
NAF Registration	2nd Floor Foyer	8:00 a.m. – 5:00 p.m.
Exhibitors	Lone Star B	8:00 a.m. – 5:00 p.m.
Exhibitors will be present as their schedules permit. If you would like to recommend a company or service provider to be an exhibitor at the conference please contact the NAF at joan@ataxia.org . If you are interested in information about exhibiting you will find more detailed exhibitor information and an application form on the NAF’s website.		
Silent Auction Item Drop Off	Lone Star C	8:30 a.m. – 4:00 p.m.
All items being donated for the Silent Auction are due in the Silent Auction room by 4 p.m.		
Silent Auction Item Bidding	Lone Star C	8:30 a.m. – 5:00 p.m.
General Sessions	Lone Star A Entrance	9:00 a.m. – 12:30 p.m.
Friday morning will start the General Sessions in the Lone Star Ballroom. They will incorporate practical aspects in addition to the research and medical topics of Ataxia. A 30-minute Question and Answer session will follow the morning General Sessions with a panel of the morning speakers.		
Lunch	On Your Own	12:30 p.m.
Small Group Sessions	Bowie B	1:00 p.m. & 4:00 p.m.

Birds of a Feather (BOF) Group A* 2:00 – 5:00 p.m.

Attendees will have the opportunity to attend small group sessions. See pages 22-23 for more information about these small group sessions. Meeting rooms will be listed in the conference program.

Southwest Meet & Greet Welcome Reception Lone Star A Entrance 5:00 p.m.

Please join us for the Southwest Meet & Greet Welcome Reception. All registered conference attendees are welcome to attend. Admittance to this event and the light appetizers that will be served are included with your registration fee. A cash bar will be available. This event will begin with attendees gathering in the seating area designated for their region. Your region will be printed on your name badge. After meeting others in your region, attendees will have the opportunity to meet with other NAF Bulletin Board and Facebook users in that designated seating area. You are encouraged to prepare contact cards to distribute at this event. Contact cards should only include information you wish to distribute. Information on contact cards can include your name, e-mail address, state, and diagnosis/affiliation. Repeat attendees are encouraged to welcome a First-Time Attendee. First-Time Attendees are identified with a First-Timer Ribbon on their name badge.

FRIDAY GENERAL SESSIONS

<i>TIME</i>	<i>TOPIC</i>	<i>SPEAKER</i>
9:00 a.m.	Welcome & Announcements	Camille Daglio, AAC Chair & Mississippi Chapter President – Hattiesburg, MS
9:30 a.m.	NAF Update	Joel Sutherland, NAF Executive Director NAF – Minneapolis, MN
10:00 a.m.	Management of Ataxia through Care Teams	Pravin Khemani, MD University of Texas Southwestern Medical Center – Dallas, TX
10:30 a.m.	From Shattered to Strength	Jason Wolfer Willamette Valley Ataxia Support Group Leader – Gervais, OR
11:00 a.m.	Approaches to Develop Therapies for Ataxias	Huda Zoghbi, MD Baylor College of Medicine – Houston, TX
11:30 a.m.	Clinical Trial Readiness	Henry Paulson, MD, PhD University of Michigan Health System – Ann Arbor, MI
Noon	Q & A Panel	
12:30 p.m.	Lunch	

FRIDAY SMALL GROUP SESSIONS

Safe Mobility Strategies; Proper Lifting/Transfers/Falls Prevention 1:00 – 2:00 p.m.

Facilitators: Jennifer Millar, MSPT and Marlena Casey, OT/L.

Jennifer and Marlena will discuss transfer/adaptive equipment and safe strategies for mobility. Proper lifting and transfer techniques will be demonstrated.

Healing Through Writing 4:00 – 5:00 p.m.

Facilitator: Jude Lally

Most people have a story, but for people living with Ataxia we literally have dozens. For us getting the words down on paper is an obstacle in itself. Whether you're still able to write sloppily with pen and paper, peck using a keyboard or speak into a headset via a voice recognition program, your hard work and effort should not be overlooked. Ataxians, caregivers and family members, please join us as we celebrate the fifth annual installment of Healing Though Writing, a writers' and discussion group focusing on the healing power of writing. Led by published poet, Jude Lally.

Birds of a Feather (BOF) Group A* 2:00 – 5:00 p.m.

Attention Parents: Birds of a Feather Sessions for attendees under 30 years old are facilitated by experienced clinicians. Mature subject matter may be discussed. These sessions are not intended for those who are under 12 years old. Children under 12 years old should not attend a BOF session. Questions regarding these sessions may be directed to Sue Hagen, NAF Patient Services Director, at susan@ataxia.org or (763) 231-2742. Birds of a Feather Informal Groups will meet from 2 – 5 p.m. in various conference rooms. Please check the conference program and hall signs for your specific group’s location. Paid PCAs are welcome to attend the BOF session with their client, but not required unless client requires it.

*The following groups are for those who have been **affected with Ataxia:**

SCA1 Birds of a Feather 2 – 5 p.m.

This Birds of a Feather session is for those who have been diagnosed with SCA1
Facilitators: Dr. Zoghbi (2 – 3 p.m.) and Dr. Schut (2 – 5 p.m.)

SCA2 Birds of a Feather 2 – 5 p.m.

This Birds of a Feather session is for those who have been diagnosed with SCA2
Facilitators: Dr. Khemani and Marlena Casey, OT

SCA3 Birds of a Feather 2 – 5 p.m.

This Birds of a Feather session is for those who have been diagnosed with SCA3
Facilitator: Dr. Paulson and Jessica Dileo, OTR/L

SCA6 Birds of a Feather 2 – 5 p.m.

This Birds of a Feather session is for those who have been diagnosed with SCA6
Facilitators: Dr. Marvel and Dr. Jimenez-Shahed

ALL Other SCAs (including SCA 5, 7, and 8) & DRPLA Birds of a Feather 2 – 5 p.m.

For this Birds of a Feather session you need to have a diagnosis of SCA other than SCA 1, 2, 3, or 6 or DRPLA. If you do not have a diagnosis of hereditary Ataxia please attend the Unknown without Family History BOF session.
Facilitators: Dr. Ranum and Dr. Opal

Over Age 30 with Friedreich Birds of a Feather 2 – 5 p.m.

Facilitator: Dr. Wilmot and Dr. Napierala

AOA 1 & 2 Birds of a Feather 2 – 5 p.m.

Facilitator: Dr. Fogel

Unknown without Family History – MSA, Sporadic & Gluten Birds of a Feather 2 – 5 p.m.

This Birds of a Feather session is for those who have been diagnosed with an Unknown Type of Ataxia without Family History, including MSA, Sporadic, and Gluten Ataxia
Facilitators: Dr. Subramony, Amanda Gallagher, CCC-SLP, and Jennifer Millar, PT

SATURDAY, MARCH 11TH

<i>EVENT</i>	<i>LOCATION</i>	<i>TIMES</i>
NAF Registration	2nd Floor Foyer	8:00 a.m. – 2:00 p.m.
Exhibitors	Lone Star B	8:00 a.m. – 4:00 p.m.
Silent Auction Bidding	Lone Star C	8:30 a.m. – 1:00 p.m.
It’s a fun way to help raise funds for NAF and for you to bid on wonderful items. Good luck! The winning bids will be posted by 3 p.m. Winners must pick up and pay for their items from 3–7 p.m.		
General Sessions	Lone Star A Entrance	9:00 a.m. – noon
Continue Saturday Morning in Lone Star Ballroom. A 30-minute Question and Answer session will follow the morning General Sessions with a panel of the speakers who presented during those sessions.		

Lunch On Your Own..... Noon

Small Group Sessions Bowie B 1:00 p.m. & 4:00 p.m.

Birds of a Feather (BOF) Group B* 2:00 – 5:00 p.m.

Attendees will have the opportunity to attend small group sessions. See pages 22-23 for more information about these small group sessions. Meeting rooms will be listed in the conference program.

Diamond Jubilee Banquet Lone Star Ballroom 7:00 p.m.

The cost of the banquet is included in your registration fee. Beverages will be available at a cash bar. The banquet includes a plated dinner entrée that you will select when you register for the conference. When you arrive at the conference **please reserve your seating and verify your entrée selection prior to the banquet.** Volunteers will be at the banquet ticket tables near the NAF registration to assist you as you obtain your banquet tickets, select your seating, and confirm your entrée selection. This is a ticketed event. Your banquet ticket will be required to enter this event. We look forward to a wonderful dinner together and a fun evening of socializing.

SATURDAY GENERAL SESSIONS

<i>TIME</i>	<i>TOPIC</i>	<i>SPEAKER</i>
9:00 a.m.	Advances in The Genetic Diagnosis of the Cerebellar Ataxias	Brent Fogel, MD, PhD UCLA – Los Angeles, VA
9:30 a.m.	My Caregiver Story	Terri Alessi, LPN Cicero, NY
10:00 a.m.	Research Update	Laura Ranum, PhD University of Florida – Gainesville, FL
10:30 a.m.	Reproductive Strategies/Wrap-up	George “Chip” Wilmot, MD Emory University School of Medicine Atlanta, GA
11:00 a.m.	Q & A Panel	
11:30 a.m.	NAF Member Business Meeting.....	Bill Sweeney, NAF President Minneapolis, MN
Noon	Lunch	

SATURDAY SMALL GROUP SESSIONS

General Exercise Recommendations 1:00 – 2:00 p.m.

Facilitator: Jennifer Millar, MSPT

General recommendations will be discussed to help guide individuals towards establishing a safe and effective exercise program, along with suggestions for potential resources. Also, included in the discussion will be highlights of the latest research related to the exercise and motor learning in people with Ataxia, supporting the benefits of exercise.

Demystifying Feeding Tubes FAQ 4:00 – 5:00 p.m.

Facilitator: Dianne Williamson, BSN, RN, Home Health Nurse

In the home setting an abdominally-placed feeding tube may be used even when individuals are taking food orally to supplement nutrition, hydration or for medication administration. They can reduce risk of complications associated with frequent aspiration or choking. This session is for those considering future use of a feeding tube. It will cover the several types available for the home setting, placement, uses, and level of care required.

