

Generations

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The National Ataxia Foundation 55th Annual Membership Meeting

“Roundin’ Up a Cure to Give Ataxia the Boot”

San Antonio, TX – March 16-18, 2012

By Lori Shogren, National Ataxia Foundation Special Projects Coordinator

The National Ataxia Foundation (NAF) Board of Directors and the National Ataxia Foundation Texas Ataxia Support Groups would like to invite you to the 55th Annual Membership Meeting. Please join us at the Grand Hyatt San Antonio Hotel in San Antonio to learn, share, network, have fun, and enjoy the sites. The annual meeting will also celebrate NAF’s 55th anniversary in serving ataxia families.

The 2012 NAF Annual Membership Meeting will bring together NAF members and their families to meet and learn from world-leading ataxia researchers and clinicians, but also to build new friendships and reunite with old friends.

The Annual Membership Meeting Registration Form is on pages 26-28 of this issue of *Generations*. You can also find the forms and the latest information available about the Annual Membership Meeting on NAF’s website at www.ataxia.org.


The Annual Membership Meeting Program you receive at the conference will be the most updated conference schedule. Please use your Meeting Program for meeting room assignments and times. Due to unforeseen circumstances the meeting schedule may change. We apologize in advance if that occurs. Any changes will be posted in the Registration Room and announced at the meeting. For that reason we encourage attendees to plan to attend the entire meeting to ensure that you will not miss a presentation.

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- Three **research opportunities** are detailed on page 19
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The deadline for the Spring issue of Generations is March 2, 2012.

**Happy New Year
from everyone at the NAF Office!**

Julie Braun, Sue Hagen, Mike Parent, Lori Shogren, Jan Stewart and Liz Werner

2012 Annual Membership Meeting
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Program Overview

Thursday, March 15

Registration Room Open – 9 a.m. to 8 p.m. Pick-up your conference program, name badge, Saturday banquet tickets, welcome bag, conference T-shirt, and check-in your Silent Auction items. The Registration Room will be open Thursday through Sunday morning.

Exhibitors – 10 a.m. to 8 p.m. Exhibitors will be present from Thursday through Sunday morning as their schedules permit. If you would like to recommend an exhibitor or if you are interested in exhibiting please contact Liz at liz@ataxia.org.

Leadership Meeting – 1 to 3 p.m. This meeting is designed to provide information and support to 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 a leader who is unable to attend the meeting, please indicate one representative who will attend in your place. If you are interested in becoming a NAF Support Group Leader or Ambassador, contact Lori at lori@ataxia.org prior to the meeting.

Fundraising Meeting – 4 to 5 p.m. This meeting is for anyone who is interested in learning more about fundraising to support NAF.

NEW AIM Poster Session – 5:15 to 6:15 p.m. This new session is an opportunity for you to view the posters presented at the fourth NAF Ataxia Investigators Meeting. Poster presenters will be present to answer questions about their posters and research projects in what should be an informative and interactive session.

Friday, March 16

General Sessions – 8:30 a.m. to noon. Friday morning will start the General Sessions in the Lone Star Ballroom. Many of the world's leading ataxia researchers and clinicians, along with other

ataxia experts, will be presenting the latest ataxia research. The sessions will incorporate practical aspects in addition to research and medical topics. A 30-minute Question and Answer session will follow with a panel of the morning speakers.

Activity Room – An opportunity to observe and play the Nintendo Wii game system will be available Friday and Saturday from 10 a.m. to 2 p.m. The Nintendo Wii system is being used by individuals with limited movement abilities who want to stay active. The activity room is open to all ages. Persons under the age of 12 must be accompanied by a parent or guardian who is age 18 or older. Temporary NAF tattoos will be available in the activity room. Volunteers will be on hand to help apply tattoos as needed.

Birds of a Feather (BOF) – 2 to 5 p.m. Attendees will meet in small group sessions by their type of ataxia or role (i.e. caregiver, spouse, or parent). This is a tremendous opportunity to meet others who share a similar situation or the same ataxia diagnosis. Medical professionals will be circulating between groups and available for questions. *Please indicate on your registration form which BOF session you will attend.*

Southwest Welcome Reception – 7 p.m. Please join us for a "Southwest Style" reception in the Lone Star Ballroom. All registered meeting attendees are welcome to attend. Admittance and food provided at this event is included with your registration. Snacks will be served (not a meal). A cash bar will be available. Attendees are encouraged to wear cowboy attire.

Saturday, March 17

General Sessions – General Sessions continue all day in the Lone Star Ballroom. A 30-minute Question and Answer session will follow the morning and afternoon General Sessions with a panel of the speakers who presented.

Church Services – 6 p.m. Catholic and Non-denominational church services will be held on Saturday for those who wish to attend.

2012 Annual Membership Meeting
Continued from page 3

Silent Auction – The Silent Auction is a fun way to help raise funds for NAF and for you to bid on wonderful items. This long-standing NAF tradition begins on Saturday afternoon with the final bidding ending at a **new time – 7 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.**

Saturday Evening St. Patrick's Day Banquet – 7 p.m. The banquet will be held in the Lone Star Ballroom. Please get your tickets – which are included in your registration fee – ahead of time in the Registration Room. All beverages will be available at a cash bar. **You must reserve seating and select an entrée choice for the banquet in advance.** The banquet will include a plated dinner with your choice of BBQ seasoned chicken or vegetarian/vegan entrée that you select on your conference registration form. All entrée choices are gluten free. Please verify your entrée selection when you obtain your banquet tickets and select your seating. Attendees are encouraged to wear green.

Sunday, March 18

General Sessions – 8:30 a.m. to 1 p.m. Sunday morning wraps-up the 2012 Annual Membership Meeting with the final round of General Sessions in the Lone Star Ballroom followed by a Question and Answer session with a panel of the speakers who presented during this time.

Additional Information

Conference Registration – Please complete the registration forms and return them to NAF by Feb. 15, 2012. Registration will also be available on the NAF website (www.ataxia.org). Please fill out the registration form completely, as we need all the information to finalize plans. There will be an additional charge for registrations received

after Feb. 15, 2012. **Registration after March 1, 2012 will only be accepted on-site at the conference.** If you are bringing an attendant, please register together on the same form. Each person that is planning on attending daily sessions, the reception, or banquet needs to register. Event entry will not be allowed without proper registration indicated by your name badge.

Registration Fees – Being a member of the National Ataxia Foundation has its benefits – one being a lower registration fee for the Annual Membership Meetings. If you are not currently a member of the Foundation or if your membership renewal is coming soon or if you are uncertain of your membership status, please call the office at (763) 553-0020 or go online at www.ataxia.org to become a member or renew your membership. This will prevent unnecessary extra fees or errors in your membership status when you register for the meeting. Thank you for taking the time to renew or become a member of the National Ataxia Foundation.

Contact Cards – You are welcome to bring contact cards with your name and additional information for exchanging with other attendees during the conference. This will help you stay connected to new friends throughout and after the conference.

Tribute Roses – Stop by the Yellow Rose Table in the NAF Registration Room to purchase a yellow rose in honor or memory of a friend, a caregiver, support group, someone you want to remember, anyone special in your life, or even yourself. Cost is \$5 per flower. Look for your flower on Saturday evening at the Banquet. Proceeds go to support the 2012 NAF AMM.

Video Taping – Video taping of the General Sessions and Birds of a Feather Sessions is prohibited without prior written consent from the National Ataxia Foundation.

Image Waiver – By attending the 2012 NAF Annual Membership Meeting, you give your consent, unless you notify us otherwise in writing, 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 website, and you waive any and all rights to these images.

Fragrance Free – For the comfort of our attendees we ask that all participants refrain from wearing perfume, cologne and other fragrances, and use unscented personal care products in order to promote a fragrance-free environment.

About San Antonio

For more information about San Antonio visit www.visitsanantonio.com.

Morgan's Wonderland – An accessible family fun park with 25 acres of rides, attractions, and activities located northeast of downtown San Antonio. More information can be found at www.morganswonderland.com.

About the Grand Hyatt San Antonio

The Grand Hyatt San Antonio is the official conference hotel of the 2012 NAF Annual Membership Meeting. 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.

Guest rooms include 32" flat panel TVs and complimentary Wi-Fi high-speed Internet access for NAF guests. **The width of the bathroom door in the standard sleeping rooms is 35"**. Please visit the Grand Hyatt San Antonio website for more information at <http://grandsanantonio.hyatt.com/hyatt/hotels/>.

Room Reservations – The National Ataxia Foundation's special group rate for rooms is \$139 per night. Please be sure to make your reservations early in order to secure the special group rate. **Some nights in the NAF room block are currently sold out. Be sure to search the nights individually and book the ones that are available when booking either online or with a reservationist by phone. Cancellations may occur. Keep checking**

the reservation website for availability. To check room availability online go to <https://resweb.passkey.com/go/NationalAtaxia>. If you would prefer to make your reservation by phone, please call 1-888-421-1442 or (210) 224-1234 and **ask for the National Ataxia Foundation Conference special rate.**

To inquire about the availability of an ADA room at the Grand Hyatt San Antonio Hotel you MUST contact Lori Shogren at the National Ataxia Foundation office at (763) 553-0020 or lori@ataxia.org.

If you need ADA equipment be sure to note that when making your room reservation. Shower chairs, tub bars, toilet frames, and detachable shower heads will be available on a first-come, first-serve basis by contacting the Grand Hyatt Front Desk upon check-in.

The National Ataxia Foundation has an additional group block at the Hilton Palacio del Rio. The Hilton Palacio del Rio is a short distance from the Grand Hyatt. The National Ataxia Foundation's special rate at the Hilton Palacio del Rio is \$189 per night. To inquire about a room reservation at the Hilton Palacio del Rio please contact Lori at the NAF office at (763) 553-0020 or lori@ataxia.org.

The Grand Hyatt San Antonio is within walking distance to other hotels. If you are unable to reserve a guest room at the Grand Hyatt you may wish to contact a reservations manager at the other hotels nearby. Some nearby hotels include Best Western Sunset Suites Riverwalk, Comfort Suites Alamo/Riverwalk, Emily Morgan Hotel, Fairfield Inn & Suites San Antonio Downtown/Alamo Plaza, Hampton Inn San Antonio Downtown, La Quinta Inn & Suites Convention Center, Marriott Rivercenter, Marriott Riverwalk, Red Roof Inn Downtown, Residence Inn Alamo Plaza, Springhill Suites San Antonio Downtown/Alamo Plaza.

Parking – The Grand Hyatt San Antonio has

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extended a discounted parking rate of \$10 per day for our conference attendees for self-parking and overnight attendees. The NAF does have a group rate for valet parking which is \$33 per day for overnight guests or day parking which is up to 10 hours for \$9. 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.

Transportation and Getting There

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

Travel Tips from the Transportation Security Administration (TSA) Contact Center – TSA encourages passengers with disability and health-related needs to contact the TSA Customer Support Manager (CSM) at their departure airport prior to travel. CSMs may be able to facilitate the screening process and make arrangements for passengers traveling with special items. CSMs may be contacted via the Talk to TSA section of the TSA website at <https://apps.tsa.dhs.gov/talktotsa/>. It is recommended that passengers contact their airport CSM at least 24 hours before traveling and inform them of the items they will be transporting or the assistance they will need.

To assist passengers further, TSA has created notification cards that travelers may use to inform Transportation Security Officers (TSOs) about any disability, medical condition, or medical device that could affect security screening. Although these cards do not exempt anyone from security screening, their use may improve communication and help travelers discreetly notify TSOs of their conditions. Notification cards are available for download at disability-related Web sites such as www.disability.gov by entering Notification Cards in the sites Search field.

Passengers requiring any in-flight assistance should contact their airline before traveling.

More information can be found on NAF's website at www.ataxia.org, select the "Links" tab at the top of the homepage. 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. You may also want to visit the website of the San Antonio International Airport which is www.sanantonio.gov/Aviation.

GO Airport Express Shuttle – NAF has a group rate with GO Airport Express Shuttle of \$17 one-way and \$30 round-trip per person. Regular scheduled shuttle service runs from the San Antonio International Airport to the downtown hotels from 7 a.m. to 1:30 a.m. daily. To make a reservation go to <http://saairportshuttle.hudsonltd.net/res?USERIDENTRY=NAF&LOGON=GO>. Or you can purchase a ticket at the baggage claim area in Terminal A and Terminal B when you arrive. Select Hyatt-Grand (not Hyatt-Riverwalk) if you are staying at the conference hotel. ADA-compliant vehicles are available by request. To make this request you will need to type in "ADA required" in the comments section provided on the reservation website. Shuttles depart from downtown hotels beginning at 4 a.m., approximately every 15 minutes, reservation required. For more information, visit goairportshuttle.com or call (210) 281-9900.

Taxis – From SAT Airport: Taxis are available at the lower level curbside, outside of baggage claim, at Terminal A and B. For assistance, please contact the Airport Ground Transportation Agent wearing an airport badge. Fare to San Antonio downtown areas are approximately \$25 to \$29 per taxicab. For a list of taxi cab companies visit www.sanantonio.gov/Aviation/taxicabs.asp. San Antonio Wheelchair Taxi: (210) 260-6740 or sanantoniowheelchairtaxi.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 and B, clearly marked. You will catch VIA bus route 5, which operates every day, and can get downtown in about 30 minutes for \$1.10. Once in the downtown area, 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 \$4 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 www.viainfo.net/AccessibleService/AccessibleServiceMain.aspx.

