

# Generations

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*The Official Publication of the National Ataxia Foundation*

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## Frequently Asked Questions about the National Ataxia Registry

**What is the National Ataxia Registry (NAR)?** NAR is a web-based “contact” registry which collects essential information on patients with ALL types of ataxias so as to facilitate clinical research, including drug trials.

**Why is a Patient Registry for those with ataxia important?** Such a registry can be a key resource to facilitate and speed up clinical research in rare disorders such as the ataxias by allowing for rapid contact between researchers performing clinical studies and those ataxia patients who may be eligible and willing to participate in such research.

**Is this registry for all types of ataxia?** The NAR will accept persons with any type of “degenerative” ataxia. This registry is not for you if you have ataxia as a symptom from other diseases like strokes, a tumor, or multiple sclerosis, for example. But if your ataxia is a result of a degeneration of the nervous system, whether it is inherited or otherwise, you are encouraged to participate. Thus, persons with a diagnosis of any form of inherited ataxia (recessive, dominant, X-linked, mitochondrial, unknown genetic type with a positive family history) as well as patients with sporadic ataxia, ataxia with multiple system atrophy, “olivopontocerebellar degeneration (OPCA)”, gluten ataxia, GAD ataxia and idiopathic ataxia can be part of the registry.

**What is the process involved in becoming a participant?** If you decide to participate in the

registry, you can click on the link on the National Ataxia Foundation website to get to the National Ataxia Registry or go directly to the registry at [www.nationalataxiaregistry.org](http://www.nationalataxiaregistry.org). You will see some explanatory notes on the home-page of the registry; then you will be asked to provide essential contact information after you create a user ID and password. Please make sure that you remember your password. You will be able to open and read the informed consent document from the home page. Once you have provided the contact information, the principal investigator or the coordinator will call you to explain the consent form. Once you agree to be part of the registry, you will be asked to sign the consent form and mail it back. If possible please include the result of a lab test that establishes your diagnosis. The coordinator will then activate your account so that you can go back to the account and complete the process by entering your diagnostic information (i.e. the exact diagnosis that you have). Note that this is a two-step process and may take a few days to complete, but it only takes a few minutes for each step.

**Who will have access to this information?** The registry coordinator and principal investigator (Phuong Deleyrolle and S.H. Subramony, MD) and their approved colleagues at University of Florida will have access to the informa-

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***The deadline for the Fall issue  
of Generations is August 13, 2010.***

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tion you provide. Two mechanisms exist with regard to getting registrants in contact with investigators who may be performing research studies on particular ataxias. During the consent process, you will be asked if the NAR can release your information to researchers who may have an interest in you or if you want to get the researchers' contact information so that you can get in touch with them. This will allow access of information regarding specific participants to specific researchers. This process will be initiated only after a request from an investigator for any specific type of ataxia patient has been reviewed and approved by a committee of experts.

### What information will I need to provide?

As noted before, at the initial step, you will provide contact information to include the following: name, gender, date of birth, address, e-mail address, and phone numbers. Once you have formally signed the consent in response to a call from the coordinator, you will go back to the website and provide information regarding your diagnosis and some essential family history (no specifics of other family members will be needed). You will be asked to give some information regarding your current walking ability. You will be requested to periodically update your information.

**I don't have ataxia, but a family member does. Should I register?** The NAR encourages persons who are at risk for an inherited ataxia to become participants. Apart from stating that you are at "risk" as your diagnosis, you will be asked to provide the specific diagnosis that has been made in other family members. This is being done because persons at risk for genetic forms of

ataxia may become candidates for research in the future.

**I do not live in the United States. Can I still register?** At the present time, the NAR is designed only for those who live in the USA.

**I don't use the Internet. Can I still register and how?** Yes. Please contact Phuong Deyle-rolle at (352) 273-9194 and you will be mailed the consent form and the registry forms that you can complete and mail back.

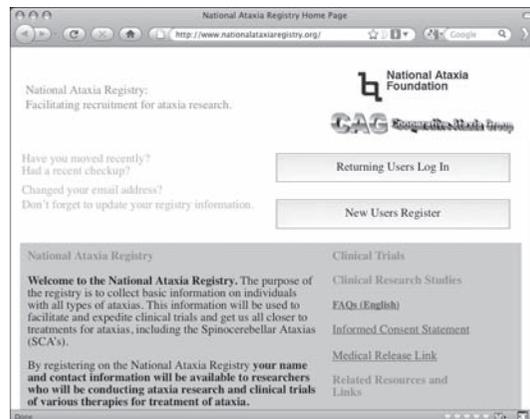
**I am already registered on the Registry at Emory University. Should I still register on this patient registry?** Dr. George Wilmot and Dr. S.H. Subramony are in contact with various

regulatory bodies to determine how a person's information that is already in the Emory patient registry can be transferred to NAR, the new registry. Further information will become available at a later date.