Birds of a Feather (BOF) Group B* 2:00 – 5:00 p.m.

Attention Parents: Birds of a Feather Sessions for attendees under 30 years old are facilitated by

experienced clinicians. Mature subject matter may be discussed. These sessions are not intended for those who are under 12 years old. Children under 12 years old should not attend a Birds of a Feather session. Questions regarding these sessions may be directed to Sue Hagen, NAF Patient Services Director susan@ataxia.org or (763) 231-2742. Birds of a Feather Sessions will meet from 2 – 5 p.m. in various conference rooms. Please check the conference program and hall signs for your specific group’s location.

Paid PCAs are welcome to attend the Birds of a Feather session with their client, but not required unless client requires it.

*The following groups have been designed for those who are **affected with Ataxia:**

Unknown with Family History, EA and Other Rare Recessives Birds of a Feather 2 – 5 p.m.

This Birds of a Feather session is for those who have been diagnosed with an Unknown Type of Ataxia with Family History.

Facilitators: Dr. Subramony and Dr. Khemani

Under Age 30 with Ataxia Birds of a Feather 2 – 5 p.m.

This Birds of a Feather session will be attended by those with any type of Ataxia who are under the age of 30.

Facilitators: Dr. Wilmot (2 – 4 p.m.), Dr. Napierala, and Emily Baudin (2 – 5 p.m.)

*The following groups have been designed for **parents of children who are affected with Ataxia:**

Parents (Non-Friedreich) Birds of a Feather 2 – 5 p.m.

This Birds of a Feather session will be attended by parents whose child(ren) are affected by any form of Ataxia other than Friedreich’s Ataxia. For this Birds of a Feather group time will be used to listen and share experiences. This will be a powerful time for everyone.

Facilitator: Dr. Fogel

Parents (Friedreich) Birds of a Feather 2 – 5 p.m.

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

Facilitators: David Zilles (2 – 5 p.m.), and Dr. Wilmot (4 – 5 p.m.)

*The following groups have been designed for **non-affected family members:**

Family Members without Ataxia (other than parents, spouses, or partners) Birds of a Feather 2 – 5 p.m.

This Birds of a Feather will be attended by family members (siblings, children, etc.) of those with Ataxia to share experiences and concerns. For the privacy of the issues talked about in this session we ask that those with Ataxia attend the BOF sessions for Ataxians.

Facilitator: John Dyer, BS, MA

*The following group has been designed for **non-affected family members:**

Spouses & Partners without Ataxia Birds of a Feather 2 – 5 p.m.

This Birds of a Feather will be attended by spouses and partners to share with other spouses and partners their experiences and concerns. For the privacy of the issues talked about in this session we ask that those with Ataxia attend the BOF sessions for Ataxians.

Facilitators: Dr. Marvel, Dr. Jimenez-Shahed, and Amanda Gallagher, MA, CCC-SLP

MEETING PRESENTATIONS AND RECORDINGS

Audio synched General Session Presentations from 2012-2015 can be purchased through Digital Conference Providers at <http://www.dcpvidersonline.com/naf/>. ❖

Become an NAF member or renew your membership online today at www.ataxia.org. YOUR MEMBERSHIP MATTERS!

“Proud Past ... Focused Future” Conference Registration Instructions



Dates: March 10 – 11, 2017 **Location:** The Grand Hyatt San Antonio
600 E. Market St.
San Antonio, TX 78205
1-888-421-1442 or (210) 224-1234
www.grandsanantonio.hyatt.com

Conference Registration: The Registration Fee includes entrance to all General Sessions, “Birds of a Feather,” exhibitor area, as well as morning coffee breaks, the Welcome Reception, and the Saturday Evening Banquet. NAF members enjoy a reduced membership conference registration fee.

Individuals eligible for the member rate include current:

- Individual Members (*Individual members may also register their spouse or caregiver at the member rate*)
- Household Members (*Household members include all the individuals living at the same address*)
- Patron Members (*Patron members include all the individuals living at the same address*)
- Lifetime Members (*Lifetime members include all the individuals living at the same address*)
- Professional Members • Recurring Gift Members

Early Registration Fee (*includes registrations received or postmarked by January 29, 2017*):

- Members: \$125/person • Non-Members: \$180/person

Registration Fee January 30 – March 3, 2017 – You are strongly encouraged to register before Jan. 29 (*includes registrations postmarked after January 29, 2017*):

- Members: \$150/person • Non-Members: \$205/person

Registration Fee after March 3, 2017 – You are strongly encouraged to register before Jan. 29 (*All registrations at the door*):

- Members: \$200/person • Non-Members: \$255/person

NOTE: The Conference Registration Fees DO NOT include hotel or transportation costs.

Instructions for Registration:

- 1. Please fill out the registration form completely** and mail with your payment to the NAF office. The requested information is necessary to complete preparations for the conference.
- 2. Registration Fees.** Whether you plan to attend the entire conference or just the General Sessions or just the banquet and/or reception, the full per person registration fee will be charged. Children attending the conference will be charged the following registration fees: children two years and under are free; children three years and over will be charged the full conference registration fee.
- 3.** Childcare services are not provided by NAF staff, session facilitators or volunteers.
- 4.** Complete and return all pages of the registration form by January 29, 2017. Please fill out the name portion of the registration form as you would like it to appear on your name badge.

NOTE: You may register for the meeting online at the NAF website: www.ataxia.org

Early Registration Deadline is January 29, 2017

Please complete all pages of the registration form and return to the following address:
National Ataxia Foundation, 2600 Fernbrook Lane, Suite 119, Minneapolis, MN 55447-4752
(763) 553-0020 Fax: (763) 553-0167 E-mail: joan@ataxia.org



“Birds of a Feather” Frequently Asked Questions

What are “Birds of a Feather (BOF)” sessions?

“Birds of a Feather” sessions are small break-out groups facilitated by medical professionals and/or trained small group leaders. The groups are organized by the type of Ataxia that the participant has been diagnosed with or the role that person has such as parent, spouse/partner or family member.

What is presented at the BOF sessions?

Information about research, clinical care, management of symptoms and questions from the group will be addressed. BOF sessions also provide a time for attendees to meet others and share similar concerns and issues that are relevant to being affected by Ataxia.

When do the BOF sessions meet?

BOF *Group A* sessions meet on Friday from 2 – 5 p.m. BOF *Group B* sessions meet on Saturday from 2 – 5 p.m. You will select only one session from either *Group A* or *Group B* to attend.

Can anyone attend a Birds of a Feather session?

Yes, anyone who is over age 12 and has registered and paid the conference registration fee can attend a session.

Do I have to attend a BOF session?

No, attendance (as with all events at the Annual Ataxia Conference) is optional to the attendee. However, many attendees in the past have said that BOF sessions were the most valuable part of the Annual Ataxia Conference for them.

Do I have to decide when I register for the Annual Ataxia Conference which session I plan to attend?

It is not necessary, but strongly encouraged. Indicating your BOF selection when you register helps the NAF in conference and room planning purposes

I am a family member without Ataxia. May I attend the Bird of a Feather session that is specific to my family member’s diagnosed type of Ataxia?

We encourage you to select a group that fits the role you have in your diagnosed family member’s life, however we understand each person’s need may be different and the goal of these sessions is to be a valuable experience for all conference attendees. You may attend the session that will be most helpful for you but keep in mind the specific focus of the group.

I am a non-family member Personal Care Assistant (PCA). May I attend a BOF session?

PCAs are welcome to attend the session with their client however it is not required unless the client needs assistance.

How do I select which Birds of a Feather Session to attend?

Your selection will be based on whether you are diagnosed with Ataxia or if you are a family member or a caregiver of a person who is diagnosed with Ataxia. Some BOF groups are also divided by the age of the attendee.

The following sessions (Group A) will meet on Friday afternoon:

- **SCA1** for those who are over 12 years old and have been diagnosed with SCA1
- **SCA2** for those who are over 12 years old and have been diagnosed with SCA2
- **SCA3** for those who are over 12 years old and have been diagnosed with SCA3
- **SCA6** for those who are over 12 years old and have been diagnosed with SCA6
- **All other SCAs and DRPLA** (including SCA 5, 7, 8) for those who are over 12 years old and have a diagnosis of SCA other than SCA 1, 2, 3, or 6



- **AOA1 & 2** for those who are over 12 years old and have been diagnosed with AOA.
- **Unknown without a family history, MSA, Sporadic and Gluten Ataxia** for those who are over 12 years old and have been diagnosed with MSA, Sporadic, or Gluten Ataxia and where there is no family history of Ataxia.
- **Over Age 30 Friedreich** for those diagnosed with Friedreich ataxia who are over the age of 30.

The following sessions (Group B) will meet on Saturday afternoon:

- **Unknown with Family History and Episodic Ataxia** for those who are over 12 years old and have been diagnosed with an Unknown Type of Ataxia or Episodic Ataxia and where there is a history of Ataxia in their family.
- **Under age 30 with Ataxia** for those diagnosed with any type of Ataxia who are 12-30 years old.
- **Spouses and Partners without Ataxia** for spouses and partners who are not diagnosed with Ataxia. For the privacy of the issues talked about in this session we ask that those with Ataxia attend the BOF sessions for Ataxians.
- **Parents (Friedreich)** for parents of a child(ren) who is/are affected by Friedreich Ataxia.
- **Parents (Non-Friedreich)** for parents of a child(ren) who is/are affected by any form of Ataxia other than Friedreich Ataxia.
- **Family Members without Ataxia** for family members such as siblings, children, grandparents, etc. other than parents, spouses, or partners to share experiences and concerns.

I have more questions. Is there someone I can email or speak with?