Paratransit Services – Paratransit services are provided on a space-available basis. Funding for the program is provided by the Texas Department of Aging and Disability Services (DADS) through the Area Council of Governments (AACOG) and the City of San Antonio. The service is free, however, donations are encouraged. Operating Hours: 6 a.m. to 6 p.m., Monday-Friday, except city holidays. Reservations are taken during office hours: 7:45 a.m. to 4:30 p.m., Monday-Friday. Please call the reservation hotline at (210) 207-6680.

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 please visit www.sanantonio.gov/Aviation/carrentals.asp.

San Antonio Area Services and Resources

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

Accessible Van Services

Premier Accessible Van Rental

1-866-755-VANS or www.premiervanrental.com/whyrent.php

ALAMO Mobility, Inc.

1-888-442-5266, (210) 697-8884 or www.alamomobility.com/rental/index.htm

AMS Vans

1-866-459-6066, (281) 220-6720 or www.accessiblevanss.com/wheelchair-van-rentals.php

AA Vans

1-888-880-8267 or www.aavans.com/Vehicles/RentHandicapVans

Wheelchair/Scooter Rentals and Repair

Tom's Wheelchair Rental

(210) 223-7878 or www.tomswheelchairs.com

Ability Scooter

(210) 315-8242 or www.abilityscooters.com/wheelchair-rental.html

Scootaround

1-888-441-7575 or www.scootaround.com

Personal Care Attendants

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

The Attendant Network

www.dars.state.tx.us/services/personalattendants.shtml

Pharmacy Options

CVS Pharmacy

www.cvs.com

Walgreens

www.walgreens.com



Research Grant Award

Efficacy of Varenicline (Chantix®) in Treating Spinocerebellar Ataxia Type 3 (SCA3)

Theresa A. Zesiewicz, MD

University of South Florida, Tampa, FL

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

Spinocerebellar ataxia type 3 (SCA3), also known as Machado-Joseph disease, is a neurological condition characterized by progressive decline in coordination and balance during movement. Other associated symptoms include difficulties in speaking, dystonia, spasticity, rigidity, tremor, double vision, and sleep disturbances. Although much has been identified with respect to the gene responsible for SCA3, there are currently no FDA-approved treatments for this family of movement disorders. However, our research at the University of South Florida Ataxia Research Center yielded a promising discovery in the treatment of SCA3 using the smoking cessation medication varenicline (Chantix®). Twenty patients with genetically confirmed SCA 3 (mean age = 51 ± 10.98 years; mean disease duration = 14 ± 9.82 years; mean SARA score = 16.13 ± 4.67) were enrolled in the study, which was conducted at the University of South Florida in Tampa, UCLA, California under the direction of Dr. Susan Perlman, and at Beth Israel Deaconess Hospital in Boston, under the direction of Dr. Penny Greenstein. The patients were randomly assigned to receive either placebo or varenicline for eight weeks. We measured the changes in symptoms of ataxia by using a standardized method of rating and assessment, called the Scale for the Rating and Assessment of Ataxia (SARA). Other clinical assessments used through-



Dr. Theresa A. Zesiewicz

out the study included measurement of balance and coordination, changes in mood and anxiety, and side effects. Following eight weeks of varenicline treatment, mean SARA scores at the end of the study were compared to those at baseline, before beginning treatment. Patients taking varenicline were observed to have significant improvements in the assessments for gait, coordination, and balance compared to patients who took placebo. Varenicline appeared to improve “axial” function, compared to “appendicular” function. It was well-tolerated throughout the study, with the most common side effect associated with varenicline being nausea, and depression actually improved during the study. However, one patient with severe ataxia developed walking impairment during the study, and had to discontinue the treatment. Overall, this study provided the

first clinical evidence for the efficacy of varenicline, or drugs acting on the nicotinic system, in treating patients with genetically confirmed SCA3. Future clinical studies will provide patients and clinicians with a better perspective of its use and other nicotinic agents in a larger group of individuals with SCA3, as well as other types of spinocerebellar ataxia. We want to thank NAF, Bob Allison Ataxia Research Center (BAARC), Dr. Harry Orr, Dr. Chris Gomez, Sue Hagen, Mike Parent, and Ms. Nancy Schneid of Tampa, Florida, for their support for ataxia research. ❖

The National Ataxia Foundation Sponsors Important Symposium on Childhood Ataxia

The Neurobiology of Disease in Children (NDC) is a symposium that has been held each year since 2001 just prior to the Child Neurology Society's annual meeting. The focus of NDC is to address clinical features, molecular mechanisms, controversies, unanswered questions and future directions of a neurological disease that affects children.

This year's symposium was titled "Childhood Ataxia" and the National Ataxia Foundation supported this important conference, which was attended by over 300 pediatric neurologists. The day-long symposium began with an overview of childhood ataxias and continued with sessions that covered genetics, clinical trials, and dilemmas in diagnosis. The symposium ended with a panel discussion on the future direction of childhood ataxia research and clinical care.

The National Ataxia Foundation was honored to provide a PowerPoint presentation on childhood ataxia and information about the Foundation during the symposium luncheon. A video, produced by NAF, was also shown about a family affected by ataxia. After the video, the mother who was featured in the film spoke on the impact of ataxia on her child, family and the need for continued research.

An important goal of the symposium is to bring junior investigators into the field. Twenty-one young investigators were invited to attend this meeting, eight of whom were nominated by the National Ataxia Foundation because of their research work and clinical careers in the field of ataxia.

Each of these investigators shared the value of attending this symposium:

**Dong-Hui Chen,
MD, PhD**

*Research Assistant Professor
Department of Neurology,
University of Washington,
Seattle, WA*



"Attending the NDC Symposium on Childhood Ataxia provided a valuable opportunity for me to learn the most current information about some common ataxias in childhood represented by Friedreich's ataxia including clinical evaluation and research in pathogenesis. Although my research focus is autosomal dominant spinocerebellar ataxia 14, mainly an adult-onset ataxia, the knowledge in Friedreich's ataxia as a well-studied disease can be used as a reference in the investigation of the ataxia diseases that I am studying. Learning from each of the presentations in the symposium, I became more affirmed that there is some common pathogenesis among the different forms of ataxia.

The NDC committee and NAF also organized several satellite meetings for our young investigators to meet the colleagues in the ataxia field and exchange updated information. I can foresee opportunities of collaboration with these researchers. We had a great time interacting with the senior researchers. I not only learned their insights in scientific research, but also the enormous encouragement for our engagement in ataxia research from these senior researchers and the meeting in general. I want to thank the NDC meeting and the sponsorship from NAF for the

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Symposium on Childhood Ataxia...
Continued from page 9

great time we all had during the meeting and beyond. Expanding my academic network and exploring multidisciplinary research will benefit my career development in research.”

Abigail E. Collins, MD

*Assistant Professor of
Pediatrics and Neurology*

*The University of Colorado
Health and Science Center,
Children's Hospital
Colorado*



“I was extraordinarily pleased to have been nominated and selected for a National Ataxia Foundation grant to attend the Neurobiology of Disease Symposium on Childhood Ataxia. Because I evaluate and manage pediatric ataxia patients in my Complex Movement Disorders Clinic weekly, the topic of the symposium was very relevant for my every day practice. What I found particularly useful was the opportunity to ask experts in the field about their approaches to the ataxia evaluation, and receive guidance from these same experts about how to move from the realm of being primarily a clinician to becoming a clinical researcher in ataxia. Finally, I enjoyed meeting other young researchers and learning about their work, with the hope that these connections will enable potential future collaborations as we move forward in our careers.”

CFC Number

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

This program provides a convenient way to donate to the Foundation, and provides great benefit to those with ataxia. Please give as generously as you can.

Xiaofei Du, MD

Research Associate

*Department of Neurology,
The University of Chicago,
Chicago, IL*



“It was my honor to attend this meeting. I believe that this meeting opened my mind to the different aspects of ataxia research and helped me keep in touch with the most advanced research in the field. This meeting established a wonderful bridge from bed to bench, which will give me more guidance in doing the basic research.”

Isabelle Iltis, PhD

Research Assistant Professor

Center for Magnetic Resonance Research, Department of Radiology, University of Minnesota, Minneapolis, MN



“As a researcher it was great because it gave me the opportunity to really grasp the clinical, but also the ethical and human considerations that are involved when working with patients with ataxia and their families. It was a great motivator and reminder of who I ultimately work for (the patients). It was also an incredible place of exchange with fellow ataxia researchers and clinicians.”

Sheng Han Kuo, MD

Movement Disorders Fellow

Columbia University, New York, NY



“It was a great honor for me to be nominated as a Young Investigator for the Neurobiology of Disease in Children Conference in Savannah, GA. I was able to meet with all the experts in the ataxia fields, which encouraged me to continue to ►►

develop my research and clinical interests in ataxia. More importantly, I discussed my research with many scientists specializing in the cerebellar system and explored the potential collaboration among several institutions. I was also fortunate to meet with several patients during the meeting and to hear their stories about living with ataxia. It was an amazing experience and it helped me to better understand ataxia research as well as improve my care for the ataxia patients.”

Sarah Ying, MD

*Assistant Professor of
Radiology, Neurology,
Ophthalmology*

*Johns Hopkins University
School of Medicine,
Baltimore, MD*



“This was a rare chance for a junior faculty member to hear from the thought leaders in the field. Not only do these meetings provide new insights, but they also set the stage to establish the necessary collaborations with more mature research groups to bring these new directions to fruition. Without the support of the NAF and the NDC, this would not have been possible for someone at my level. My only hope is that this will bring us all one step closer to better understanding and treatment of ataxia.”

Guangbin Xia, MD, PhD

Assistant Professor

*Department of Neurology,
University of Florida,
Gainesville, FL*



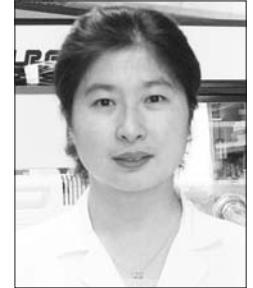
“Thank you to NAF and Dr. Maria, who made it possible for Young Investigators to meet in Savannah. The symposium provided a platform for us to know the current neurobiology in childhood ataxia. It was also a great opportunity for us to meet the national and international experts in ataxia. I hope we can all

meet again in San Antonio at the Ataxia Investigators Meeting to report our progress.”

Keyi Zhu, MD, PhD

Postdoctoral Associate

*Department of Molecular
and Human Genetics,
Baylor College of Medicine,
Houston, TX*



“I am a junior investigator in the field of spinocerebellar ataxia (SCA) at Baylor College of Medicine. The focus of my research is to explore common pathogenic mechanisms among ataxias, in particular SCA1, 2 and 7 using genome-wide genetic screens in *Drosophila*. As of today, there are no cures for SCAs. I believe that this project will lead to the identification of therapeutic targets to better treat ataxia patients including affected children.

I recently received generous support from NAF to attend the symposium on Childhood Ataxia held in Savannah. It is the first ataxia conference I have attended, and I am grateful for having this great opportunity to meet experts in the field and learn the most updated research findings of ataxic disorders. One of the touching moments during the symposium was watching videos of affected children and their families. I was shocked by the rapid disease progression in children. I could feel the pain and despair of their families when they knew that almost nothing could be done to save their children. I also realized that it is very important to spread the awareness of the SCAs and other ataxias widely by educating people who take care of the ataxia patients. Therefore, caregivers will understand the patients’ needs in advance and provide better help to them.

There is a desperate need to identify effective treatments by revealing the pathogenic mechanisms of different types of SCAs. I am confident that my research project involving three SCAs (SCA1, 2 and 7) will provide global and novel insights into the pathogenesis of SCAs and accelerate the discovery of therapeutic targets.”❖

Celebrating International Ataxia Awareness Day

The National Ataxia Foundation (NAF) would like to thank all of the individuals and ataxia support groups who organized events and activities to recognize International Ataxia Awareness Day (IAAD) on Sept. 25. Through Walk n' Roll events, golf outings, information tables, and outreach activities, individuals throughout the U.S. and beyond raised awareness about ataxia and funds for the important work of the National Ataxia Foundation.

Northern California Ataxia Support Group 2011 Walk n' Roll

By Joanne Loveland

This was our third year to gather at Bayland's Park in Sunnyvale, CA to enjoy being outdoors and raise donations for research grants. Research scientists around the world are working diligently to discover a way to arrest ataxia and many central nervous system disorders. Every dollar that goes into research gets us that much closer to finding a cure.

Thank you to everyone who attended. We were honored to have Dr. Gail Kang, a neurologist from UCSF; Jaime Fong, a genetic counselor from USCF; and James Huo from Beijing, China, as special guests. James has ataxia. He and his neurologist have founded China Ataxia Association to help people in China with ataxia. The association is just one year old. He is reaching out to NAF for ideas and direction.

Tim Fritts was our talented MC again. Announcing the activities, the raffle items, the gift baskets, and all the winners kept Tim (and his great voice) busy. Jenny DeRuntz (an aerobics teacher) got us all bending, breathing and stretching before everyone took off for the Walk n' Roll.

Our food, paper goods and the decorated tables were all from Shirley Hanks. Two years ago her sister, Sharon Baggett, passed away after 11 years with ataxia. Sharon's family contributed generously last year and this year to our event. Shirley wants to honor her sister by helping to buy what is not donated.