Yes, you may contact Lori Shogren at lori@ataxia.org or (763) 231-2743 or Sue Hagen at susan@ataxia.org or (763) 231-2742. ❖

Genes in Inherited Neurologic Disorders Study #HUM00041414

Dr. Burmeister at the University of Michigan is recruiting individuals with ataxia for the research study Genes in Inherited Neurological Disorders. This study is designed to find what and how changes in the genetic material (DNA) cause inherited neurologic disorders, such as ataxia. We are recruiting individuals with inherited ataxia, their affected relatives (such as a brother or sister, a cousin, or a parent), and their unaffected family members, where possible. We are currently recruiting persons with an unknown form of ataxia, so at least one affected in your family should first be tested for the most common known causes of ataxia and found to be negative. We are recruiting both subjects with or without other affected family members.

In this study, you will be asked to provide information about your symptoms and diagnosis, if other relatives are similarly affected, and about your ethnic background. You will also be asked to donate a blood sample (up to 8 teaspoons of blood) for DNA testing and related experiments. The blood sample can be drawn by your local physician; you will not need to travel to the University of Michigan.

The lab has already identified several novel ataxia genes, and additional cases with newer known ataxia genes as well as mutations in genes causing other diseases involving ataxia and other, seemingly unrelated, symptoms such as tooth problems, although most subjects in our study have ataxia as main symptom.

More detailed information about this study is available in the consent forms: Affected Subjects Consent, Unaffected Relatives Consent.

If you would like further information or are interested in participating, please contact:

Dr. Margit Burmeister, PhD or Dr. Erin Sandford
Molecular & Behavioral Neuroscience Institute, University of Michigan
5063 BSRB, 109 Zina Pitcher Place, Ann Arbor MI 48109-2200
Telephone: (734) 6472186; (734) 615-3359
E-mail: margit@umich.edu or esandfor@umich.edu

2017 NAF Annual Ataxia Conference Registration

Online registration available at www.ataxia.org. Instructions can be found on page 21.

The NAF will send out all conference materials and handouts through e-mail. For those who do not have access to e-mail, materials will be mailed out and a limited number of hard copy handouts will be available at the meeting upon request.

1. *Full Name: _____ Name on Badge: _____
 *Address: _____ *City/ State/ Zip: _____
 Country: _____ *Phone: _____ E-mail: _____
 Adult (18+) Teen/Child (3-17) Infant (2 & under) PCA Is this your first NAF AAC? Yes No

2. *Full Name: _____ Name on Badge: _____
 *Address: _____ *City/ State/ Zip: _____
 Country: _____ *Phone: _____ E-mail: _____
 Adult (18+) Teen/Child (3-17) Infant (2 & under) PCA Is this your first NAF AAC? Yes No

3. *Full Name: _____ Name on Badge: _____
 *Address: _____ *City/ State/ Zip: _____
 Country: _____ *Phone: _____ E-mail: _____
 Adult (18+) Teen/Child (3-17) Infant (2 & under) PCA Is this your first NAF AAC? Yes No

4. *Full Name: _____ Name on Badge: _____
 *Address: _____ *City/ State/ Zip: _____
 Country: _____ *Phone: _____ E-mail: _____
 Adult (18+) Teen/Child (3-17) Infant (2 & under) PCA Is this your first NAF AAC? Yes No

Please complete the following for each person:	#1	#2	#3	#4
1. Are you attending the Saturday evening banquet? <i>(included with your registration fee)</i> Y or N				
2. If you are attending the Banquet, you have the following meal options: Beef Selection (B) or Vegetarian/Vegan Selection (V) Both are gluten free. <i>Your meal selection for the Saturday Banquet is only available on this registration form and cannot be made at the meeting</i> B or V				
3. Will you be using a Scooter (S), Manual Wheelchair (M), Electric Wheelchair (E), or a Walker (W)? Blank, S, M, E or W				
4. Will you be bringing an assistance dog? Y or N				
5. Are you a current paid member of NAF? <i>(If you are unsure of your membership status, contact NAF before submitting your registration form.)</i> Y or N				

*Indicates required information. PCA = Personal Care Attendant.

2017 NAF Annual Ataxia Conference Registration

Please indicate the Birds of a Feather (BOF) session you plan to attend in question 6 below.

— Group A on Friday —

A: SCA1 **B:** SCA2 **C:** SCA3 **D:** SCA6 **E:** AOA 1 & 2 **F:** All other SCAs (including 5, 7, 8) & DRPLA **G:** Unknown w/o Family History, MSA, Sporadic & Gluten **H:** Over 30 w/FRDA

— Group B on Saturday —

I: Spouses & Partners w/o Ataxia **J:** Under 30 w/Ataxia **K:** Family Members w/o Ataxia
L: Parents (non-FRDA) **M:** Parents (FRDA)
N: Unknown w/Family History, Episodic & Other Rare Recessive Ataxias (does not include FRDA)

Please complete the following for each person (continued from page 24):	#1	#2	#3	#4
6. Please indicate the Birds of a Feather session you plan to attend from Group A Friday (A-H) or Group B Saturday (I-N) Select one session only				
7. Do you plan on attending the small group session on Friday: Safe Mobility Strategies from 1–2 p.m.? Y or N				
8. Do you plan on attending the small group session on Friday: Healing Through Writing from 4–5 p.m.? Y or N				
9. Do you plan on attending the small group session on Saturday: General Exercise Recommendations from 1–2 p.m.? Y or N				
10. Do you plan on attending the small group session on Saturday: Demystifying Feeding Tubes from 4–5 p.m.? Y or N				

TRAVEL INFORMATION

Flying? Yes No *If no, how will you be traveling (i.e., driving, bus)?* _____

If driving, does your vehicle exceed 6' 8": Yes No

Air Carrier/Flight Number: _____ Arrival Date/Time: _____

Departure Date: _____

VOLUNTEER INFORMATION

Volunteers donating their time contribute greatly to the success of each National Ataxia Foundation Annual Ataxia Conference. We need volunteers for the 2016 AAC to be held in San Antonio, TX on March 10-11.

To sign up as a volunteer at the 2017 AAC or to get more information about the volunteer opportunities, please contact Dianne Williamson at (256) 520-4858 or diannebw@aol.com to sign up.

IMAGE CONSENT POLICY

By attending the 2017 NAF Annual Ataxia Conference you give your consent, unless you notify us otherwise, to use your image captured during the conference through video, photographs, or digital imagery, to be used by the National Ataxia Foundation in promotional materials, publications, and web site and waive any and all rights to these images.

VIDEOTAPING/FILMING/RECORDING POLICY

The recording of any audio/or video taping of conference sessions, or at any venue of the NAF Annual Ataxia Conference is forbidden, without prior approval in writing by the National Ataxia Foundation. PowerPoint presentations will be available on the NAF website after the completion of the conference. Attendees at the Annual Ataxia Conference expect, and deserve, the right to privacy. The NAF does photograph and record at the AAC, and will make photographs and other media available for news, educational, and promotional purposes.

SOLICITATION POLICY

Soliciting funds for organizations other than the National Ataxia Foundation or for individual benefit is prohibited at all NAF events. Any materials distributed seeking funds for other organizations or for individual benefit will be removed.

— AAC Registration continues on page 26 —

2017 NAF Annual Ataxia Conference Registration

Not sure if your membership is current?

Review the back cover of this issue of *Generations* for your membership status and expiration date.

Take advantage of the MEMBER RATE and JOIN TODAY!	Quantity	Total
<p>Yes, I would like to be a member of NAF! Please add an ADDITIONAL</p> <p><input type="checkbox"/> \$40 (Annual Individual) <input type="checkbox"/> \$60 (Annual Household)</p> <p><input type="checkbox"/> \$100+ (Annual Patron) <input type="checkbox"/> \$500 (Lifetime) <input type="checkbox"/> \$65 (Annual Professional)</p> <p><input type="checkbox"/> \$55 (Individual Outside U.S.) <input type="checkbox"/> \$75 (Household Outside U.S.)</p> <p><input type="checkbox"/> Recurring membership \$_____ /month (for more information, please call the NAF)</p> <p>You may register for the conference as a member if you sign up today!</p> <p><i>*Household, Patron and Lifetime memberships include all individuals who share the same residence.</i></p>		
<p>Yes, I'd like to support the Annual Conference Fund (provides travel grants, offsets registration fees, helps cover costs associated with the conference)</p> <p>Here is my sponsorship contribution!</p> <p><input type="checkbox"/> \$125 (Offset of Registration) <input type="checkbox"/> \$400 (Travel Grant)</p> <p><input type="checkbox"/> Other: \$_____ (Any amount is helpful!)</p>		

REGISTRATION FEES (includes all General Sessions, reception, and banquet)	On or Before 1-29-2017	From 1-30 to 3-3-2017	After 3-3-2017 at the door	Quantity	Total
<input type="checkbox"/> NAF Member (applies to NAF members who have an Individual, Household, Patron, Recurring or Lifetime membership (<i>member rate is applied to one caregiver per individual member with ataxia</i>)) No registration refunds will be made after February 24th	\$125	\$150	\$200		
<input type="checkbox"/> Non-Member No registration refunds will be made after February 24th	\$180	\$205	\$255		

TOTAL CHARGES:

PAYMENT INFORMATION: Visa MasterCard Discover AMEX Check enclosed

Name of Card Holder: _____

Address: _____

City: _____ State: _____ Zip: _____ Country: _____

Phone Number: _____ E-mail: _____

Credit Card Number: _____ Expiration Date: _____

3- or 4-Digit Number on Back: _____ Signature of Card Holder: _____

Early Registration Deadline is January 29, 2017

Please complete all pages of the registration form and return to the following address:
 National Ataxia Foundation, 2600 Fernbrook Lane, Suite 119, Minneapolis, MN 55447-4752
 (763) 553-0020 Fax: (763) 553-0167 E-mail: joan@ataxia.org

2017 AAC Conference Information and Resources

Hotel Reservations

The Grand Hyatt San Antonio is the official conference hotel of the 2017 NAF Annual Ataxia Conference. The Grand Hyatt San Antonio is located nine miles from the San Antonio International Airport (SAT) in the heart of downtown San Antonio at 600 E. Market St., San Antonio, TX 78205. For your stay and planning purposes at the Grand Hyatt, the following information is provided:

- All ADA rooms **must** be reserved through the NAF office by contacting (763) 553-0020 or lori@ataxia.org. ADA rooms cannot be reserved through the hotel. Availability of ADA room is limited. If you need ADA equipment you are encouraged to bring those items with you or make arrangements to rent equipment locally.