We also received donations from Noah's Bagels, Starbuck's as well as muffins and donuts and fresh fruit donated by participants. Thanks to all of you and to the Baggett family.



The Northern California Ataxia Support Group raised \$6,400 for ataxia research at their 2011 Walk n' Roll event.

Finally, I want to thank those of you who donated hours of time before and during IAAD: Shirley and Barry Hanks, Brian Wong, Ralph Sherman, Terry Airaudi, Dawn and Minkz Ngo, Fernando Wu and Carolyn Williams, who got us singing as she played guitar.

And last but not least, thanks to Lori Shogren at NAF. Lori's ideas, support and "can do" attitude kept me going – thank you Lori. Finally, thanks to all of you, your family and friends for generously donating items, money and time to the raffle and silent auction items. Thanks to everyone we raised \$6,400. We are all helping to make a difference! ▶▶

AT&T Pioneers Event

By Travis Ruffin

In conjunction with IAAD, the AT&T Pioneers hosted a silent auction and awareness event at the Nashville, TN, headquarters building on Sept. 25.

Free fresh popcorn, a Nashville Predators dancer, several volunteers, and my smiling face were on hand to help draw the attention of people passing through the lobby at lunchtime. Some of the items auctioned were two AT&T 4G Smartphone's, two specialty cakes, a Middle Tennessee State University football autographed by their head coach, a banner autographed by the Nashville Predators David Legwand, and a hockey stick autographed by the Predators Mike Fisher. We raised \$1,200 at the event.

Seek A Miracle Ataxia Group (SAMAG) IAAD Activities

By Satish Kumar and Sailaja Dayanand

On Sept. 25, SAMAG conducted an International Ataxia Awareness Day (IAAD) event in association with the Lions Club of Charminar, at Lions Bhavan, Secunderabad, Andhra Pradesh, India.

The event began with lighting of the lamp by chief guests for the event Dr. Waseem Gul Lone (ataxia researcher, Kamineni Hospitals); Lion Ravinder Reddy (MJF); Mrs. Sunitha Anand (Lion, MJF); Lion Mir Yousuf Ali (President, Lions Club of Charminar); and Dr. John Thomas (Clinical Psychologist; health and wellness expert and SAMAG Medical Panel Advisor).

Satish Kumar Pabba, SAMAG's chief volunteer, then conducted a session on how the public can help SAMAG and ataxia patients. He explained the different methods to help ataxia patients and how everyone can help spread awareness about ataxia. Satish also spoke about how one can help others in their daily lives.

As a special way to acknowledge the efforts of volunteers, appreciation letters along with mementoes were given to Anandeshi Vinay,

ES.Sai Kiran, ES. Jyotsna, Sailaja Dayanand (NGO Development Manager) Manju, Janardhan, Bapji, Bunny, Maha Lakshmi and Satish Kumar (chief volunteer of SAMAG and IBM Unix Admin Manager). This was followed by dinner, which concluded the IAAD 2011 event.

Atlanta Walk n' Roll

By Lynn Robinette, Greg Rooks, and Dave Zilles

The Atlanta Walk n' Roll for Ataxia was held Sept. 24. Being our first time hosting this event we didn't know what to expect. Our expectations were exceeded and it was a great success! The weather was absolutely beautiful. There were approximately 65 people in attendance and everyone seemed to enjoy themselves.



The Atlanta Walk n' Roll raised more than \$6,900 for ataxia research, with Team Olivia leading the way.

On behalf of the National Ataxia Foundation we thank all of the participants and donors. You all did a fantastic job of fundraising. Our top team was Team Olivia raising \$2,190. Great job Team Olivia! Donations are still open online if you know someone who still wants to contribute. We raised more than \$6,900.

We also thank all the volunteers, Lealan LaRoche for designing our logo, Costco for providing our water and snacks, Sandy Haynes for getting the Costco donation, Atlanta Soundworks and Will Morris for providing the sound system, and Camp Dream for providing art, crafts, and volunteers.

*International Ataxia Awareness Day
Continued from page 13*

Auburn Walk n' Roll

By Dana Mauro

Sept. 18 was a beautiful day for a Walk n' Roll. This year's event was the biggest yet with the most people in attendance. We had representation from three different states: Connecticut, Massachusetts, and New Hampshire. It was a great day with old and new friends alike.



The Auburn Walk n' Roll included representatives from three states.

I would like to acknowledge and thank Bill Darby who made trikes available for people to ride; Team UMass Cognition and Action Lab for raising funds and coming out to walk; all who donated items for the raffle; all who donated their time to help with the event; Finz for coming down and spending time with us; Tony Kapulka for playing our walking tunes and capturing some great photos; Ed and Sharon Murphy for grilling some tasty burgers and hot dogs; Doug Windler for help with the set-up and break down; Denise Kapulka for helping to promote the event and for all her hard work the day of the event registering participants; Eleena Rioux-Olson for taking such terrific photos; Deb Hanna and family for coming down from New Hampshire to walk and to Deb's daughter for spending her birthday with us; and everyone who generously donated to fund ataxia research.

Detroit Walk n' Roll

By Michelle DeCiantis

Our third Annual Detroit Walk n' Roll was a very successful event. We managed to reach out to many people who came for the first time this



Members of the Detroit Area Ataxia Support Group with an award presented by Michigan state senator Virgil Smith.

year. Our walk took place right by the Detroit Riverfront at William G. Milliken State Park and Harbor. We raised around \$3,500 and brought awareness about ataxia to Detroit and the surrounding Metro Areas.

We had a silent auction that featured donated items from many local artists. Dr. John Pispidikis of the Spinal Recovery Center in Warren, MI, sponsored bottled water for the walk and supported other fundraising initiatives for the event. We also received a Special Tribute Award presented by Senator Virgil Smith (State Senator 4th District Detroit).

We were so excited to have the support of many local artists. Ortheia Barnes-Kennerly invited us to appear on her new local television show on WHPR Detroit TV 33. Her show is also broadcast live on the Internet and I had many friends out of state from the NAF Facebook group who watched it. She also performed a few songs for us. Our event was also announced on local Fox 2 Detroit all day Friday, Sept. 23, and placed on their community page on Fox 2 online. Also present at the event was Brian O'Neal (humanitarian, founder of the DO Foundation helping the homeless, and musician for Motown recording artist KEM), who also has his own music label. Brian recorded my story while we were walking and plans to have it ►►

printed in his own magazine. Carlos O'Banion, photographer for the DO Foundation, took pictures during the event.

A great gift was a performance by Khary Kimani Turner, an author, artist, poet, and member of Black Bottom Collective. He performed for us a popular number of his called "L-O-V-E" and then read a poem he wrote about ataxia.

Golf 4 Ataxia

By Vicki Tyler

On Sept. 23 the Middle Tennessee Ataxia Support Group celebrated IAAD with a golf tournament in Franklin, TN. Although it rained in the morning, by our 1 p.m. tee time the sun was out and we had a perfect day for golf. When the golfing began, members of the support group and their friends and family relaxed on a large deck overlooking the golf course. We had plenty of time to share stories, laugh, eat, drink, and enjoy each other's company. We also did some shopping at the silent auction.



The Middle Tennessee Ataxia Support Group's Golf 4 Ataxia event raised more than \$6,000.

In addition to the silent auction, we sold dinner, mulligan, and raffle tickets to win a hockey stick donated by the Nashville Predators and signed by Shea Weber. We also sold "I am the Strength behind Ataxia" IAAD T-shirts.

All in all, with the donations we've received to date, we raised more than \$6,000.

By 6 p.m. we set-up for dinner and we all enjoyed a southern barbecue. Friends and family of the golfers as well as individuals with ataxia

joined us for dinner to show their support. After dinner, prizes were awarded for longest drive, closest to the pin, longest putt, and best team score. In addition, the raffle and silent auction winners were announced. Then the whole group got together for a picture and a short video that we hope to have aired on the weekend Good Morning America's three-word announcement. Ours was entitled "Raising Ataxia Awareness."

Denver's Run, Walk n' Roll Report

By Charlotte DePew

The Greater Denver Ataxia Support Group conducted their Inaugural Run, Walk n' Roll (RWnR) for ataxia awareness and fundraising on Sept. 24 at the beautiful Denver City Park. The event was dedicated to ataxia members who passed: three in the spring of 2011 (Michael Williams, Jessica Jerke, and Robert Winslow) and a fourth (Russell Crystal) in 2009.

To our amazement, the event was more successful than we anticipated in monies raised for research; attendance; membership enthusiasm and participation; and the beautiful sunny warm Colorado weather that morning. Initially we thought we'd be blessed to raise \$7,500. Within two months of establishing our donation web page, we exceeded that goal and then raised it to \$20,000. Thanks to our members and additional donations at the Sept. 24 event, we raised \$25,000 without corporate sponsorship.

Being our first RWnR, we had about 168 runners, walkers, and "rollers." Additionally, about 30 to 40 others attended and we had a surplus of volunteers. Participants came from surrounding states including three from Washington.

Entertainment began with music before the 8 a.m. registration and continued throughout the four-hour event. We had an enthusiastic and experienced DJ/MC with a great sound system who volunteered his equipment and time. A yoga instructor provided a five minute warm-up

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International Ataxia Awareness Day *Continued from page 15*

session before participants ran and walked. Because of the park's flexible routes, participants could select their desired distance up to 5K. Refreshments of bananas, bagels, and water were available after the event as well as booths to visit and a drawing of about 20 donated items from area merchants. Booths included an NAF information table; an honoree table with pictures and bios of each; free massages (two vendors), face painting; Freedom Service Dogs, Inc.; and four more businesses.



Participants stretch out before the start of the inaugural Greater Denver Ataxia Support Group Run, Walk n' Roll event. The event raised more than \$25,000.

The guest speaker was Dr. Abigail Collins, assistant professor of pediatrics and neurology at the school of medicine, University of Colorado, and The Children's Hospital, Aurora, CO. She completed a two-year fellowship in movement disorders at Columbia University Medical Center focusing on ataxias in all ages. Topics in her 10-minute talk included what ataxia is; no cure yet; exponential research progress; NAF's vital research support and role in ataxian's quality of life; and that she may be granted privileges to see adult ataxia patients at University of Colorado's adult Mobility Disorders Clinic.

We thank our membership for their support and enthusiasm. Above all, we owe our first RWNr success to the dedicated and resourceful



The Central Texas Ataxia Support Group raised more than \$6,000 during their third annual Walk n' Roll event.

committee members who would travel distances from Albuquerque, NM to Laramie, WY.

Texas Walk n' Roll

By Linda Crawley

We had a beautiful day for our third Walk n' Roll. We had about 50 people in attendance and even a few four-legged friends joined in. We had our barbecue team, "Boot Scootin' BBQ," who has prepared and served our food for the past three walks. We also had a silent auction and raffle and a booth set up with some beautiful handmade items to be sold.

It was great to once again meet people from all around Texas and to see all the people together for such a wonderful cause. This year we raised more than \$6,000, and we hope to watch the totals grow over the upcoming years!

My family was taken by complete surprise when a friend specially made "Team Joe" T-shirts just for the family of Joe Thell, my son who had SCA 2 and became an angel on Nov. 14, 2008. He is my inspiration.

New Hampshire Ataxia Support Group IAAD Activities

By Jill Porter

In an effort to reach out to the community and raise awareness for IAAD, I distributed the press release in the IAAD Kit on the NAF website. I realized this was a great way to reach the community and that I had the opportunity to have ►►

it placed in the monthly newsletter of my church, Grace Episcopal Church, and other churches where I had connections.

Initially, I sent the editor of our newsletter the link to access the IAAD Kit. The editor was able to use the press release, adding my husband Kenneth's name and his symptoms where appropriate. We spoke on Sept. 25 during our church services and explained the need to raise awareness about ataxia. We inserted the IAAD bookmarks into our church's Sunday bulletin as well. Our Reverend designated the discretionary collection on IAAD for ataxia on behalf of Kenneth. The discretionary fund supports the immediate needs of our parish and Manchester community as well as organizations like the National Ataxia Foundation.

Seattle Walk n' Roll Event

By Milly Lewendon

The Seattle Ataxia Support Group held its third annual Walk n' Roll event on Sept. 17. Our walk was held at Alki Beach – a beautiful site located right on Puget Sound with views of ferries and freighters going by. We had more than 75 participants and volunteers and raised approximately \$5,500. This was more than last year and considering today's economy we are so pleased with the results. As in the past a portion of our fundraising efforts were designated to travel grants for individuals with ataxia to attend the NAF Annual Membership Meeting.

Thanks are due to those volunteers who made this event a success again this year. The walk started off with our banner carriers Cooper Brandt (age 12) and Indivar Falk (age 10). We had participants from Bellingham and Spokane, as well as Cornwall, England and Portland, Oregon. Registration and set-up was done by Jori Acacio, Lila Brandt, Phoebe Falk, Bobbie Healy, and Mike Healy. First Baptist Church of Kirkland participants and volunteers included Pastors Vince Armfield and Eric Malone. One of the highlights of this year's walk was the "chowder stop" provided by Duke's Chowder



Members of the Seattle Area Ataxia Support Group pose for a photo during their IAAD activities, which raised over \$5,000.

House. Greg Green, manager of the West Seattle Duke's served up chowder to the walk participants. Duke Moscrip, owner of the restaurant chain, was on hand to greet the participants as well.

The West Seattle Blog provided excellent media coverage by sending a reporter down to take pictures and interview participants.

All in all a fun day, and the most important part is that we were able to raise awareness about ataxia.

San Diego Walk n' Roll for Ataxia

By Earl McLaughlin

The San Diego Ataxia Support Group celebrated International Ataxia Awareness Day by holding the Fifth Annual Charley McLaughlin Walk n' Roll for Ataxia. The Walk n' Roll took place on the bay-front in beautiful downtown San Diego.

Despite the cool weather, 250 walkers and rollers helped raise awareness of ataxia, and nearly \$25,000 for ataxia research.

Walk n' Roll – San Diego was named in memory of Charley McLaughlin who passed away from complications of Friedreich's Ataxia in 2007. This year's honoree was Barbara Doogan, a member of the support group.

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International Ataxia Awareness Day
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Many thanks to the more than 75 volunteers working at the event. The Planning Committee members were Ann Foster, Joan Hay, Jane Jaffe, Larry Jaffe, Lisa Jaffe, Earl McLaughlin, Jeff Smith, Karen Smith, Walter Wallenborn, Harold Ward, Pat Ward, June Wood, and Roger Wood.

The Sixth Annual Charley McLaughlin Walk n' Roll for Ataxia will be held on Saturday, Sept. 29, 2012.



The second annual Minnesota Walk n' Roll for Ataxia event was held Sept. 17 and raised more than \$36,000. ❖

Research Opportunity for the SCA's

Recruitment continues for additional research participants for a Natural History study. Participants must have a confirmed diagnosis of SCA 1, 2, 3, or 6. Please use the information below to inquire about participation or to contact the research coordinator of the institution nearest to you.

University of California, Los Angeles

UCLA Ataxia Center
Susan Perlman, MD
Los Angeles, CA 90095
Phone: (310) 794-1195
sperlman@ucla.edu

Emory University

Movement Disorders Center

George Wilmot, MD, PhD
Atlanta, GA 30329
Phone: (404) 728-4909
Research Coordinator: Bettye Robinson
bnrobin@emory.edu

University of Utah Dept. of Neurology

Stefan M. Pulst, MD
Salt Lake City, UT 84112
Phone: (801) 585-1077
Research Coordinator: Pattie Figueroa
karlaf@genetics.utah.edu

Columbia University

Sheng-Han Kuo, MD
New York, NY 10032
Phone: (212) 305-5558
sk3295@mail.cumc.columbia.edu

Johns Hopkins Ataxia Center

Sarah Ying, MD

Baltimore, MD 21287

(410) 502-5816

Research Coordinator: Ann Fishman
ataxiaresearch@jhu.edu

University of Minnesota Ataxia Center

Khalaf Bushara, MD
Minneapolis, MN 55455
(612) 625-2350

Research Coordinator: Diane Hutter
hutte019@umn.edu

University of Michigan Medical Center

Henry Paulson, MD, PhD
Ann Arbor, MI 48109-2200
Phone: (734) 232-6247
Research Coordinator: Elizabeth Sullivan
elizsull@umich.edu

Massachusetts General Hospital Ataxia Unit

Jeremy D. Schmahmann, MD
Boston, MA 02114
Tel: (617) 726-3216
Research Coordinator: Jason MacMore
jmacmore@partners.org

USF Parkinson's Disease and Movement Disorders Center

Theresa Zesiewicz, MD, FAAN
Tampa, FL 33606 • (813) 974-5909



Research Coordinator: Kelly Sullivan
kbarber@health.usf.edu

University of Florida
Movement Disorders Center
Tetsuo Ashizawa, MD, FAAN

S.H. Subramony, MD
Gainesville, FL 32610-0236
Phone: (352) 273-9194
Research Coordinator: Becca Beaulieu
becca.beaulieu@neurology.ufl.edu



Ataxia Investigators Meeting (AIM) 2012

The National Ataxia Foundation has hosted an Ataxia Investigators Meeting every two years since the meeting's inception in 2005. World-leading ataxia clinicians and scientists attend these important conferences to help accelerate world-wide ataxia research by advancing the understanding of ataxia disease mechanisms and in facilitating the push towards therapies for this class of diseases.

These meetings create a forum for presenting the latest developments in translational research on ataxia. Senior and junior investigators meet to achieve three primary goals: 1) Identify common disease mechanisms, 2) Explore therapeutic strategies, and 3) Help establish the future

leaders of ataxia research.

The 2012 Ataxia Investigators Meeting (AIM 2012) – “Advancing Toward Therapeutics” – will take place in San Antonio, TX from March 13–16, 2012, just prior to NAF’s Annual Membership Meeting.

Lead organizers for this meeting are Dr. Henry Paulson and Dr. Christopher Gomez. A major emphasis of AIM 2012 will be to highlight junior investigators and encourage them to continue their research efforts in ataxia.

We are grateful for the generous support for AIM 2012. Those supporting organizations will be published in the upcoming Spring issue of *Generations*.



Research Opportunities

SCA 3 Study

The University of South Florida in Tampa has an ongoing study for SCA 3 patients and ambulatory FA patients. The study lasts almost four months and will be testing Intravenous Immunoglobulin.

For more information, please contact Amber Miller at (813) 974 1414 or (813) 974 5909 or email *amiller@health.usf.edu*.

Study Participants Needed

Persons with Spinocerebellar Ataxia types 1, 2, 3, or 6 or Multiple System Atrophy are needed for a magnetic resonance imaging (MRI) study to evaluate the chemistry of the brain in ataxias at the Center of Magnetic Resonance Research at the University of Minnesota, Minneapolis, MN.

Research participants will lie in the scanner

for one-and-one-half hours while listening to the music of their choice. Expenses will be covered. In addition, participants will be reimbursed for their time.

If you are interested in participating or have questions, please call Diane Hutter at (612) 625-2350 or email *hutte019@umn.edu*.

University of Massachusetts Study

The Cognition and Action Laboratory at the University of Massachusetts-Amherst is recruiting individuals with movement disorders and/or neurological damage to the cerebellum.

If you are interested in being contacted by Professor Rebecca Spencer, the director of the lab, to participate in the study, please call Professor Spencer at (413) 545-5987 or email her at *rspencer@psych.umass.edu*.

BOOKS

— ATAXIA RESOURCES —

Evaluation and Management of Ataxic Disorders for Physicians

by Susan Perlman, M.D.

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

Healing Wounded Doctor-Patient Relationships

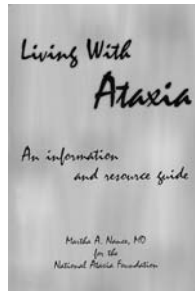
by Linda Hanner with contributions by John J. Witek, M.D. and doctors and patients around the nation

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

Living with Ataxia: An Information and Resource Guide

by Martha Nance, M.D.

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



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

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

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

— FICTION & PERSONAL STORIES —

Summer Born: A Life with Cerebellar Ataxia

By Cheryl Wedesweiler

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

Ten Years to Live

by Henry J. Schut

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

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

by Dave Lewis

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

— COOKBOOKS —

Recipes and Recollections

by Kathryn Hoefler Smith

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

Cooking for a Cause

by Julie Karjalahti for FRDA research

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

Recordings of presentations from the 2011 Annual Membership Meeting are now available to order. Please call (763) 553-0020 for more information.

Merchandise

SHIRTS/MISCELLANEOUS

International Ataxia Awareness Day T-Shirt

Available in youth L, and adult small to XXX-large. \$10

2011 Annual Membership Meeting T-Shirt

Gray, short-sleeved with the "Bringing the Ataxia World Together" logo. Sizes medium to XX-large. \$10

NAF Shoulder Bag

Blue with white NAF logo. 11x15x2 inches. \$10

NAF Polo Shirts

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

NAF Denim Shirt

Denim with white embroidered NAF logo. \$27.50

"Ataxia is Not a Foreign Cab" T-Shirt

White. New design. Sizes small to XXX-large. \$10

"Ataxia is Not a Foreign Cab" Sweatshirt

White. Sizes small to XXX-large. \$20



Window Cling or Bumper Sticker

\$1 ea. or 6 for \$5

NAF Ataxia Awareness Band Blue

One size. \$2

NAF Ataxia Awareness Ribbon Magnet

Blue with white lettering/logo. \$4

Reusable Grocery Bag with NAF Logo

\$5

VIDEO/CD

Ballads of a Family Man CD

10 songs in memory of Billa Ballard. \$5 of purchase price goes to support the work of the NAF. \$13

"Together There is Understanding" VHS or DVD

A discussion of ataxia. 50 minutes. VHS \$20 or DVD \$25

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

ORDER FORM

Description	Qty.	Size	Each	Total

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Shipping within U.S.: Add \$5.00

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Symposium Attendees Have One Thing in Common

By Marcia Kohl, Brainerd, MN

On Oct. 26, I was given the opportunity to accompany Mike Parent, National Ataxia Foundation executive director, and Sue Hagen, NAF patient services director, to gorgeous Savannah, Georgia for a symposium hosted by the Neurobiology of Disease in Children (NDC). This year's topic was "Childhood Ataxia" and the Foundation was a co-sponsor of this very important symposium.

My role was to put a face on ataxia and show the human side of the disease. Although I do not have ataxia, my 13-year-old son and husband have SCA 2. Also, my daughter has a 50 percent chance of getting this horrible disease.

I was honored to have the opportunity to meet so many people who are involved in finding a cure or treatment for ataxia. The progress they have made in research over the past 16 years is

amazing. Someday there will be a cure or treatment, but we all need to do our part. We, as parents and family members may not see, know, or even understand the work being done in ataxia research, but researchers are working hard and getting closer every day.



Marcia Kohl and her son Jordan enjoy a laugh.

While I was at the conference, I realized how important it is for everyone with ataxia to participate in clinical trials. Since ataxia is rare, recruiters have a hard time finding enough people to participate in the trials, so I encourage everyone to register on the National

Ataxia Registry by going to NAF's website at www.ataxia.org and clicking on the "Ataxia Patient Registry" button on the homepage.

Although we all had various roles at the conference, we all had one thing in common; we all want to find a cure or treatment for ataxia. ❖

Macy's 'Shop for a Cause' Recap

By Denise Drake

I recently participated in Macy's Shop for a Cause event at my local mall in Kenner, LA. All the tickets I had available were sold from our table the day of the Macy's Shop for a Cause Event. I purchased some extra myself to give as gifts to family or friends. I've even given them to extremely kind strangers. Often the extra

25 percent discount applies to already marked-down sale purchases. After I finished staffing our table I was able to bargain shop.

The National Ataxia Foundation participated in this charity event since it began nationally. Our Louisiana Chapter did it locally over 15 years ago. It was such a pleasure and a blast for us too. I look forward to next year.

*The National Ataxia Foundation Board of Directors and the
the National Ataxia Foundation Texas Ataxia Support Groups
Cordially Invite You to the 2012 Annual Membership Meeting*

“Roundin’ Up a Cure to Give Ataxia the Boot”

Dates: March 16-18, 2012

Location: Grand Hyatt San Antonio
600 E. Market St.
San Antonio, TX 78205
1-888-421-1442

Registration Fees: Registration includes access to all General Sessions, as well as participation in exhibits, breaks, the Welcome Reception, and the Saturday Evening Banquet.

Individuals eligible for the member rate include current:

- Individual Members (*Individual members may also register their spouse or caregiver for 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

Early Registration Fee (*includes registrations received or postmarked by February 15, 2012*):

- Members: \$95/person
- Non-Members: \$150/person

Registration fee after February 15, 2012 – NOT RECOMMENDED (*includes registrations postmarked after February 15, 2012 and all registrations at the door*):

- Members: \$120/person
- Non-Members: \$175/person

NOTE: The Registration Fees DO NOT include hotel or transportation fees!

Instructions for Registration:

1. Complete the enclosed registration form and mail, with your payment, to the NAF office. **Please fill out the form completely.** The requested information is necessary to complete preparations for the meeting.
2. **Registration Fees.** If you plan to attend either just the conference or just the banquet, the full per person fee will still be charged. If you are bringing your children to the meeting, the following fees will be charged: children two years and under are free; children three years and over will be charged the full meeting fee.
3. Childcare services will not be provided by NAF or its local volunteers.
4. Complete and return both pages of the registration form by February 15, 2012. Please fill out the name portion of the registration exactly 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 February 15, 2012

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: naf@ataxia.org

2012 NAF Annual Membership Meeting Agenda

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

THURSDAY, March 15

Event	Location	Time
NAF Registration	San Jacinto/Goliad	9:00 a.m. - 8:00 p.m.
Exhibitors	Pre-Function A	10:00 a.m. - 8:00 p.m.
Leadership Meeting	Lone Star C	1:00 p.m. - 3:00 p.m.
Fundraising Meeting	Lone Star C	4:00 p.m. - 5:00 p.m.
AIM Poster Session	Lone Star D	5:15 p.m. - 6:15 p.m.

FRIDAY, March 16

Event	Location	Time
NAF Registration	San Jacinto/Goliad	8:00 a.m. - 5:30 p.m.
Exhibitors	Pre-Function A	8:00 a.m. - 5:30 p.m.
General Sessions	Lone Star A-C	8:30 a.m. - Noon
Activity Room	Bowie C	10:00 a.m. - 2:00 p.m.
Lunch	On Your Own	Noon
Birds of a Feather	Various Meeting Rooms	2:00 p.m. - 5:00 p.m.
Southwest Welcome Reception	Lone Star Ballroom	7:00 p.m.