- The NAF is unable to provide ADA equipment however the Grand Hyatt may have a limited number of shower chairs, grab bars, or detachable shower heads available. **Be sure and request these items when making your reservation if needed.**

- Standard room reservations at the Grand Hyatt can be made online at <https://resweb.passkey.com/go/2017AnnualConference>. For guests who prefer to phone in their reservation call Hotel Reservations at 1-888-421-1442 and ask for the National Ataxia Foundation's group rate which is under the group name, "2017 Annual Ataxia Conference." Reservations at the group rate will be available until **February 13, 2017**. The NAF group rate starts at only \$169 + tax for Standard Rooms. ***The width of the bathroom door in the standard sleeping rooms is 33"***.

- Self-parking and valet parking are available. The Grand Hyatt San Antonio has extended a discounted parking rate of \$10 per day for our conference attendees staying at the Grand Hyatt

for self-parking and overnight attendees. The NAF does not have a group rate for valet parking which is \$33 per day for overnight guests or day parking for those not staying at the Grand Hyatt which is up to 10 hours for \$29. Overnight guests use their room key for unlimited discounted in and out access. There is a height restriction of 6' 8" into the parking ramp. There are a few parking spots available at ground level for oversize parking.

- Internet is complimentary in guest rooms for AAC attendees. A password to access the complimentary internet will be supplied to guests at check in by the hotel.

- Hotel will offer a 15% discount in Bar Rojo and PERKS Coffee for AAC attendees that show their name badge.

- Service Dog Areas are located on the Riverwalk level on the grassy areas outside of Ruth's Chris Steakhouse. Please pick up after your service animal.

- Please visit the Grand Hyatt San Antonio website for more information: <http://grandsan.antonio.hyatt.com/hyatt/hotels/>.

- The National Ataxia Foundation has an additional group block at the Hyatt Regency. The Hyatt Regency is a short distance from the Grand Hyatt. The National Ataxia Foundation group rate at the Hyatt Regency is \$169 + tax per night. To inquire about a room reservation at the Hyatt Regency please contact NAF at naf@ataxia.org.

- The Grand Hyatt San Antonio is within walking distance to other hotels. If you are unable to get a guest room that you require at the Grand Hyatt or Hyatt Regency you may wish to contact a reservations manager another nearby

Conference Information and Resources
Continued from page 27

hotel. Some nearby hotels include the Hilton Palacio del Rio, Marriott Riverwalk, Marriott Rivercenter, La Quinta Inn & Suites Convention Center, Best Western Sunset Suites Riverwalk, Fairfield Inn & Suites San Antonio Downtown/Alamo Plaza, Springhill Suites San Antonio Downtown/Alamo Plaza, Residence Inn Alamo Plaza, Comfort Suites Alamo/Riverwalk, Red Roof Inn Downtown, Emily Morgan Hotel, and Hampton Inn San Antonio Downtown.

Conference Registration

The conference registration is available online and in this issue of *Generations* on pages 24-26. Please fill out the registration form completely, including your travel information, as we need all the information to finalize plans. You are encouraged to register before **January 30, 2017** to receive the discounted **early** registration rate. General registration rates apply after **January 29**. Registrations after **March 3** will only be accepted on-site at the conference (additional “on-site” registration fee will apply). If you are bringing an attendant, please register together on the same registration form. Each person who is planning on attending daily sessions, the reception, or banquet needs to register. Event entry will be allowed only with properly registered name badges. The conference registration fee includes

attendance at all the sessions, light appetizers at the Friday evening Meet & Greet Reception and a plated meal at the Saturday evening Banquet.

Registration Fees

Before January 30:

- NAF Member \$125
- Non-Member \$180

January 30-March 3:

- NAF Member \$150
- Non-Member \$205

After March 3 – On Site:

- NAF Member \$200
- Non-Member \$255

No refunds of registration fees for cancellations received after February 24. Registration at the door is not recommended.

Member Registration Discount

Being a member of the National Ataxia Foundation has its benefits – one benefit is paying a lower registration fee for the Annual Ataxia Conference. If you are not currently a member of the Foundation or if your membership renewal is coming soon visit www.ataxia.org to become a member or renew your membership online. If you are uncertain of your membership status, please inquire by contacting the office at (763) 553-0020 or joan@ataxia.org. This will prevent unnecessary extra fees or errors in your membership status when you register for the ▶▶



Explore San Antonio

Request a free “Visit San Antonio” guide book, provided by the San Antonio Convention and Visitor’s Bureau, to help you plan your trip to the 2017 NAF Annual Ataxia Conference. This complementary book is filled with information about the city, food, arts and major events for 2016-2017. This free guide can be ordered by calling 1-800-447-3372, or may be requested or downloaded instantly by following this link: <http://visitsanantonio.com/english/Leisure-Guide-Request-Form>. Please allow up to four weeks for your guide book to arrive.

To find out more about the 2017 NAF Annual Ataxia Conference, please visit the NAF’s website, www.ataxia.org.

2017 Annual Ataxia Conference. Thank you for taking the time to renew or become a member of the National Ataxia Foundation.

Conference Deductions by attendees

<http://www.irs.gov/pub/irs-irbs/irb00-19.pdf>

Rev. Rul. 2000-24, page 963 (In part) Medical expenses.

Amounts paid by an individual for expenses of admission and transportation to a medical conference relating to the chronic disease of the individual's dependent are deductible as medical expenses under section 213 of the Code (subject to the limitations of that section), if the costs are primarily for and essential to the medical care of the dependent. The cost of meals and lodging while attending the conference are not deductible as medical expenses under Code section 213.

Travel Grant Program

Please see page 32 for more information on how to support the Arnie Gruetzmacher Annual Ataxia Conference Travel Grant Fund Program or how to apply.

About San Antonio

San Antonio is the seventh-largest city in the United States of America and the second-largest city within the state of Texas, with a population of 1.33 million. The city was named for San Antonio de Padua, whose feast day is on June 13,

when a Spanish expedition stopped in the area in 1691. Famous for Spanish missions, the Alamo, the River Walk, the Tower of the Americas, the Alamo Bowl, Marriage Island and host to SeaWorld and Six Flags Fiesta Texas theme parks, the city is visited by approximately 26 million tourists per year according to the San Antonio Convention and Visitors Bureau. For a map of the San Antonio metro area, please visit <http://tinyurl.com/h3uveza>.

Morgan's Wonderland was built in the true spirit of inclusion to provide a place where all ages and abilities can come together and play in a fun and safe environment. Morgan's Wonderland, the world's first ultra-accessible family fun park, encompasses 25 acres of rides, attractions and activities for everyone and all are welcome!

"People, pride, passion, and promise have long been the pillars of San Antonio and these are the reasons you don't just visit our city. You are welcomed, enchanted, inspired, moved, and renewed – deeply" (San Antonio Convention & Visitors Bureau). To start planning your trip visit www.visitsanantonio.com.

VIA Metropolitan Transit – VIA's streetcar service offers stops to or near most hotels, restaurants, the convention center and many visitors hot spots. For added convenience, VIA offers \$2.75 Day Pass for purchase online and in

Continued on page 30

2017 AAC Exhibitors, Sponsors Wanted

The National Ataxia Foundation is looking for companies or individuals who have products or services that would be helpful for those with Ataxia to submit an exhibitor application to exhibit at the National Ataxia Foundation 60th Anniversary Annual Ataxia Conference. The 2017 conference will be held in San Antonio, TX on March 10-11. Please e-mail joan@ataxia.org for an exhibitor application.

The NAF is grateful to those organizations that

have provided generous support of the annual Ataxia conference. Please consider being a sponsor of the 2017 Annual Ataxia Conference. For more information on becoming a sponsor please e-mail Joel Sutherland at joel@ataxia.org.

If you are affected by Ataxia or are a caregiver and know of a product or service that has been helpful for you, please let us know by calling (763) 553-0020 or e-mail joan@ataxia.org.

Conference Information and Resources

Continued from page 29

advance of your trip. A Day Pass is good for unlimited rides on all regular bus and streetcar service for the one day indicated on the pass. The Day Pass will be activated the first time boarding the bus or streetcar.

For more details, visit www.viainfo.net or call 1-866-362-2020. Accessible services provided by VIA can be found at <http://www.viainfo.net/Service/AccessibleServiceMain.aspx>.

Weather – The month of March is characterized by rising daily high temperatures, with daily highs ranging from 72° to 78°F over the course of the month.

The following information can be used as a guide as you plan your stay and transportation needs in San Antonio. The National Ataxia Foundation does not endorse products, services, or manufacturers. Those mentioned are included for your information only. The NAF assumes no liability for the use or contents of any product or service mentioned.

Transportation and Getting There

To help you with planning, the NAF encourages you to access the links to important websites that will inform you of your rights and your responsibilities when traveling by air. Go to the NAF's website at www.ataxia.org and select the Links tab at the top of the home page. You will be directed to a list of links. Select the category "Accessible Travel" to find websites such as Transportation Security Administration and the U.S. Department of Transportation.

Passengers requiring any in-flight assistance should contact their airline before traveling. Airlines will generally work with passengers to try to meet their in-flight needs. Also, visit the TSA Cares website <https://www.tsa.gov/travel/passenger-support> for contact information to request screening assistance, scooter assistance, service animal assistance, and any other accessi-

ble services that you may need at the airports you utilize during your travels. For your safety and for the safety of other travelers please do not leave your baggage unattended at any airport you visit during your travels. For a video on how to navigate an airport in a wheelchair, please visit <https://www.youtube.com/watch?v=LFBN1vIJo0>.

San Antonio International Airport works hard to make the travel experience easy and safe for all passengers. The airport is fully accessible to individuals with physical challenges, those traveling with infants and small children, the elderly and others with special needs. Please let us know if there is anything we can do to make your experience at SAT more comfortable. Note: Too much collateral packed in your checked luggage may flag your bag(s) and delay your flight. Please carry large amounts of collateral in your carry-on luggage. For more information and resources visit <http://www.sanantonio.gov/SAT/AtTheAirport/Accessibility.aspx>.

San Antonio International Airport Ground Transportation

Super Shuttle – Super Shuttle is San Antonio International Airport's authorized and single shared-ride shuttle service. Shuttles depart from 7 a.m. to 1:30 a.m. daily to downtown hotels every 15 minutes. Passengers may purchase tickets at the airport's baggage claim area.

Arrangements should be made in advance if travelers need transportation in a wheelchair accessible vehicle. Tickets are \$19 per person to downtown hotels or \$34 for a round-trip ticket if booked online. Visit <http://saairportshuttle.hudsonltd.net/res> or call (210) 281-9900 for additional information.

Taxis from SAT Airport – Taxi cabs are available at the lower level curbside, outside of baggage claim, at Terminal A & B. For assistance, please contact the Airport Ground Transportation Agent wearing an airport badge. Fares to downtown areas start at \$29 per taxicab. For a list of taxi cab companies please visit <http://www.sanantonio.gov/Aviation/taxicabs.asp>. ▶▶

Travelers who will need ground transportation in wheelchair accessible vehicles from the Airport should make arrangements in advance of their arrival. The following Taxi Cab companies offer ADA services:

- AAA Taxi – <http://www.etaxisa.com/>
- San Antonio Taxis – <http://sataxis.com/>
- Yellow Cab – <http://www.yellowcabsa.com/>

Rideshare – Approved rideshare services (or ride-hailing or ride-booking service companies) meet customers curbside lower level Terminal B. The following rideshare service companies are approved for operations at SAT:

- Uber – <https://www.uber.com/>
- Lyft – <https://www.lyft.com/>
- Get Me – <https://www.getme.com/>

Public Buses and Street Car Service – VIA Metropolitan Transit is San Antonio's public transportation agency offering service throughout the city including streetcar service within the downtown area. To get downtown from the airport, go to the Lower Roadway (Arrivals/Baggage Level in Terminal A and B), across the marked crosswalk to the outer curb. VIA's stop will be halfway between Terminals A & B, clearly marked. You will catch VIA bus route 5, which operates every day, and can get to beautiful downtown San Antonio in about 30 minutes for only \$1.30.

Once in the downtown area, VIA's streetcar service offers stops to or near most hotels, restaurants, the convention center and many visitor hot spots. For added convenience, VIA offers a \$2.75 Day Pass for purchase online and in advance of your trip. A Day Pass is good for unlimited rides on all regular bus and streetcar service for the one day indicated on the pass. The Day Pass will be activated the first time boarding the bus or streetcar.

For more details, visit www.viainfo.net or call 1-866-362-2020. Accessible services provided by VIA can be found at <http://www.viainfo.net/Service/AccessibleServiceMain.aspx>.

Paratransit Services – VIA Metropolitan Transit / VIATrans Accessible Services – Provides transportation for mobility-impaired persons who are unable to use regular VIA bus service as a result of their disability. Must meet eligibility criteria to be certified for the service. ** VIA-trans now also has a Taxi Subsidy Service for people with disabilities who cannot use the regular bus service. Information Line: (210) 362-2020 / Reservation Line: (210) 362-2140. http://bexar.tx.networkofcare.org/aging/services/agency.aspx?pid=VIAMetropolitanTransitVIATransAccessibleServices_687_1_0.

Car Rentals – There are several companies to choose from when renting a car at San Antonio International Airport. Please contact the company of your choice for more information. Car rental counters are located in Terminal A. Passengers can use the courtesy phones provided in the baggage claim area of Terminal A to request shuttle transport to the car rental company of their choice after hours or can proceed to the shuttle pick up area located outside the baggage claim area. To find the rental company that best suits your needs visit <http://www.sanantonio.gov/SAT/GroundTransportation/RentalCar.aspx>.

Accessible Van Services

Premier Accessible Van Rental

1-866-755-VANS

<http://www.premiervanrental.com/whyrent.php>

ALAMO Mobility, Inc.

1-888-442-5266 or (210) 697-8884

<http://www.alamomobility.com/rental/index.htm>

ams vans

1-866-459-6066 or (281) 220-6720

<http://www.accessiblevanss.com/wheelchair-van-rentals.php>

AA Vans

1-888-880-8267

<http://www.aavans.com/Vehicles/RentHandicapVans>

Conference Information and Resources
Continued from page 31

San Antonio Area Services & Resources

The following may be used as a helpful guide for your convenience:

Accessible Equipment

Primo Medical Supplies – (210) 519-5311

<http://www.sanantoniomedicalequipment.com/>

Wheelchair & Scooter Rentals & Repair

Tom's Wheelchair Rental – (210) 223-7878

<http://www.tomswheelchairs.com/>

Ability Scooters – (210) 315-8242

<http://www.abilityscooters.com/wheelchair-rental.html>

Scootaround – 1-888-441-7575

<http://www.scootaround.com/>

Personal Care Attendants

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

The Attendant Network

<https://www.attendantnetwork.org/attnet/index.jsp>

Pharmacy Options

CVS Pharmacy

www.cvs.com

Walgreens

www.walgreens.com



NAF AAC Travel Grant Program Needs Your Support

“Being around other people with ataxia at the meeting helps me feel less alone.”

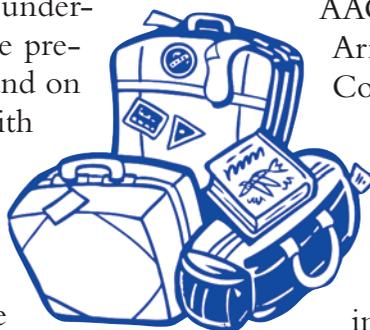
The National Ataxia Foundation's Annual Ataxia Conference (AAC) connects the Ataxia community. The conference program is designed to foster learning and understanding by providing informative presentations about Ataxia research and on living with Ataxia. Connecting with those who understand and face the same challenges is also an important component in which individuals with Ataxia, their family members, and caregivers have the opportunity to share and network.

Traveling to an Annual Ataxia Conference can be financially difficult. To help those with Ataxia who are unable to financially attend the AAC, the NAF established an AAC Travel Grant

Program to help with some of the costs associated with attending the AAC.

You can help someone with Ataxia attend the AAC by making a donation to the NAF Arnie Gruetzmacher Annual Ataxia Conference Travel Grant Fund Program. Your gift to the AAC Travel Grant Fund will make an immense difference in someone's life. Thank you for your support and for making the ACC experience possible for an individual affected by Ataxia who

would not have been able to attend without your help. You can make your donation to the Arnie Gruetzmacher Annual Ataxia Conference Travel Grant Fund by following this link: <http://tinyurl.com/AGAACTGF2017>.



Applying for a Travel Grant

Because of the generosity of several donors, the National Ataxia Foundation is able to offer Travel Grants to help with a portion of the travel costs associated with attending the conference. Adults or children with Ataxia are eligible to apply for a travel grant. Individuals interested in the program are required to submit a Travel Grant application.

Visit the NAF website, www.ataxia.org, to download the application. If you would like

an application sent to you in the mail, contact the NAF at (763) 553-0020 or by e-mail at naf@ataxia.org to request one. Applications will be accepted until **January 6, 2017**. Travel Grant applicants will be notified of the status of their application after the application deadline and after all applications have been reviewed.

You can also download the forms by following these links:

Adult: <http://tinyurl.com/nlqsczr>

Children: <http://tinyurl.com/n98gp28> ❖

Don't forget about your SILENT AUCTION item Donation!!

Please have your card filled out and attached to your item prior to bringing it into the registration room. Thank you!!

Item Description _____

Minimum bid (if Any) \$ _____

Name _____

Name of Group _____

Address _____

City _____ *State* _____ *Zip* _____

Phone Number _____ 2017

Email Address _____

Item Number _____

Office Use only

2017 AAC Silent Auction

The Silent Auction held during the National Ataxia Foundation Annual Ataxia Conference (AAC) is a fun way to support the NAF and for you to bid on quality items from various states and countries. This long-standing NAF tradition begins Friday, March 10 at 8:30 a.m., with final bidding ending on Saturday at 1 p.m. Winners must pick up and pay for their items from 3-7 p.m. on Saturday.

Auction items should range from something that represents your state or country, art work, sports memorabilia, theme baskets, hand-

crafted items, hotel stays and weekend get-aways. Items being donated should be dropped off at the registration area on Friday, March 10 by 4 p.m. Please complete and include the form above with your items.

If you are not able to attend the conference, but have a quality item that you would like to donate, please call (763) 553-0020 or e-mail Joan at joan@ataxia.org for details on where to ship your item. Donate an item and then have fun bidding on the items of your choice!

Thank you for supporting this event.

Chapter and Support Group News
from Around the Country

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Delaware Ataxia Support Group – Albany

Submitted by Joe DeCrescenzo

The Delaware Support Group held its Fall Meeting on October 15. The meeting featured OFC Anthony Pierce of the New Castle County Police Department Community Relations Division. His presentation on Senior Safety and Scams was well received by everyone. Joe DeCrescenzo gave a presentation on the NAF – its employee make-up, its financial status and standing with independent auditors, its importance in the Ataxia research community and its relevance to members. He also discussed the benefits of attending the Annual Ataxia Conference (AAC).

After a refreshment break, the attendees spent time discussing among themselves their personal dealings with the disease.

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Greater Denver Area Ataxia Support Group

Submitted by Charlotte DePew

At our quarterly meeting on October 15 we had a most interesting presentation and group discussion about Colorado’s Proposition 69, Colorado Care, on our November ballot. Most attendees were not aware of details and implications regarding this proposed amendment to the Colorado Constitution which led to questions. Fortunately, our speaker, Bill Jerke, was well-informed to the point where one listener said they could not tell if he was for against the proposed amendment. Among the group was an internist, daughter of an Ataxia member, and she provided an additional unique perspective to this complex proposed amendment.

.....
Treasure Coast Ataxia Support Group

Submitted by Lisa Cole & Roberta Santa Croce

The Treasure Coast Ataxia Support Group met at the Port St. Lucie, Florida Community Center on Saturday, September 10. We had eight people come and a few were new members, including Dan Freedland.