Friday General Sessions

Time	Topic	Speaker
8:30 a.m.	Welcome and Announcements	Camille Daglio, AMM Co-Chair, and TX Support Groups
9:00 a.m.	NAF Update	Michael Parent, NAF Executive Director
9:30 a.m.	Medications and Therapies for Ataxia	Joseph Savitt, MD, PhD
10:00 a.m.	Physiotherapy in Ataxia	Ludger Schöls, MD
10:30 a.m.	Assistive Technology and	Richard Hopkins, MEd, ATP, Program Specialist
	Home and Vehicle Modifications	
11:00 a.m.	Affirming Yourself for Life's Challenges	Janet Edmunson, MEd
11:30 p.m.	Q&A Panel	
12:00 p.m.	LUNCH	

Birds of a Feather

Birds of a Feather (BOF) Informal Groups will meet from **2:00 to 5:00 p.m.** in various meeting rooms. Please check the hall signs for your specific group's location. *Tentative* room assignments are listed below. Paid PCAs are welcome to attend the Birds of a Feather session with their client, but not required unless client requires it. Please welcome the Ataxia Investigators Meeting attendees to your BOF session. They will be present to hear concerns and questions of persons affected by ataxia. They appreciate this valuable opportunity to interact with persons with ataxia, their families, and caregivers.

Session	Location	Facilitator(s)
SCA1	Bonham C Room	Drs. Opal & Orr
SCA2	Bonham D Room	Drs. Oz & Savitt
SCA3	Presidio B Room	Drs. Paulson & Zesiewicz
SCA6	Bowie B Room	Dr. Gomez
All other SCAs	Lone Star E Room	Drs. Ranum & LaSpada
Sporadic/MSA	Lone Star B Room	Drs. Schmahmann & Ashizawa
Over 30 with Friedreich's Ataxia	Lone Star C Room	Dr. Puccio; Drs. Perlman, Lynch & Payne (2-4)
Under 30 with Ataxia	Lone Star F Room	Dr. Ying, Matthew Bower, Dr. Wilmot (3-5)
Unknown/Episodic 1-7/AOA 1 & 2	Lone Star A Room	Drs. Jen & Schut (2-3:30)
Parents (non-Friedreich's)	Bonham E Room	Dr. Subramony, Dr. Wilmot (2-3), Dr. Schut (3:30-5)
Parents (Friedreich's)	Lone Star D Room	David Zilles; Drs. Perlman, Payne & Lynch (4-5)
Spouse/Partners	Bonham B Room	Janet Edmunson (2-3:30)
Siblings	Bonham A Room	Janet Edmunson (3:30-5)

View the latest information available about the Annual Membership Meeting on our Web site, www.ataxia.org.

2012 NAF Annual Membership Meeting Agenda

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

SATURDAY, March 17

Event	Location	Time
NAF Registration	San Jacinto/Goliad	8:00 a.m. - 5:00 p.m.
Exhibitors	Pre-Function A	8:00 a.m. - 5:00 p.m.
General Sessions	Lone Star Ballroom	8:30 a.m. - Noon
Activity Room	Bowie C	10:00 a.m. - 2:00 p.m.
Lunch	On Your Own	Noon
NAF Business Meeting	Lone Star Ballroom	1:45 p.m. - 2:00 p.m.
General Sessions	Lone Star Ballroom	2:00 p.m. - 5:00 p.m.
Silent Auction	Mission A & B	3:00 p.m. - 7:00 p.m.
Catholic Service	Presidio B	6:00 p.m. - 6:45 p.m.
Nondenominational Service	Bowie B	6:00 p.m. - 6:45 p.m.
NAF St. Patrick's Day Banquet	Lone Star Ballroom	7:00 p.m.

Saturday General Sessions

Time	Topic	Speaker
8:30 a.m.	Ataxia Investigators Meeting Review	Henry Paulson, MD, PhD
9:00 a.m.	SCA 1	Puneet Opal, MD, PhD
9:30 a.m.	MJD/SCA3	Patricia Maciel, PhD
10:00 a.m.	Genetics and Family Planning	Matthew Bower, MS, CGS
10:30 a.m.	Stem Cell Research for Ataxia	Helene Puccio, PhD
11:00 a.m.	MRI	Gulin Oz, PhD
11:30 a.m.	Q&A Panel	
Noon	LUNCH	
1:45 p.m.	NAF Business Meeting	Char Danielson, NAF President
2:00 p.m.	Office of Rare Disease Research	Stephen Groft, PharmD
2:30 p.m.	Patient Registry Update	S.H. Subramony, MD
3:00 p.m.	The Heart in Friedreich's Ataxia:	R. Mark Payne, MD
	What Happens and Why Does it Matter	
3:30 p.m.	Occupational Therapy Strategies	Bridgett Piernik-Yoder, PhD, OTR
	in the Management of Ataxia	
4:00 p.m.	Speech and Swallowing	Laura Gregory, MA, CCC-SLP
4:30 p.m.	Q&A Panel	

SUNDAY, March 18

Event	Location	Time
NAF Registration	San Jacinto/Goliad	8:00 a.m. - 11:00 a.m.
Exhibitors	Pre-Function A	8:00 a.m. - Noon
General Sessions	Lone Star Ballroom	9:00 a.m. - 1:00 p.m.

Sunday General Sessions

Time	Topic	Speaker
9:00 a.m.	Financial Planning	Mary Anne Ehlert, CFP
10:00 a.m.	Cognition and Ataxia	Jeremy Schmahmann, MD
10:30 a.m.	Barriers to Treatment	George Wilmot III, MD, PhD
11:00 a.m.	Research Review	Harry Orr, MD, PhD
11:30 a.m.	What We Have Learned	Susan Perlman, MD
Noon	Q&A Panel	
12:30 p.m.	Closing Remarks	Camille Daglio, AMM Co-Chair

View the latest information available about the Annual Membership Meeting on our Web site, www.ataxia.org.

2012 NAF Annual Membership Meeting Registration

1. *Full Name: _____

Name on Badge: _____

*Address: _____

*City/State/Zip: _____

Country: _____ *Phone: _____

E-mail: _____

Adult (18+) Teen/Child (3-17) Infant (2 & under) PCA

Please indicate the Birds of a Feather session you plan to attend:

- SCA1 All other SCAs
 SCA2 Sporadic/MSA
 SCA3 Unknown/Episodic/AOA
 SCA6 Siblings
 Spouses/Partners
 Parents (non-Friedreich's Ataxia)
 Parents (Friedreich's Ataxia)
 Under age 30 with Ataxia
 Over age 30 with Friedreich's Ataxia

2. *Full Name: _____

Name on Badge: _____

*Address: _____

*City/State/Zip: _____

Country: _____ *Phone: _____

E-mail: _____

Adult (18+) Teen/Child (3-17) Infant (2 & under) PCA

Please indicate the Birds of a Feather session you plan to attend:

- SCA1 All other SCAs
 SCA2 Sporadic/MSA
 SCA3 Unknown/Episodic/AOA
 SCA6 Siblings
 Spouses/Partners
 Parents (non-Friedreich's Ataxia)
 Parents (Friedreich's Ataxia)
 Under age 30 with Ataxia
 Over age 30 with Friedreich's Ataxia

3. *Full Name: _____

Name on Badge: _____

*Address: _____

*City/State/Zip: _____

Country: _____ *Phone: _____

E-mail: _____

Adult (18+) Teen/Child (3-17) Infant (2 & under) PCA

Please indicate the Birds of a Feather session you plan to attend:

- SCA1 All other SCAs
 SCA2 Sporadic/MSA
 SCA3 Unknown/Episodic/AOA
 SCA6 Siblings
 Spouses/Partners
 Parents (non-Friedreich's Ataxia)
 Parents (Friedreich's Ataxia)
 Under age 30 with Ataxia
 Over age 30 with Friedreich's Ataxia

4. *Full Name: _____

Name on Badge: _____

*Address: _____

*City/State/Zip: _____

Country: _____ *Phone: _____

E-mail: _____

Adult (18+) Teen/Child (3-17) Infant (2 & under) PCA

Please indicate the Birds of a Feather session you plan to attend:

- SCA1 All other SCAs
 SCA2 Sporadic/MSA
 SCA3 Unknown/Episodic/AOA
 SCA6 Siblings
 Spouses/Partners
 Parents (non-Friedreich's Ataxia)
 Parents (Friedreich's Ataxia)
 Under age 30 with Ataxia
 Over age 30 with Friedreich's Ataxia

2012 NAF Annual Membership Meeting Registration

NAF will send out all pre-registration materials and meeting handouts through e-mail. For those who do not use e-mail, materials will be mailed and hard copy handouts will be provided at the meeting.

Please complete the following table for each person:	#1	#2	#3	#4
1. Is this your first NAF Annual Meeting? Y or N				
2. Are you attending the Saturday evening banquet? <i>(included with your registration fee)</i> Y or N				
3. If you are attending the Banquet, you have the following meal options: Chicken entrée (C), Vegetarian (V) or Vegan (VE) – all are gluten-free. Please indicate your preference. C, V or VE				
4. Will you be using a Scooter (S), Manual Wheelchair (M), Electric Wheelchair (E), or a Walker (W)? Blank, S, M, E or W				
5. Will you be bringing an assistance dog? Y or N				
6. Are you a current paid member of NAF? (If you are unsure of your membership status, contact NAF before submitting your registration form.) Y or N				

TRAVEL INFORMATION

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

For parking arrangements at the hotel we need to know if you will be driving a van with a lift: Yes No

Air Carrier: _____ Flight Number: _____

Arrival Date/Time: _____ Hotel Check-in Date: _____

Departure Date/Time: _____ Hotel Check-out Date: _____

VOLUNTEER INFORMATION

If you are interested in volunteering at the 2012 Annual Membership Meeting, please contact Linda Crawley at (512) 635-9478 or lcrawley57@gmail.com.

By attending the 2012 NAF Annual Membership Meeting 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.

Early Registration Deadline is February 15, 2012

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: naf@ataxia.org

2012 NAF Annual Membership Meeting 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"/> \$35 (Annual Individual) <input type="checkbox"/> \$55 (Annual Household)</p> <p><input type="checkbox"/> \$100+ (Annual Patron) <input type="checkbox"/> \$500 (Lifetime) <input type="checkbox"/> \$55 (Annual Professional)</p> <p><input type="checkbox"/> \$50 (Individual Outside U.S.) <input type="checkbox"/> \$70 (Household and Professional Outside U.S.)</p> <p>You may register for the meeting 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 Meeting Fund (provides travel grants, offsets registration fees, helps cover costs associated with the meeting)</p> <p>Here is my sponsorship contribution!</p> <p><input type="checkbox"/> \$95 (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 Feb. 15, 2012	After Feb. 15, 2012	Quantity	Total
<input type="checkbox"/> NAF Member (applies to NAF members who have an Individual, Household, Patron, or Lifetime membership; <i>member rate is applied to one caregiver per individual member with ataxia</i>)	\$95	\$120		
<input type="checkbox"/> Non-Member	\$150	\$175		

TOTAL CHARGES:

PAYMENT INFORMATION: Visa MasterCard Discover 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 February 15, 2012

Please complete all three 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: naf@ataxia.org

National Ataxia Foundation
55th Annual Membership Meeting - Recordings
 March 16-18, 2012
 Grand Hyatt San Antonio Hotel - San Antonio, TX



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Cash:		Money Order:		

SPECIAL Visit www.dcprovideronline.com/naf/ for
 A Free Session View from the 54th Annual Membership Meeting

Caregiver's Corner

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

Safe Transfers – Proper Lifting

Oh, My Aching Back!

As a caregiver, you may have to help the person in your care move from place to place by lifting her. When you learn how to control and balance your own body, you can safely control and move another person. You can injure your back by not focusing on what you are doing, whether you are bending improperly to pick a paperclip up off the floor or loading the washing machine. Being a caregiver puts you at even more risk for back injuries. Many occur when lifting, moving, transferring or changing the position of the one in your care. Improper movements can cause injury to the person being moved, such as abrasions to skin, strains, sprains and tears – even fractures.

General Rules to Prevent Back Injury

Use the same procedure for all transfers, so that a routine is set up:

- Never lift more than you can comfortably handle.
- Create a base of support by standing with your feet 8-12 inches (shoulder width) apart with one foot a half step ahead of the other.
- DO NOT let your back do the heavy work: USE YOUR LEGS. (The back muscles are *not* your strongest muscles.)
 - If the bed is low, put one foot on a foot stool. This relieves pressure on your lower back.
 - Consider using a back support belt.
 - If sitting for extended periods, get up every 20 minutes to give your spine relief.
 - Stay fit by exercising and strengthening back and abdominal muscles.
 - Gently stretch often during the day.
 - Maintain a healthy weight to reduce pressure on your spine.

- Have a program to manage stress such as yoga, meditation or even simple walking.
- Quit smoking, as nicotine slows the flow of blood to the vertebrae and disks and impairs their function. Smokers tend to lose bone faster than nonsmokers, putting them at risk for osteoporosis.