Lisa arrived early, helped set up room, supplied bottled water and had fruit and veggies available. (Let's not overlook the chocolate chip cookies!) The resource table had various “must know” Ataxia-related materials for everyone.



Dan Freedland

Everyone was there at kickoff! So the group rolled up their sleeves and got right into it! Carly and her BFF (aka mother) Helen introduced us to FARA or the Friedreich's Ataxia Research Alliance. On November 13th, “Carly's Cruisers” take to the road as a fundraiser and awareness tool.

.....

Greater Atlanta Ataxia Support Group

Submitted by Dave, Greg, Diane and Lealan

The Greater Atlanta Ataxia Support group held their last meeting of the year on November 5. It was a great meeting and we had some new people from Chattanooga join our group. Marinda and Fiora Cauley who have FA and Sarah Gelbard who is studying at Emory and worked with FARA and Dr. Lynch.

Lealan gave an excellent presentation about ►►



Members of the Greater Atlanta Ataxia Support Group at their November meeting

accessible housing that she had presented to the FARA symposium. You can download the presentation here – <http://tinyurl.com/grxv692> – and the handout here – <http://tinyurl.com/gvuw2wc>.

The 2016 Atlanta Walk n’ Roll raised over \$25,000 for the NAF. Thank you to all who participated and supported our event.

Elections for 2017 Officers were Dave Zilles, Greg Rooks, Diane Mitchel, Lealan Sims and Berhe Gebrekristos.

Willamette Valley Ataxia Support Group – Albany

Submitted by Jason Wolfer

The Willamette Valley Albany Support Group met Friday, September 9, at a small park for their annual summer picnic. The summer gathering is usually in July, but due to busy



Members of the Willamette Valley Ataxia Support Group at their September picnic

schedules, and other events that went on during the main summer months, the picnic was a little later this year. However, the benefit to this was that we had a cooler and much more pleasant time.

Everyone who attends the monthly meetings was able to be there, with the exception of one of the oldest members who just recently transitioned to a care facility. We had a good time visiting, catching up with one another, and of course, eating more than any of us thought was a possibility.

New Hampshire Ataxia Support Group – Celebrating 5 Years!

Submitted by Jill Porter

The New Hampshire group met on Saturday, September 24 with six members in attendance from around the state and north of Boston. The meeting was very informative with Akshata Sonni, UMass Amherst Sleep Researcher, as our speaker. We learned about the importance of sleep, about our sleep patterns and about the current research study for individuals with cerebellar ataxia who may be eligible to participate in an in-home sleep study.

We participated in the New England Walk n’ Roll, Saturday, September 10 at the Bristol Town Beach in Bristol, Rhode Island in recognition of IAAD. ❖



New Hampshire Ataxia Support Group members: (seated, left to right) Ken Porter, Lori Giotis, Jeff Mansfield, and Donna Brown; (standing) Missy Mansfield and Jill Porter

NAF Directory of Chapters, Support Groups, Social Networks 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, joining a chapter or support group without the NAF's written permission is strictly prohibited.

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NAF CHAT ROOM

Moderator – Della (ddpokernut@yahoo.com)

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NAF FACEBOOK PAGE

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

NAF YOUTUBE CHANNEL

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

Please note: The hometown of each Support Group Leader or Ambassador is noted below. For group meeting locations please refer to the Calendar of Events.

Chapters, Support Groups and Ambassadors

Please note: Hometown of each Support Group Leader or Ambassador is noted below. For group meeting locations please refer to the Calendar of Events on pages 44-46.

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 (608) 237-6090

E-mail: kstab77@yahoo.com
www.ataxia.org/chapters/Wisconsin/default.aspx

International Support Groups & Ambassadors

– CANADA –**OTTAWA SUPPORT GROUP LEADER**

Prentis Clairmont – Ottawa, Ontario
 (613) 864-8545

E-mail: prentis.clairmont@gmail.com **Facebook Group:**
www.facebook.com/groups/1468963499991380/
www.ataxia.org/chapters/Ottawa/default.aspx

– INDIA –**INDIA SUPPORT GROUP LEADER**

“Seek a Miracle Ataxia Group” (SAMAG)

Chandu Prasad George

Hyderabad, Secunderabad, India
 Mobile: 0091-9989899919, 0091-9885199918

E-mail: sam_ataxiaindia@yahoo.com
 S.G. E-mail: india.ataxiagroup@gmail.com
Facebook Group: www.facebook.com/ataxiain
 S.G. Website: www.ataxia.in
www.ataxia.org/chapters/Chandu/default.aspx

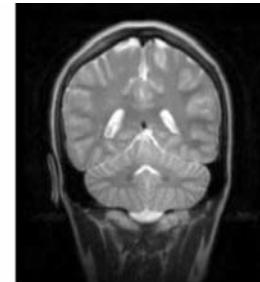
– PAKISTAN –**AMBASSADOR**

Sajjad Haider – Karachi, Pakistan
 0092-(300) 828-1784

E-mail: sajjadhaiderb@hotmail.com



**PATIENTS with
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

Friedreich's Ataxia Clinical Trial at Mayo Clinic with Medication Epicatechin

Study # NCT02660112

Dr. Gavrilova and team at Mayo Clinic Rochester Minnesota are recruiting individuals with Friedreich's ataxia to participate in a drug clinical trial. This clinical trial is designed to determine if the study medication Epicatechin will improve the neurological or heart functions of patients with Friedreich's ataxia. Epicatechin is an organic based medication with a good safety record. We are recruiting children and adults (age 10-50 years) with a confirmed diagnosis of Friedreich's ataxia and neurological and heart related symptoms. The participants' disease duration should be of 7 years or less.

In this clinical trial, you will be evaluated at Mayo Clinic Rochester during three separate visits over a 6 month period. After the first visit, if you qualify for participation and if you are willing to take part in the study, you will be asked to take an oral medication three times per day for six months. At each visit you will be evaluated by neurology, cardiology, endocrinology, genetic and physical medicine specialists. You will also have an MRI and an echocardiogram. Blood and urine samples will be obtained at each visit to the clinic.

More detailed information about this clinical trial is available in the consent form and on the website clinicaltrials.gov, Mayo, NAF and FARA websites.

If you would like further information or are interested in participating, please contact:

Please refer to this study by its ClinicalTrials.gov identifier: NCT02660112

Contacts

Contact: Gillian A Currie, BSc 507-293-0792 Currie.Gillian@mayo.edu

Contact: Kayla M Ehlenfeldt 507-266-2967 Ehlenfeldt.Kayla@mayo.edu

Locations

United States, Minnesota

Mayo Clinic Recruiting

Rochester, Minnesota, United States, 55905

Contact: Gillian A Currie, BSc 507-293-0792 Currie.Gillian@mayo.edu

Contact: Jennifer Kemppainen, MS, CGC 507-266-2967
Kemppainen.Jennifer@mayo.edu

Principal Investigator: Ralitza H. Gavrilova, MD

Ataxia Awareness Ride

Submitted by Greg Ostrom

On the morning of September 25, International Ataxia Awareness Day, I found myself in Mount Brydges, Ontario. I was about to embark on a 27-kilometer trike ride to raise awareness for Ataxia during a fundraiser for the National Ataxia Foundation. My nervousness was replaced with pride in doing something I thought would only be a dream. Twenty-seven kilometers isn't that far for most cyclists, but for a beginner cyclist of my ability, it was far enough and the perfect distance for anybody to come out and ride with me next year. The route stretched along a fairly flat country road, paved and semi-paved, that had no towns on it. My sister Tarryn and sister-in-law Suzanne offered to join me for the ride and I was happy to have the opportunity to discuss raising awareness about Ataxia and my goals for future rides.

This was the beginning of a dream come true.

I was diagnosed with Olivocerebellar Degeneration when I was 14 years old. Today it is referred to as Spinocerebellar Ataxia (SCA). Besides my fine motor skills starting to deteriorate (especially noticeable was my handwriting) and the odd trip on an inanimate object, my disease was somewhat invisible. I remember as a teenager growing up in a small town and doing normal teenager stuff like camping, hiking and riding my bike. By the time I moved out on my own in my early 20s, my condition had progressed to the point where my independence was dwindling. This was mostly because I didn't want to walk due to the stigma related to those

who have Ataxia, where people assume you have had too much alcohol. Despite having tons of support from my family, I still found it was a chore to do things or go anywhere. During the years leading up to my present age of 45, I have lived with numerous aids to help me with daily activities. Most prevalent was walking, for which I was granted a three-wheeled mobility scooter and later a manual wheelchair for places my mobility scooter couldn't access. These aids and devices have allowed me much more independence.

At home, I used a walker/rollator and for the most part my balance issues had been solved. But after years of injuries to my feet, mainly from falling with my walker due to weak ankles and atrophied foot muscles, almost eight years ago my neurologist prescribed some fully rigid and very supportive leg braces.

These custom-made leg braces help me with my drop foot, orthotics and, of course, ankle support but most of all it feels like I have new and also improved legs and ankles, stronger than ever before. With my new ability, I wanted to do something positive for myself and people like me.

When I was 38 I met a fantastic woman named Rebecca. She happened to live in the area where I grew up, which was a bonus since my family still lived there. After I finished college I moved back home to the quaint, small town of Glencoe, Ontario. Rebecca and I enjoy road tripping, hiking, camping and various outdoor activities. Nowadays we can even cycle together, something I thought I would never be able to do ►►



Greg Ostrom

again. I have not been able to ride a bicycle since I was 19 and, while there is no cure for this debilitating disease, keeping my body strong and fit is essential. For many years, I went to the gym just to ride the exercise recumbent bicycle and now I can get an outdoor recumbent bicycle. Because of my balance issues I felt it had to be a trike. This past spring, after I was awarded a Catrike Trail Recumbent Trike from the Friedreich's Ataxia Research Initiative's (FARA) Ataxian Athlete Initiative, my mind started focusing on raising money. Being able to do something you never thought you would do is so rewarding. I can now get my exercise as well as enjoy the outdoors. With my renewed fondness of cycling, I know I can help where help is needed. I will be able to participate in marathons for the National Ataxia Foundation (NAF).