Rules for Moving a Person in Bed

Moving a person in bed can injure the person in care or you, the caregiver, if certain basic rules are not followed:

- Never grab or pull the person's arm or leg.
- If the medical condition allows, raise the foot of the bed slightly to prevent the person from sliding down.
- If moving him is difficult, get him out of bed and back in the wheelchair and start over by putting him in bed closer to the headboard.

Moving a Person Up in Bed

1. Tell the person what you are going to do.
2. Lower the head of the bed to a flat position and remove the pillow – never try to move the person "uphill."
3. If possible, raise the bed and lock the wheels.
4. Tell the person to bend his knees and brace his feet firmly against the mattress to help push.
5. Stand at the side of the bed and place one hand behind the person's back and the other underneath the buttocks.
6. Bend your knees and keep your back in a neutral position.
7. Count "1-2-3" and have the person push with his feet and pull with his hands toward the head of the bed.
8. Replace the pillow under his head. ►►

Note

A drawsheet – a sheet folded several times and positioned under the person to be moved in bed – prevents irritation to his skin. The sheet should be positioned from the shoulders to just below the knees.

TIP – Lighten Your Load

A too-heavy handbag can cause muscle soreness, nerve compression and back and shoulder pain. A bag should weigh no more than 10 percent of your body weight. Weigh your bag on the bathroom scale to make sure you're not putting unnecessary strain on your body. If you have to carry a heavy load on a regular basis, consider a bag with wheels.

Source: American Chiropractic Association

Taking Care of Yourself – Changes in Attitude Relieve Stress

Here are some suggestions to help reduce your stress level:

- Learn to say no. Good boundaries improve relationships.
- Control your attitude: don't dwell on what you lack or what you can't change.
- Find simple ways to have fun: Play a board game, organize family photos, listen to music you enjoy, read an engrossing book.
- Learn a time-management tool, like making a to-do list (specifically include items that you enjoy).
- Knowledge is empowering: get information about the condition of the person in your care.
- Limit coffee and caffeine and be sure to have good nutrition regularly during your day.
- Find a support system and share your feelings with someone who wants to listen.
- Keep a gratitude journal – record three new things you are grateful for every day.

Don't Fall – Be Safe

Try Moving to Music – Seniors who were unsteady on their feet and took a weekly hour-long class of movement to music maintained

their balance and walked with a more regular gait.

Source: Archives of Internal Medicine.

Using Two People to Move a Person

① • Tell the person what you are going to do even if the person seems to be unconscious or not understanding.

- Remove the pillow.
- If possible, raise the bed and lock the wheels.

② • Stand on either side of the bed.

• Face the head of the bed, with feet 8-12 inches apart, knees bent, back in a neutral position.

• Roll the sides of the draw sheet up to the person's body.

③ • Grab the draw sheet with your palms up.

• Count "1-2-3" and then shift your body weight from the back to the front leg, keeping your arms and back in a locked position. Together, slide the person smoothly up the bed.

- Replace pillows under the person's head.
- Position the person comfortably.

Quick Quiz

Improper lifting technique can lead to back, leg and arm pain. Poor technique can cause both acute injury, and serious chronic effects. Learning the right way to lift will help you avoid these problems. Answer True or False to the questions below.

1. When you learn how to control and balance your own body, you can safely control and move another person. *T F*
2. Never lift more than you can comfortably handle. *T F*
3. When lifting, you can injure your back by not focusing on what you are doing. *T F*
4. Smoking cigarettes does not slow the flow of blood to the vertebrae and impair their function. *T F*
5. When moving or lifting a person, never grab

Continued on page 32

Caregiver's Corner
Continued from page 31

or pull the person's arm or leg. *T F*

6. Always tell the person what you are going to do even if the person seems to be unconscious or not understanding. *T F*

7. To reduce stress, find a support system and share your feelings with someone who wants to listen. *T F*

8. Your back muscles are your strongest muscles. *T F*

9. Carrying a too-heavy handbag can cause

muscle soreness, nerve compression and back and shoulder pain. *T F*

10. Improper movements can cause injury to the person being moved, such as abrasions to skin, strains, sprains and tears – even fractures. *T F*

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

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From the Desk of the Executive Director

The National Ataxia Foundation is currently reviewing this year's nearly 90 ataxia research applications from 13 countries, more than double the number of applications from last year. Due to the generosity of an anonymous donor, supporters who contributed to the annual ataxia research drive, The Gordon and Marilyn Macklin Foundation, fund-raisers, International Ataxia Awareness Day events, corporate and foundation friends, contributors, and you, the National Ataxia Foundation will be able to fund significant ataxia research throughout the world.

We are humbled by the generosity of those who have supported NAF's important research efforts. We are also honored by those who have made their first research donation and to those who have continued to support NAF's vital research programs. Research announcements for FY 2012 funded studies will be reported in early January 2012 on NAF's website, www.ataxia.org, through E-Blasts, and also in the next issue of "Generations." Your support made it possible to fund the most promising and best science in the world. Thank you.

International Ataxia Awareness Day events were held throughout the country beginning in mid-September and ending in early October,

2011. Walk n' Rolls continued to grow as well as other events including golf tournaments. We are truly grateful to the lead organizers, support groups, sponsors, donors, members, and volunteers who made these events so successful. Your efforts and support raise ataxia awareness and funds to support promising ataxia research and programs for ataxia families.

In March 2012 NAF will be hosting its fourth International Ataxia Investigators Meeting (AIM). Leading ataxia scientists and clinicians from around the world will be part of this international meeting on ataxia. The intent of these conferences is to help accelerate worldwide ataxia research by presenting the latest developments in basic science and translational research on all forms of ataxia, hereditary and sporadic, as well as bringing young investigators into the field of ataxia research.

The day the 2012 AIM concludes, the 2012 NAF Annual Membership Meeting (AMM) begins. We are very excited about the caliber of this year's AMM presenters, including a number of international speakers. This is the first time NAF has held an AMM in beautiful San Antonio, Texas. A special thank you to the Texas support groups for hosting this excellent conference. We look forward in seeing you all in San Antonio!



Michael Parent



Chapter and Support Group News from Around the Country

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Northern California Ataxia Support Group Update

By Joanne Loveland

The NCASG meeting was Oct. 8 at Our Savior’s Lutheran Church in Lafayette. After a “mix and mingle” session we had lunch and a short business meeting.

A summary of our International Ataxia Awareness Day Walk n’ Roll held Sept. 25 was shared by Joanne Loveland. Thanks to everyone who generously donated time, talents and resources to make our event fun and successful. More people are aware of ataxia because of our efforts. We are grateful to Dr. Gail Kang and Genetic Counselor Jamie Wong from UCSF for attending. Another guest at our Walk n’ Roll was James Huo from Beijing, China. He is one of the founders of China Ataxia Association.

Our guest speaker was Robert Schick, DC. He spoke to us about a “cutting-edge” new treatment called Quantum Neurology. He evaluates every major nerve and muscle in the body for weakness. Using a red laser light he can strengthen muscle, joint mobility, improve balance and coordination immediately. He asked several volunteers to be his patient in front of the group. We all could see muscles become stronger against resistance after the correct nerve was stimulated. Stimulating major nerves throughout the body rehabilitates the nervous system. Dr. Schick discloses that this is not a cure for neurological disorders, but it helps stabilize us and may slow down the progression. Thank you Robert Schick, DC.

Our next meeting will be on Jan. 14, 2012.

We are planning to have a speaker inform us about all the work of California Institute for Regenerative Medicine (CIRM).

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Louisiana Chapter Update

Elizabeth Tanner is the newest president of the Louisiana Chapter of NAF. She is from Baton Rouge, Louisiana. She is a CPA for a public accounting firm in Baton Rouge, and her husband is an attorney. Elizabeth’s family is originally from Ferriday, Louisiana. She has two sisters, Ginny and Danielle; her mother is a retired school teacher, and her father is a civil engineer. She enjoys exercising, reading books, and spending time with her nieces, Ellie and Evie.

Elizabeth’s mother, Susan, was diagnosed with SCA-3/Machado Joseph Disease about 10 years ago. Elizabeth’s grandfather and two uncles also suffered with the disease. While this disease was completely unfamiliar to Elizabeth’s family when her mother began displaying symptoms, she wanted to find out as much information as possible. She found the National Ataxia Foundation’s website and subsequently found a doctor in the New Orleans area, Dr. Michael Wilensky. Her mother became his patient, and he piqued her interest in the local Louisiana Chapter of NAF. Elizabeth and her mother attended their first meeting last month, and she is the new president. While there will be a large learning curve, she is excited to be involved and looks forward to getting to know everyone and to bringing new ideas to the Chapter.

Continued on page 34

Chapter and Support Group News
Continued from page 33

**Central New York
Ataxia Support Group Update**

By Mary Jane Damiano and Judy Tarrants

The Central New York Ataxia Support Group met Sept. 24. We celebrated International Ataxia Awareness Day with a luncheon and a ceremony. Thirteen members were present. Cheryl and her friend Debbie traveled the farthest distance to the meeting – they came from Fort Drum, New York. We had a nice lunch. Everybody brought a nice dish to pass. We ended the lunch with an Ataxia Awareness Day cake.

Pat Gustafson presented a proclamation on behalf of the Village of North Syracuse Mayor, Mark Atkinson. Ed Lueck presented a proclamation on behalf of County Executive, Joanne Mahoney, and Syracuse Mayor, Stephanie Miner. Village of North Syracuse Trustee, Alfred E. Ferguson, conducted a candle lighting ceremony symbolizing the hope and unity shared by those affected by ataxia and their caregivers. Each member received a packet of materials to distribute to their friends and family members about ataxia.

This meeting concludes our 2011 meeting schedule. Our 2012 meeting schedule will include spring, summer, and fall meetings. The first meeting of the 2012 season will be in April. The exact date will be announced in January. For more information, please contact Judy Tarrants at email jtarrants@aol.com or by phone at (315) 683-9486.

Alabama Ataxia Support Group Update

By Becky Donnelly

The Alabama Ataxia Support Group will hold its first meeting of 2012 on Jan. 28 at Covenant Presbyterian Church, Homewood, AL, from 10 a.m. to 2 p.m. There will be a program and luncheon. We will also have a meeting on April

28 (same time, same place).

The Alabama Ataxia Support Group enjoyed a summer social at Railroad Park in Birmingham, Alabama. Our group sponsored a table at the CFC Charity Information Fair, a combined Federal charity awareness event held in Birmingham, on Sept. 8. Federal employees attended this event. Ronnie and Beverly English gave out NAF literature and reported that most of the people they spoke with had never heard of hereditary ataxia. Our group provided a \$25 door prize, and showed off Alabama Ataxia Support Group shirts and our banner.

Our Oct. 29 meeting convened at Covenant Presbyterian Church in Homewood, Alabama. Dr. Andrew Daniel, urologist, gave a program on ataxia and bladder function. Dr. Daniel graciously spent well over an hour describing bladder structures and causes of problems, as well as ways to prevent them. Members had many questions and comments, which Dr. Daniel patiently answered. Members brought sack lunches and enjoyed a time of food and fellowship. A brief business meeting was held, and then Ms. Juanita Dorroh of Hoover, Alabama, spoke on “Reflections and Encouragement.” Her remarks were a reflection of having read “Keep A’ Going,” a book of personal stories of those who have ataxia. Three of the stories were written by our group members.

Orange County Ataxia Support Group

By Theresa Gonzales

The Orange County Ataxia Support Group meets every other month, February through October, on every third Saturday at Orange Coast Memorial Medical Center – Breast Center Building Classroom 1A (building nearest to Talbert Ave. and Foster St.), 9900 Talbert Ave., Fountain Valley, CA 92708, from 2 p.m. to 4 p.m.

On Aug. 20 massage therapist Terry Solomon and various massage therapy students provided therapeutic massages to all attendees. We all ▶▶

said goodbye to Terry as this was his last session with us because he’s moving to Nevada. Also, we had a very informative presentation for “Forever Active” which customizes modifications to your home (whether owning or renting) to make it more accessible for disabled persons. For more information, visit www.foreveractivemed.com.

On Sept. 24 the Orange County Support Group collaborated with the Los Angeles Support Group to host The Third Annual Walk n’ Roll for ataxia awareness. Through this event we raised over \$40,000 in donations. It was a great day altogether.

On Oct. 15 we held our last meeting of the year. We had an informative presentation and demonstration of an upright walker from Dashaway (phone number is 1-866-968-3274 and web address is www.dashaway.net). Two college graduates majoring in physical therapy also came to our meeting. The two discussed how they were geared towards learning more about ataxia and how they can help patients. This is very encouraging to hear young people reaching out to those with ataxia through physical therapy.

For more information on the Orange County Ataxia Support Group, please visit www.ataxia.org/chapters/OrangeCounty/default.aspx.

Denver Ataxia Support Group Update

By Charlotte DePew

After a great potluck lunch, the 29 individuals present at our October meeting introduced themselves and briefly commented about their ataxia. Three new members were present and we gained four new members as a result of advertising for our inaugural Run, Walk n’ Roll (WRnR) on Sept. 24.

Kathryn and Charlotte, the Support Group co-leaders, reported that as of Oct. 14 we had over \$24,800 in donations from our first WRnR. An appreciative “thank you” was given to all who had any part in this amazing fundraising success. The Run, Walk n’ Roll in Denver City Park had a professional quality thanks to Keri Naccarato’s

expertise. The weather was also wonderful.

An experienced and knowledgeable social worker was our speaker. She informed the group about federal, state, county, private for-pay, and free non-profit programs regarding health care insurance, home care, home evaluation for handicap needs, assistance in finding handicap adapted housing, and much more. She agreed with the group that becoming a consumer of all that is available is confusing. Resources for navigating the various programs are available through insurance case managers, doctor’s offices, hospitals, county social work offices and more. She provided information brochures, books, and a website list. Our next meeting is January 21, 2012.

DE/PA Ataxia Support Group Update

By Joe DeCrescenzo and Chris Rakshys

The DE/PA Support Group meeting was held on Saturday, Oct. 22 at Christiana Hospital in Newark, DE. Our first guest speaker was Jay S. Kogon, the Physical Therapy Clinical Supervisor at Wilmington Hospital (another hospital in Delaware within the Christiana Care network). His talk focused on current exercises for movement disorders and caregiver and home tips. He also spoke very highly of a rehabilitative program known as BIG, offered through a company called LSVT. They believe that intensive and repetitive exercise, in combination with or without medication, is needed for gait improvement for a neurodegenerative disorder/disease. He demonstrated a few very simple and basic exercises for us, and we were very grateful for his doing so.

Our second guest speaker was Kyle Bryant, the highly inspirational cyclist who has Friedreich’s Ataxia. He shared with us some personal history of his disease and how he overcame his disability to experience the most amazing adventures. At times, Kyle’s presentation was very laid-back and humorous – gentle reminders to us that life is

Chapter and Support Group News
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good and that we gotta' keep movin' on.

Our next meeting will be held in the spring of 2012 in Hershey, PA. Please stay tuned in the new year for further information.

**Greater Cincinnati Area
Ataxia Support Group Update**

By Jennifer Mueller

On Oct. 1, although the temperature was cold, we planned a Caregivers Appreciation Picnic to celebrate IAAD, but scheduling conflicts forced us to postpone our meeting until the following weekend. We chose to meet at the Mt. Airy Forest park, which has a completely wheelchair accessible tree house called "Everybody's Treehouse." It was an amazing site. For more information, please visit www.cincyparks.com/bm~doc/treehouse.pdf.

Chesapeake Chapter News

By Carolyn Davis

The Chesapeake Chapter is holding a raffle for a Cruise Getaway on the Royal Caribbean line. The prize is a \$2,000 gift certificate for a cruise leaving from any port from which they operate. The drawing will be held March 24, 2012.

Tickets are \$5 each and can be ordered from Joe DeCrescenzo (jdecr@comcast.net), who is spearheading the fundraiser.

**Northeast Florida
Ataxia Support Group Update**

By Ann Mayo

At our last meeting, Meredith Rodriguez, MS, CCC-SLP Speech Pathologist at St. Vincent's Medical Center, spoke about "Strategies for Improving Communication and Swallowing." She had a question-and-answer session after her talk. She's worked with one of our members and is familiar with problems individuals with ataxia might encounter. She can be reached at (904) 308-2888 if you would like to contact her.

Bob Smithers has made an updated list of addresses and phone numbers and is also trying to compile another list showing the type of ataxia each person has. Please send this information to Bob at smithersb@yahoo.com. Bob also has made nametags for us all to wear at the meetings. I know the group joins me in thanking Bob for all his help.

We talked about the Royal Caribbean Cruise arranged by the West Central Florida Support Group Leader, Cindy Steever-Ziegler. There are only four inside accessible rooms, three outside accessible rooms, and one balcony accessible room left as well as a good number of non-accessible rooms. For reservations or information contact Jessica Chiarito at jchiarito@aaasouth.com or (813) 289-5800 ext. 7938.

I also announced at the meeting that I am resigning as a leader of the Northeast Florida Ataxia Support Group due to various ataxia-related health concerns. It has been my pleasure to have been a group leader. I sincerely hope someone will step up to the plate and volunteer to be the support group leader for the Northeast Florida Ataxia Support Group. Please give this matter your careful consideration and contact Lori Shogren at NAF (lori@ataxia.org) if you are interested.

Tissue Donation

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

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NAF Directory of Chapters, Support Groups and Ambassadors

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

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

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

Social Networks

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Moderator – Atilla

www.ataxia.org/forum/toast.asp

NAF CHAT ROOM

Moderator – Della (blondie.echat@gmail.com)

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

NAF FACEBOOK GROUP

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

NAF FACEBOOK CAUSES

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

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E-mail: wpgmagic@gmail.com

www.ataxia.org/chapters/TerryGreenwood/default.aspx

— INDIA —

INDIA ATAXIA SUPPORT GROUP LEADER

Chandu Prasad George. CH,

Secunderabad, India

Phone: 0091-040-27961269

Mobile: 0091-9949019410 Fax: 091-040-27971043

E-mail: sam_ataxiaindia@yahoo.com

www.ataxia.org/chapters/Chandu/default.aspx ❖

Matching Gifts

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

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

Calendar of Events

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

SUPPORT GROUP MEETINGS

– Saturday, January 7, 2012 –

Central Texas Ataxia Support Group Meeting

Time: 11 a.m. – 1:30 p.m.

Location: The Dell Children's Medical Center of Central TX, 4900 Mueller Blvd., Austin, TX 78723. We will meet in Central Conference Room 4E.031 A&B (located between 4N & 4C) on the fourth floor. The medical center's main number is (512) 324-0000.

Details: For more information contact Linda Crawley at (512) 635-9478 or calebsnana2@msn.com. www.ataxia.org/chapters/Linda/default.aspx

West Central FL Ataxia Support Group Meeting

Time: Noon – 3 p.m.

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

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

– Wednesday, January 11, 2012 –

Willamette Valley Ataxia Support Group Meeting

Time: 11:30 a.m. – 1 p.m.

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

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

– Thursday, January 12, 2012 –

Tri-State Ataxia Support Group Potluck Meeting

Time: 6 p.m. – 8 p.m.

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

Details: For more information contact Denise Mitchell at (212) 844-8711 or markmeghan2@gmail.com. www.ataxia.org/chapters/Tri-State/default.aspx

– Saturday, January 14, 2012 –

Central MN Ataxia Support Group Meeting

Time: 10 a.m. - noon.

Location: Saint Cloud Public Library, 1300 W. Saint Germain St., Saint Cloud, MN 56301.

Details: Guest speaker, Dan Weaver from Northern

Star Therapy on balance dysfunction. For more information contact Marsha Binnebose at marsha_binnebose@yahoo.com or (320) 240-9391. www.ataxia.org/chapters/StCloud/default.aspx.

Los Angeles Area Ataxia Support Group Meeting

Time: 2 p.m. – 4 p.m.

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

North Texas Ataxia Support Group Meeting

Time: 10 a.m. – noon.

Location: The Las Colinas Cancer Center Located at 7415 Las Colinas Blvd., Irving TX 75039. Parking is free and the building is handicap accessible. We meet in the front lobby of the Las Colinas Cancer Center. It is a one story building behind the Regions Bank. There is a map on their website: www.LasColinasCancerCenter.com.

Details: Guest speaker Shirley Thompson will show us some Tai Chi exercises. Most of the meeting time is for sharing and asking questions about the difficulties and successes we have in our everyday life with ataxia. For additional information please contact David Henry Jr. at cheve11e@sbcglobal.net. Please check the group's web page for updates. www.ataxia.org/chapters/NorthTexas/default.aspx

Northern CA Ataxia Support Group Meeting

Time: 11:30 a.m. – 2 p.m.

Location: Our Savior's Lutheran Church (Recreation Hall), 1035 Carol Ln., Lafayette, CA.

Details: Guest speaker will be Don Gibbons, Senior Science and Education Communications Officer of the CA Institute for Regenerative Medicine (CIRM). The mission for CIRM is "Turning Stem Cells into Cures." The cost to attend is \$7 per person with lunch or \$4 per person without lunch. For more information please contact Joanne Loveland at joaneloveland@gmail.com. www.ataxia.org/chapters/NorthernCalifornia/default.aspx

San Diego Ataxia Support Group Meeting

Time: 1 p.m. – 3 p.m.

Location: Sharp Rehabilitation Center, 2999 Health Center Dr. on the East side of Hwy 163 between Genesee Ave. and Mesa College Dr. behind Sharp Memorial Hospital. Plenty of free parking.

Details: For more information contact Earl McLaughlin at (619) 447-3753 or sdasg@cox.net. ►►

www.ataxia.org/chapters/SanDiego/default.aspx

Tarheel NC Ataxia Support Group Meeting

Time: 2 p.m. – 4 p.m.

Location: BestHealth in Hans Mall, 3320 Silas Creek Parkway, Winston-Salem, NC.

Details: Call (336) 713-2378 to RSVP. For more information contact Jerry Hauser at (336) 998-2942 or deaconwfu@msn.com. www.ataxia.org/chapters/Tarheel/default.aspx

– **Saturday, January 21, 2012** –

Denver Area Ataxia Support Group Meeting

Time: 1 p.m. – 4 p.m.

Location: The Swedish Medical Center, 501 E. Hampden Ave., Englewood, CO 80113. We meet in meeting room Spruce A & B.

Details: For more information contact Charlotte DePew at (720) 783-3190 or cldepew77@comcast.net. www.ataxia.org/chapters/Denver/default.aspx

Maine Ataxia Support Group Holiday Gathering

Time: Noon.

Location: Captain Newicks Restaurant, Portland, ME.

Details: For more information contact Kelley Rollins at rollins@gwi.net. www.ataxia.org/chapters/Maine/default.aspx

Twin Cities Ataxia Support Group Meeting

Time: 10 a.m.

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

Details: The Twin Cities Ataxia Support Group meets once a month. Family and friends of an afflicted individual are always welcome! For more information contact Lenore Healey Schultz at (612) 724-3784 or shultz.lenore@yahoo.com. www.ataxia.org/chapters/TwinCities/default.aspx

– **Saturday, January 28, 2012** –

Alabama Ataxia Support Group Meeting

Time: 10 a.m. – 2 p.m.

Location: Covenant Presbyterian Church, Homewood, AL.

Details: This meeting will include a luncheon. For more information contact Becky Donnelly at (205) 987-2883 or donnelly6132b@aol.com. www.ataxia.org/chapters/Birmingham/default.aspx

– **Saturday, February 4, 2012** –

Greater Atlanta Ataxia Support Group Meeting

Time: 1 p.m. – 3 p.m.

Location: Emory Center for Rehabilitation Medi-

cine, 1441 Clifton Rd., Room 101, Atlanta, GA 30322.

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

– **Wednesday, February 8, 2012** –

Willamette Valley Ataxia Support Group Meeting

Time: 11:30 a.m. – 1 p.m.

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

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

– **Saturday, February 11, 2012** –

Arizona Ataxia Support Group Meeting

Time: 1:30 p.m. - 3:30 p.m.

Location: The Disability Empowerment Center, (DEC), Classroom A on the second floor, Arizona Bridge to Independent Living (ABIL), 5025 E. Washington St., Ste. 200, Phoenix, AZ 85034.

Details: Guest speaker will be Dr. Lawrence Schut, neurologist and past NAF board member. Topic TBD. For more information contact Rita Garcia at (480) 726-3579 or rtg22@cox.net, or Mary Fuchs at (480) 883-7633 or mary11115@msn.com. www.ataxia.org/chapters/Phoenix/default.aspx

Central MN Ataxia Support Group Field Trip

Time: 10 a.m. – 12 p.m.

Location: Field trip to SCSU speech language and hearing clinic, St. Cloud State University – Brown Hall, St. Cloud, MN.

Details: Information will be provided on devices for assisting with speech difficulty in ataxia disorders, and a clinic one on one with students and teachers will be held. We have parking outside Brown Hall for five vehicles which will be reserved for the group. There is a campus map on the home webpage for SCSU, university.www.stcloudstate.edu/campusmap/default.asp. For more information and to RSVP contact Marsha Binnebose at marsha_binnebose@yahoo.com or (320) 240-9391. www.ataxia.org/chapters/StCloud/default.aspx

Kansas City Area Ataxia Support Group Meeting

Time: 2 p.m. – 4 p.m.

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

Details: For more information contact Lois Goodman at (816) 257-2428 or Jim Clark at (816)

*Calendar of Events**Continued from page 43*

468-7260 or clarkstone9348@sbcglobal.net. www.ataxia.org/chapters/KansasCity/default.aspx

North Texas Ataxia Support Group Meeting**Time:** 10 a.m. – noon.

Location: The Las Colinas Cancer Center at 7415 Las Colinas Blvd., Irving, TX 75039. The parking is free and the building is handicap accessible. We meet in the front lobby of the Las Colinas Cancer Center. It is a one-story building behind the Regions Bank. There is a map on their website: www.LasColinasCancerCenter.com.

Details: Most of the meeting time is for sharing and asking questions about the difficulties and successes we have in our everyday life with ataxia. From time to time we do have an outside speaker address some of our concerns from the caregivers, patients and families. For additional information please contact David Henry Jr. at cheve11e@sbcglobal.net. Please check the group's web page for updates. www.ataxia.org/chapters/NorthTexas/default.aspx

South FL Ataxia Support Group Meeting**Time:** 12 – 3 p.m.**Location:** TBA.

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

– **Saturday, February 18, 2012** –

Greater Cincinnati Area Ataxia Support Group Meeting**Time:** 1 p.m. – 3 p.m.

Location: Groesbeck Public Library, 2994 W. Galbraith Rd., Cincinnati, OH.