My ride on September 25 was taking me back to Glencoe, the town where I grew up. My heart was full of pride as we pedaled the last few hundred meters together. As we approached the finish line, my three-year old nephew Taten joined us on his bike for the last few hundred meters; I found more family and friends waiting to welcome and congratulate us in Glencoe. Just then I suddenly realized that my ride was bigger than I had first thought. Our efforts had brought people from as far away as Bayfield, Ontario. Plans are already underway for a bigger ride next year as well as a Walk n' Roll in London next spring.

Please feel free to go to my personal blog at www.facebook.com/AnAthleticAtaxian, where I will post pictures and notes, or e-mail me at fregs@live.ca. ❖

Deadline

The deadline to submit materials for the Spring edition is February 3, 2017. Please submit content by e-mail to joan@ataxia.org, or by mail to the address inside the front cover.

Fundraisers

Crusin Cajun Country

Submitted by Cruisin Cajun Country

In May we had our annual Cruisin Cajun Country Cruise In. For the 2016 event, Cruisin Cajun Country donated \$1,000 to the National Ataxia Foundation at their Cruisin Cajun Country Arceneaux Ford Sugar Daddy Car Show held on September 24.

The donation to the NAF was made in memory of Mary Romero.



Wilson Romero (left) accepts the donation in honor of Mary Romero on behalf of all members of Cruisin Cajun Country. To the right of Wilson is the President of Cruisin Cajun Country, Wayne Hollier, and Co-Vice Presidents Richard LeBlanc and Lamar Hutchinson.

Students Run LA Cares

The broad purpose of SRLA Cares is to raise the students' awareness of and involvement in the process of "giving back" to their communities. SRLA has asked students participate in a series of "giving back" projects associated with each of the community races in which they participate. In October at the 5K run, the project was to collect pennies for Ataxia.

Representing their "Pennies from Heaven" effort, the students, staff and Board of Directors of Students Run LA supported the National Ataxia Foundation by presenting a check for \$2,000, monies raised by their students, one penny at a time, through SRLA Cares.

The NAF had a table with Ataxia information at the Students Run LA "Pennies from Heaven" Kick Off Rally on October 8th.

Calendar of Events

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

Why Attend an Ataxia Support/Social Group?

Many of you may ask, "Why should I attend a support group meeting?" Support groups can remind us that we are not alone and that while each individual may experience Ataxia in a different way, together we have many things in common. A benefit of attending a support group is simply to have a chance to talk with others and learn how different people deal with the same disease.

Attending a support group meeting may give you a glimpse into the many different stages and types of the disease. This can help by using some of the strategies that have been beneficial to others in order to avoid and/or plan for some of the same challenges that others have faced in the progression of their Ataxia. Hopefully attending a support group meeting will leave you with a sense of hope and inspiration, knowing that if others can cope, so can you.

Come. Learn. Share. But most of all, know that you are NOT alone.

SUPPORT GROUP MEETINGS

– Saturday, January 7, 2017 –

Central Pennsylvania Ataxia Support Group Meeting

Time: 11 a.m. – 1 p.m.

Location: Muhlenberg Community Library, Laureldale, PA

Details: Guest speaker will be Jennifer Millar, PT from Johns Hopkins Ataxia Center. For additional information contact Mike Cammer at (610) 996-5814 or michael.cammer62@hotmail.com.

New Hampshire Ataxia Support Group Annual Lunch Out

Time: TBD

Location: TBD

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

– Thursday, January 12, 2017 –

Tri-State Ataxia Support Group Potluck Meeting

Time: 6:30 – 8:30 p.m.

Location: Beth Israel Medical Center, Phillips Ambulatory Care Center (PACC), Second Floor Conference Room, 10 Union Square East, New York, NY

Details: For more information contact Kathy GINGERELLI at kgingerelli@msn.com or Denise Mitchell at markmeghan2@gmail.com.

– Saturday, January 14, 2017 –

Central Minnesota Ataxia Support Group Meeting

Time: 10 a.m. – noon

Location: 1038 Sunset Ridge Rd., St. Cloud, MN 56303

Details: For additional information contact Marsha

Binnebose at (320) 248-9851 or mbinnebose@hotmail.com.

North Texas Ataxia Support Group Meeting

Time: 10 a.m. – noon

Location: Ben Washington Baptist Church, Rev. Jr. Sheppard Educational Center, 615 Davis St., Irving, TX 75061

Details: The meeting room is in a separate building from the church. For more information contact David Henry at cheve11e@sbcglobal.net.

– Saturday, January 21, 2017 –

Denver Area Ataxia Support Group Meeting

Time: 1 – 4 p.m.

Location: Accessible Systems, 3025 W. Jefferson Ave., Englewood, CO 80110

Details: RSVP is needed by January 14, 2017. For more information contact Charlotte DePew at (720) 379-6887 or cldepew77@comcast.net.

Nebraska Ataxia Support Group Social

Time: 11 a.m.

Location: Durham Western History Museum, Omaha, NE

Details: For additional information contact Linda Snider at (402) 212-3060 or lindasnider@cox.net.

Orange County Ataxia Support Group Meeting

Time: 2 – 4 p.m.

Location: Orange Coast Memorial Medical Center Hospital, Breast Cancer Center Conference Rm. A, 9900 Talbert Ave., Fountain Valley, CA 92708

Details: For more information contact Cindy DeMint at cindyocataxia@gmail.com.

NCASG–Sacramento Area Ataxia Support Group Meeting

Time: The group meets on the third Saturday of ►►

each month at 1:00 p.m.

Location: Sutter Roseville Medical Center, 1 Medical Plaza Dr., Roseville, CA 95661

Details: For more information contact Teresa Bredberg at (916) 215-2686 or tbredberg@sbcglobal.net.

Twin Cities Ataxia Social Group Meeting

Time: 10 a.m. on the third Saturday of every month (approximately two hours)

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 schultz.lenore@yahoo.com.

– **Saturday, February 4, 2017** –

Arizona Ataxia Support Group Meeting

Time: 1 p.m.

Location: Ability 360, 5025 E Washington St., Phoenix, AZ 85034.

Details: For more information contact Mary Fuchs at (480) 212-6425 or mary11115@msn.com.

Treasure Coast Ataxia Support Group Meeting

Time: 1 – 3:30 p.m.

Location: Port St. Lucie Community Center, 2195 SE Airoso Blvd., Port St. Lucie, FL 39484

Details: For more information contact Lisa Cole at (772) 370-3041 or lc02234@gmail.com.

– **Saturday, February 11, 2017** –

Central Minnesota Ataxia Support Group Meeting

Time: 10 a.m. – noon

Location: 1038 Sunset Ridge Rd., St. Cloud, MN 56303

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

Mid-Atlantic Social Support Group Meeting

Time: 10 a.m. – 2 p.m.

Location: John Hopkins Wellness Center, Medical Pavilion at Howard County Hospital, 10710 Charter Dr., Ste., 100, Columbia, MD 21044

Details: Learn how to limit choking, improve swallowing and when to go to the emergency room. Please register by January 30 at <http://tinyurl.com/jvfyqm9> or by calling Donna Neuwirth at (410) 616-2811 or ddeleno1@jhmi.edu.

Kansas City Ataxia Support Group Meeting

Time: 2 – 4 p.m.

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

Details: For more information contact Stephanie Wilkins at (816) 623-3318 or swilkins@yahoo.com.

North Texas Ataxia Support Group Meeting

Time: 10 a.m. – noon

Location: Ben Washington Baptist Church, Rev. Jr. Sheppard Educational Center, 615 Davis St., Irving, TX 75061

Details: The meeting room is in a separate building from the church. For more information contact David Henry at cheve11e@sbcglobal.net.

– **Saturday, February 18, 2017** –

Nebraska Ataxia Support Group Meeting

Time: 11 a.m. – 1 p.m.

Location: Methodist Hospital, 8303 Dodge St., Omaha, NE 68114

Details: For additional information contact Linda Snider at (402) 212-3060 or lindasnider@cox.net.

Orange County Ataxia Support Group Meeting

Time: 2 – 4 p.m.

Location: Orange Coast Memorial Medical Center Hospital, Breast Cancer Center Conference Rm. A, 9900 Talbert Ave., Fountain Valley, CA 92708

Details: For more information contact Cindy DeMint at cindyocataxia@gmail.com.

NCASG–Sacramento Area Ataxia Support Group Meeting

Time: The group meets on the third Saturday of each month at 1:00 p.m.

Location: Sutter Roseville Medical Center, 1 Medical Plaza Dr., Roseville, CA 95661

Details: For more information contact Teresa Bredberg at (916) 215-2686 or tbredberg@sbcglobal.net.

Twin Cities Ataxia Social Group Meeting

Time: 10 a.m. on the third Saturday of every month (approximately two hours)

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 schultz.lenore@yahoo.com.

– **Saturday, February 25, 2017** –

New Hampshire Ataxia Support Group Meeting

Time: 10 a.m. – noon

Location: Villa Crest Nursing and Retirement Home, 1276 Hanover St., Manchester, NH

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

*Calendar of Events**Continued from page 45***– Thursday, March 9, 2017 –****Tri-State Ataxia Support Group Meeting****Time:** 6:30 – 8:30 p.m.**Location:** Beth Israel Medical Center, Phillips Ambulatory Care Center (PACC), Second Floor Conference Room, 10 Union Square East, New York, NY**Details:** For more information contact Kathy Gingerelli at kgingerelli@msn.com or Denise Mitchell at markmeghan2@gmail.com.**– Friday, March 10, 2017 –****Palo Alto Ataxia Support Group Meeting****Time:** 1 – 2:30 p.m.**Location:** Stanford Neuroscience Health Center, Rm. 3871, Stanford, CA**Details:** For more information contact Victoria Tanoury, RN, CNRN, at (650) 736-1399 or vtanoury@stanfordhealthcare.org or Sarah Kahn, Nurse Coordinator, at skahn@standfordhealth.org.**– Saturday, March 11, 2017 –****Central Minnesota Ataxia Support Group Meeting****Time:** 10 a.m. – noon**Location:** 1038 Sunset Ridge Rd., St. Cloud, MN 56303**Details:** For additional information contact Marsha Binnebose at (320) 248-9851 or mbinnebose@hotmail.com.**North Texas Ataxia Support Group Meeting****Time:** 10 a.m. – noon**Location:** Ben Washington Baptist Church, Rev. Jr. Sheppard Educational Center, 615 Davis St., Irving, TX 75061**Details:** The meeting room is in a separate building from the church. For more information contact David Henry at cheve11e@sbcglobal.net.**– Saturday, March 18, 2017 –****NCASG-Sacramento Area Ataxia Support Group Meeting****Time:** The group meets on the third Saturday of each month at 1:00 p.m.**Location:** Sutter Roseville Medical Center, 1 Medical Plaza Dr., Roseville, CA 95661**Details:** For more information contact Teresa Bredberg at (916) 215-2686 or tbredberg@sbcglobal.net.**Twin Cities Ataxia Social Group Meeting****Time:** 10 a.m. on the third Saturday of every month (approximately two hours)**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 schultz.lenore@yahoo.com.**INFORMATIONAL, AWARENESS,
AND IAAD EVENTS
AND FUNDRAISERS****– Friday, January 20-22, 2017 –****Toronto Abilities Expo****Time:** Friday and Saturday 11 a.m. – 5 p.m., Sunday 11 a.m. – 4 p.m.**Location:** International Centre, 6900 Airport Rd., Mississauga, ON, Canada L4V 1E8**Details:** Admission is free.www.abilitiesexpo.com/toronto/**– Tuesday, February 28, 2017 –****Rare Disease Day****Details:** Research brings hope to people living with a rare disease. February 28 the 10th Rare Disease Day will see thousands of people from all over the world come together to advocate for more research on rare diseases. Rare Disease Day is open to everyone! Individuals, patients, patient organizations, health professionals, researchers, drug developers, public health authorities – the more people involved the better! As you'll find out, there are many ways to participate. Join in our efforts to give hope to rare disease patients all over the world!<http://www.rarediseaseday.org/article/get-involved>**– Friday, March 10-11, 2017 –****60th NAF Annual Ataxia Conference (AAC)****Location:** Grand Hyatt San Antonio, San Antonio, TX**Details:** New this year, the conference will end with the banquet on Saturday night. Registration fee required to attend. See pages 14-33 for more information or visit our website, www.ataxia.org.**– Friday, March 24-26, 2017 –****Los Angeles Abilities Expo****Time:** Friday and Saturday 11 a.m. – 5 p.m., Sunday 11 a.m. – 4 p.m.**Location:** Los Angeles Convention Center, West Hall A, 1201 South Figueroa Street, Los Angeles, CA 90015**Details:** Admission is free.www.abilitiesexpo.com/losangeles/

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 August 2016 through October 2016. 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.

Michael Athey	Salmonella Dorsey	Sarah Lane	Gregory Pettit	Lisa Snow-Kelso
Judith Bandaries	Katherine	Ruth Lapp	Nello Poli	Leon Spears
Cindy Bean	Dzieszkowski	Beth Lawton	Ted & Renee Poli	Joseph Stamer
Jim Bean	Agnes Fauteux	Jennifer Leader	Marriage	Janette St. George
Curtis Benedetto	Vincenzo Ferranti	Kayden Leone	Ken Porter	Robert St. George
Antonio Bermudez	Jerry Frey	Van Light	Zexia Pourney	Ellen Stamelos
James Braswell	Kathy Gardner	Cindy Linari	John Prola	David Stein
Harold Brennan III	Kathleen	Scott Lund	Sunaro Prom	Perry Stio
Jaime Brooks	Gingerelli	Page Martin	Scott Quinn	Marie Straetmans
Angela Brown	Melvin Goodman	Anthony Masci	Roseann Rash	Sweeney Family
Karen Burns	Nicholas Grace	Brent Masserant	Janet Riley	Trudy Swentko
Barbara Bynum	Kathy Griggs	Brent Masserant	Greg Rooks	Kyle Swier
Peter Caparelli	Thomas Gunnigle	Marie Matykowski	Bill Sanders	Stephanie Swier
Matthew Castle	Kim Hanson	Alisa McFarland	Tom Sanders	Ernest Talarico Jr.
Abraham Cavazos	Carol Haukos	Linda Meier	Santa Croce	Dorothy Torsen
Mary Clement	James Hay	Bob Michaels	Family	Van Schoick
Joe Coffey	Jeffrey Helman	Bill Moore	Donald	James Vingo
Tiffinay Compiano	Eric Herrera	Joan Mork	Santa Croce	Team Vinny
Joseph Cox	Krista Humes	Juanita Morrison	Schnobrich Family	Jeannette Viveiros
Richard Cox	Jacob Family	Theresa	Lenore Schultz	Barry Washburn
Russell Crystal	Lisa Jaffe	Morrisette	Ed Schwartz	Josie Wasney
Chaos Cup	Carolyn Johnson	Keri Naccarato	Derek Semler	David Westrick
Therese Curto	Marjorie Kadue	Sam Naccarato	Cheryl Serge	Anna Widing
Pamela D`Ermilio	Christian Kahl	Jessica Oberlin	Jackie Shears	Mike Williams
Gordon Davis	Mac Kelso	Steve Ofenstein	Mike Shears	Mary Wlodarski
Kennon Davis	Marty Keniley	Blanch Paluso	Steve Shears	Roy Yamamoto
Page Davis	Wayne Kist	Paula Partilla	Cara Shier	Allan Yousten
John Demarie	Donna Klotz	Asa Peabody	Carra Shier	Dr. Allan Yousten
DeMint Family	Jamie Kozieracki	Bridget Peck	Dana Simpson	Curt Zamec
Charlotte Depew	Sandy Lamaack	Erin Peterson	Dr. James Skok	Gary Zweig





Individuals with SCA6 and SCA8 are Needed to Participate in Research Studying Ataxic Movements at the Kennedy Krieger Institute

Participation will involve 2-4 hours of behavioral testing and a neurological exam, with multiple visits to our lab possible.

Behavioral testing may involve having small sticky markers placed on your arms and legs so that a computer can detect your movement as you stand, balance or walk on a treadmill.

It may also involve reaching with your arms while sitting at our KinArm robot.

We may also ask you to do non-invasive, very low intensity brain stimulation.

Through our studies we hope to gain a better understanding of why cerebellar disease makes movements ataxic and whether different behavioral therapies can help rehabilitate ataxia symptoms.

There are no significant risks associated with our studies. Participants will be paid \$20 per hour of study time and lunch will be provided.

Contact **The Center for Movement Studies**
by email at ataxiastudies@kennedykrieger.org
for more information.

Principle Investigator: Amy J. Bastian, PhD
Kennedy Krieger Institute

Funded by the National Institutes of Health
JHM IRB Application #: NA_00043851

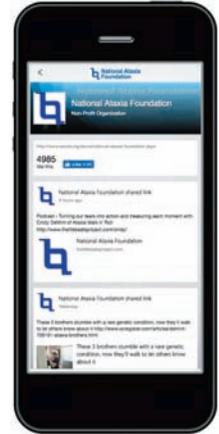
Connect and engage with the ataxia community through the new National Ataxia Foundation App!



<http://tinyurl.com/NAF-Google-App>



<http://tinyurl.com/NAF-Itunes-App>



Desktop version – ataxia.echurchapps.com/#!section=14600426

GIFT – HONOR – MEMORIAL

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

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

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

My contribution is:

- In Memory In Honor Gift Membership

Name _____

Occasion _____

Send Acknowledgment Card to:

Name _____

Address _____

City/State/Zip _____

From:

Name _____

Address _____

City/State/Zip _____

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

MEMBERSHIP

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

- Lifetime membership – \$500

Annual Memberships:

- Patron membership – \$100-\$499
 Professional membership – \$65
 Individual – \$40 Household – \$60
 Addresses outside the U.S. please add \$15

Recurring Gift Membership Program:

If you wish to contribute monthly or quarterly, please consider the Recurring Gift Membership Program.

For more information contact the NAF office or visit www.ataxia.org/giving/default.aspx.

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 NAF.

Total Amount Enclosed \$ _____

Card: Visa MasterCard Discover AMEX

Name on Card _____

Card # _____

Exp. Date _____ CVV # _____

Signature _____

Phone Number _____



National Ataxia Foundation
 2600 Fernbrook Lane, Suite 119
 Minneapolis, MN 55447-4752
 (763) 553-0020

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Join CoRDS

You hold a piece
of the puzzle.



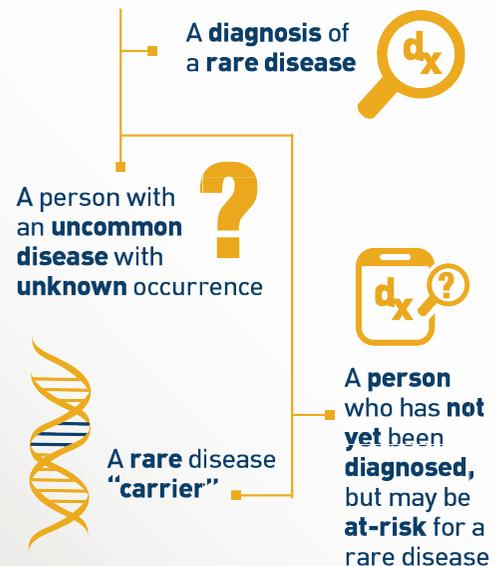
You can help researchers see the whole picture. Play a vital role in finding cures and improving treatments by joining the Coordination of Rare Diseases at Sanford (CoRDS).

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

SANFORD
 RESEARCH

How to join NAF's CoRDS Registry

 **ANY PATIENT WITH THE FOLLOWING CAN ENROLL:**



YOU CAN REMOVE YOUR INFORMATION FROM THE REGISTRY AT ANY TIME.

 **Enroll now at**
sanfordresearch.org/CoRDS
 by selecting **Enroll Now**.