Details: For more information contact Jennifer Mueller at (513) 834-7002 or jenmu@yahoo.com. www.ataxia.org/chapters/JenniferM/default.aspx

Orange County Ataxia Support Group Meeting**Time:** 4 p.m. – 5 p.m.

Location: Orange Coast Memorial Medical Center, Breast Center Building, Classroom 1A (building nearest to Talbert Ave. & Foster St.), 9900 Talbert Ave., Fountain Valley, CA 92708.

Details: For more information contact Daniel Navar at (323) 788-7751 or danieln27@gmail.com. www.ataxia.org/chapters/OrangeCounty/default.aspx

Twin Cities Ataxia Support Group Meeting**Time:** 10 a.m.

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

Details: The Twin Cities Ataxia Support Group meets once a month. Family and friends of an afflicted individual are always welcome! For more information contact Lenore Healey Schultz at (612) 724-3784 or shultz.lenore@yahoo.com. www.ataxia.org/chapters/TwinCities/default.aspx

– **Saturday, March 3, 2012** –

Central Texas Ataxia Support Group Meeting**Time:** 11 a.m. – 1:30 p.m.

Location: The Dell Children's Medical Center of Central TX, 4900 Mueller Blvd., Austin, TX 78723. We will meet in Central Conference Room 4E.031 A&B (located between 4N & 4C) on the fourth floor. The medical center's main number is (512) 324-0000.

Details: For more information contact Linda Crawley at (512) 635-9478 or calebsnana2@msn.com. www.ataxia.org/chapters/Linda/default.aspx

Chesapeake Chapter's 29th Annual Medical Meeting**Time:** 9 a.m. – 3 p.m.

Location: Theatre-Arts Auditorium, Montgomery College, 51 Mannakee St., Rockville, MD.

Details: For more information contact Carolyn Davis at (703) 759-2008 or ccnafpres@gmail.com. www.ataxia.org/chapters/Chesapeake/default.aspx

West Central FL Ataxia Support Group Annual Picnic**Time:** Noon – 3 p.m.**Location:** TBD.

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

– **Thursday, March 8, 2012** –

Tri-State Ataxia Support Group Meeting**Time:** 6 p.m. – 8 p.m.

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

Details: For more information contact Denise Mitchell at (212) 844-8711 or markmeghan2@gmail.com. www.ataxia.org/chapters/Tri-State/default.aspx

– **Saturday, March 10, 2012** –

Los Angeles Area Ataxia Support Group Meeting ▶▶

Time: 2 p.m. – 4 p.m.

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

North Texas Ataxia Support Group Meeting

Time: 10 a.m. – noon.

Location: The Las Colinas Cancer Center Located at 7415 Las Colinas Blvd., Irving, TX 75039. Parking is free and the building is handicap accessible. We meet in the front lobby of the Las Colinas Cancer Center. It is a one-story building behind the Regions Bank. There is a map on their website: www.LasColinasCancerCenter.com.

Details: Most of the meeting time is for sharing and asking questions about the difficulties and successes we have in our everyday life with ataxia. From time to time we do have an outside speaker address some of our concerns from the caregivers, patients and families. For additional information please contact David Henry Jr. at cheve11e@sbcglobal.net. Please check the group's web page for updates. www.ataxia.org/chapters/NorthTexas/default.aspx

– **Sunday, March 11, 2012** –

San Diego Ataxia Support Group Pizza Party

Time: 5 p.m. – 7 p.m.

Location: Round Table Pizza in the La Mesa Springs Shopping Center, 8032 La Mesa Blvd.

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

– **Wednesday, March 14, 2012** –

Willamette Valley Ataxia Support Group Meeting

Time: 11:30 a.m. – 1 p.m.

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

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

– **Saturday, March 17, 2012** –

Twin Cities Ataxia Support Group Meeting

Time: 10 a.m.

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

Details: The Twin Cities Ataxia Support Group meets once a month. Family and friends of an afflicted individual are always welcome! For more information contact Lenore Healey Schultz at (612) 724-3784 or shultz.lenore@yahoo.com. www.ataxia.org/chapters/TwinCities/default.aspx

– **Sunday, March 25, 2012** –

Chicago Area Ataxia Support Group Meeting

Time: 1 p.m.

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

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

– **Wednesday, April 11, 2012** –

Willamette Valley Ataxia Support Group Meeting

Time: 11:30 a.m. – 1 p.m.

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

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

– **Saturday, April 14, 2012** –

Kansas City Area Ataxia Support Group Meeting

Time: 2 p.m. – 4 p.m.

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

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

North Texas Ataxia Support Group Meeting

Time: 10 a.m. – noon.

Location: The Las Colinas Cancer Center located at 7415 Las Colinas Blvd., Irving, TX 75039. Parking is free and the building is handicap accessible. We meet in the front lobby of the Las Colinas Cancer Center. It is a one-story building behind the Regions Bank. There is a map on their website: www.LasColinasCancerCenter.com.

Details: Most of the meeting time is for sharing and asking questions about the difficulties and successes we have in our everyday life with ataxia. From time to time we do have an outside speaker address some of our concerns from the caregivers, patients and families. For additional information please contact David Henry Jr at cheve11e@sbcglobal.net. Please check the group's web page for updates. www.ataxia.org/chapters/NorthTexas/default.aspx

Northern CA Ataxia Support Group Meeting

Time: 11:30 a.m. – 2 p.m.

Location: Our Savior's Lutheran Church (Recreation

*Calendar of Events**Continued from page 45*

Hall), 1035 Carol Ln., Lafayette, CA.

Details: The cost to attend is \$7 per person with lunch or \$4 per person without lunch. For more information contact Joanne Loveland at joanne_loveland@gmail.com. www.ataxia.org/chapters/NorthernCalifornia/default.aspx

San Diego Ataxia Support Group Meeting

Time: 1 p.m. – 3 p.m.

Location: Sharp Rehabilitation Center, 2999 Health Center Dr. on the East side of Hwy 163 between Genesee Ave. and Mesa College Dr. behind Sharp Memorial Hospital. Plenty of free parking.

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

South FL Ataxia Support Group Meeting

Time: Noon – 3 p.m.

Location: TBA.

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

Tarheel NC Ataxia Support Group Meeting

Time: 1 p.m. – 3 p.m.

Location: BestHealth in Hans Mall, 3320 Silas Creek Parkway, Winston-Salem, NC.

Details: Call (336) 713-2378 to RSVP. For more information contact Jerry Hauser at (336) 998-2942 or deaconwfu@msn.com. www.ataxia.org/chapters/Tarheel/default.aspx

EveryLife Art Contest

Artists are invited to participate in the Third Annual EveryLife Art Contest. The competition is open to all artists affected by a rare disease ages five and older, as well as close friends, family members or care-takers of those with a rare or undiagnosed disease.

Prizes will be awarded, including an iPod Touch. Entries must be received by Friday Jan. 31, 2012. Go to www.rareartist.org/main/about_contest for more details.

– **Sunday, April 15, 2012** –

Metro Chicago Ataxia Support Group Meeting

Time: 1 p.m.

Location: Ravenswood Chiropractic & Wellness Center, 5215 N Ravenswood Ave., Ste. 105, Chicago, IL.

Details: For more information contact Christopher Marsh at (312) 662-1127 or cmars34@ameritech.net. www.ataxia.org/chapters/ChrisMarsh/default.aspx

INFORMATIONAL AND ATAXIA AWARENESS EVENTS

– **Saturday, January 21, 2012** –

2nd Annual Rock n' Roll for Ataxia

Time: 8 p.m. – 1 a.m.

Location: The Canal Club, 1545 Cary St., Richmond, VA 23219.

Details: Join us for music, raffle prizes, and family fun. Featuring live local band favorites: Rev D-Ray and the Shockers, Road Less Traveled, Crossroad Voodoo, and Weeping Molly. Visit the Canal Club website for advance tickets. For more information contact Tracy Holcombe at (804) 264-0545 or tckorn@yahoo.com. www.thecanalclub.com

– **Tuesday, March 13, 2012** –

NAF Ataxia Investigators Meeting

The Ataxia Investigators Meeting 2012 (AIM 2012) "Advancing Toward Therapeutics" will take place in San Antonio, TX from March 13-16, 2012. Lead organizers for the meeting are Dr. Henry Paulson and Dr. Christopher Gomez. This meeting is intended for physicians and researchers who are involved or have an interest in ataxia. For registration information please contact Sue Hagen at susan@ataxia.org. www.ataxia.org/research/ataxia-investigators-meeting.aspx

– **Friday, March 16, 2012** –

NAF 55th Annual Membership Meeting

The National Ataxia Foundation (NAF) Board of Directors and the NAF Texas Ataxia Support Groups would like to welcome you to the 55th Annual Membership Meeting. Please join us at the Grand Hyatt San Antonio Hotel March 15-18 to learn, share, network, and have fun. The meeting will celebrate NAF's 55th anniversary in serving ataxia families. www.ataxia.org/events/annual-meeting2012.aspx

Friday, March 30, 2012

Abilities Expo

March 30 – April 1 at the LA Convention Center. www.abilitiesexpo.com/losangeles/index.html ❖

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 September 2011. We are sorry that we cannot separate the memorial contributions from those made in honor of someone, as sometimes the person making the contribution does not let us know if the contribution is a memorial or in honor of their friend or family member.

Gordon & Marilyn Macklin Foundation	Russ Crystal Russell Crystal Charles Davis	Hubert Heard Alice Hicks Arthur Hollis	Diana Moxon Grace Mutschler John Norton	Mary Schlickbernd Lucia Schone John Schooley
The Gabe & Izzy Foundation	Jeannette Davis Michelle Deciantis	Jordan Hubbard Sydney Hubbard	John Ober Genevieve Olive	Mary Segura Derek Semler
Jennifer Alexander Crystal Allsopp Russell Anderson	Paul Dolan Olivia Douglass Joseph Drakos	Krista Humes Lisa Jaffe Jeff Kaun	Patricia Orr Laddy Ospanik Dave Paige	Terry Snider Joseph Stamer Wallace Stigsell
Diwan Arora Sharon Baggett Lynn Ball	Dawn Dudley Denise Dudley Margaret Duggan	Arnold Kaye Lisa Kelso Mary Kolakosky	Marylynne Pelletier Eric Petersen Gary Peterson	Peter Streuli Vicky Sullivan John Surabian
Brandon Barker Nancy Bellamy Rahul Bhide	Diane Dusiber Robert Ellsperman Trinity Falk	Jamie Kosieracki Marcella Kukulhan John Lane	Gerald Peterson Mark Peterson Nina Piatetsky	Sweeney Family Thorston Sword Katie Taylor
Dorothy Biniek Joseph Botelho, Sr. Ed Boyles	Robert Fischer Kevin Fleming Laureen Flynn	Soula Lane Kate Lapham Erica Lehrer	Ken Porter Wayne Quimby Charity Ranger	Joe Thell Gert Tracey Penny Tressler
Mike Bredberg Angela Brown Emma Brumbach	Maxine Freeman Albert Frei, Sr. Jon Frei	Tony Lewendon Rita Lobascio Angelo Matricciano	Bernie Reed Jennifer Reintjes Jim Richards	Kandy Turpin Denise VanVoorhis Barry Washburn
CAASG William Candia Peter Caparelli	Mary Jo Frei Donna Giles Richard Goldman	Earl McLaughlin Vivian Mestayer Connie Mitchell	Kathleen Richards Janet Riley Michael Robinson	David Westrick Dr. & Mrs. Richard Whipple
Eugene Clark Les Cooley Roger Cooley	Penny Golminas Richard Gregory Rob Guptill	Frank Mittan Minnie Molini Rosalie Moura	Faye Rose Donald Santa Croce Ace Santa Croce	Edith Whipple Stephanie Whipple Curt Williams
Nolan Cotton, Jr.	Bryon Hackett		Santa Croce Family	Robert Winslow ❖

Remembering NAF in Your Will

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

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 honored by their selfless commitment in helping others.

Over the years these individuals have given anywhere from a few thousand dollars to nearly one million dollars. Their forethought and benev-

olence has enabled the Foundation to support promising ataxia research and provide meaningful programs and services to ataxia families. It is because of these quiet heroes that many research studies and programs have been funded. Their kindness impacts ataxia families today and will be felt for years to come.

We are truly thankful for their humanitarian and compassionate acts and we will be eternally grateful for the impact they have made in helping ataxia families. Their legacy lives on in the hope they have given ataxia families.



National Ataxia Foundation

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

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

GIFT – HONOR – MEMORIAL

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

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

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

My contribution is:

- In Memory In Honor Gift Membership

Name _____

Occasion _____

Send Acknowledgment Card to:

Name _____

Address _____

City/State/Zip _____

From:

Name _____

Address _____

City/State/Zip _____

MEMBERSHIP

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

- Lifetime membership \$500

Annual memberships:

- Patron membership \$100-\$499
- Professional membership \$55
- Individual \$35
- Household \$55
- Addresses outside the U.S. please add \$15

Name _____

Address _____

City/State/Zip _____

Phone _____

E-Mail _____

- Yes, sign me up for NAF e-mails

PAYMENT INFORMATION

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

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

Total Amount Enclosed \$ _____

Credit Card: Visa MasterCard Discover

Name on Card _____

Card # _____

Exp. Date _____ CVV # _____

Signature _____

Phone Number _____