### Is the website hosting the National Ataxia Registry secure?

The web-based transfer of data submitted by participants will be done using a secure

system. To quote from the approved protocol: "For data transmission from the website to web server, an industry-standard encryption mechanism (SSL) will be used with all data being encrypted including user name, password and all other participant data (the same standard used by banks for online transactions). In addition, the passwords will be encrypted using a one-way mechanism (called Hash) before they are stored. There is no mathematical means to calculate the password from the encrypted data and even the database administrator cannot tell the user's passwords. If a password is forgotten, it will have to be reset. Participants will have password protected access to their accounts."



### NAR website

*FAQ about the National Ataxia Registry*  
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The web hosting company has assured us that the security certification will be displayed on the website.

**Will the potential users of the registry, such as pharmaceutical companies, be charged a fee for that use?** The informed consent that participants agree to states the following: “CAG (Cooperative Ataxia Group) and NAF reserve the right to charge third parties (such as pharmaceutical companies) a fee for registry data in order to cover some of the costs associated with the registry. It is possible that new treatments, medicines, therapies, or

products could be created from studies that use your data. If that happens, NAF, CAG, the Principal Investigator, and the University of Florida could receive significant financial benefits. You will not be offered any payment or any other financial benefit.”

This means that any fees generated (if at all) by allowing pharmaceutical or other companies use of the registry data will be used to offset the costs associated with the registry, which is jointly owned by NAF and the CAG. The financial benefits for the University and investigators mentioned are related to any revenue from additional research done using the participants identified in the registry and not related to any revenue from the registry itself. ❖

## ‘I Am the Strength Behind Ataxia’ Friends of NAF Personal Profiles

We are currently in the process of redesigning the National Ataxia Foundation’s current website, [www.ataxia.org](http://www.ataxia.org). We invite you to become a part of NAF’s new website by participating in a new section called “I Am the Strength Behind Ataxia,” which will feature personal profiles from the ataxia community.

Below is a listing of the information that should be included with your personal profile. Ataxians, family of ataxians, friends of ataxians, and ataxia medical professionals are all encouraged to send in a profile. Please limit your profile to 250 words.

The following is an *example* of the information we ask you to submit:

- **Self/Family Picture:** A photo in JPEG format
- **Name:** Mary Anderson
- **How are you impacted by ataxia:** Diagnosed with SCA 7 at age 23 and have other family members affected by ataxia.
- **Your actions to help the ataxia community and efforts to build awareness:** For the past two years my family and I have observed International Ataxia Awareness Day by conducting an

NAF event to raise ataxia awareness in our community and funds to help support the important work of NAF.

• **The impact of NAF programs and support in your life and ataxia community:** NAF’s local ataxia support group has given my family and me an opportunity to meet other ataxians who share the same issues and challenges. The support group brings in speakers who help address many questions and concerns that my family and I have regarding ataxia. Perhaps even more importantly, the friendships I have developed through my association with the support group. As a member of NAF, I receive the quarterly news publication *Generations*, which informs me of the current ataxia research efforts being conducted throughout the world, along with personal glimpses into the lives of fellow ataxians who share many of the challenges I face.

• **City, State, and Country:** Minneapolis, MN, USA

Please submit your profile for review and consideration to [lori@ataxia.org](mailto:lori@ataxia.org).

We welcome your submission. Thank you!

# Psychological Aspects of Genetic Testing

By John Rolland, MD

*The following was presented at the 2010 NAF Annual Membership Meeting in Chicago, IL and edited for publication in Generations.*

Diseases are handled in a family context. Ataxia affects all aspects of family life. Some family dynamics can positively affect how people deal with their disease and also can adversely affect it. The key question I go over with families is “what’s the fit between your family’s strengths and vulnerabilities and the demands of ataxia over time?” All of us, all families, all of us as individuals have our strong points and then the areas where we’re more vulnerable. Some families are better at communicating about practical issues and some families are better at communicating about emotional issues. I think it is particularly important, to have an understanding of yourselves as a system ... How [does your family] think into the future together as a team?

## **A psychosocial understanding of ataxia**

Questions to ask ... When in the life cycle does it occur? What part of your development and what part of your life is it going to affect? Are there treatments that are available that will make things better, or are there no treatments? How severe is it, what ways is it going to be disabling? What parts of your life might it interfere with and what parts might it not interfere with and how do we [as a family] work around that?

## **Understanding developmental issues**

The health care team is interested in how a disease progresses. The thing that’s left out of that is also where is the family in its development? In other words, if you’re starting a family, if you’re getting married, if your kids are leaving home, or if one individual is about to leave

home – those transition points are very crucial and often are when people feel they’re having more psychological difficulty. That can go under the radar of the health care team because the health care team only notices generally if there is a medical change. But some people living with many chronic diseases nothing has changed medically, but someone is leaving home – for example graduating high school or getting married. All those things often create a crisis. So what I often do is help families think “when is there a transition coming up in your family?” either for an individual family member or for the whole family as a system, and what are the beliefs that guide you as a family?

## **Pre-testing**

Considering who may be at risk and who to inform [about genetic testing] I think is particularly important. I think there’s a very fine line between privacy and a secret. I pay a lot of attention to if someone is going to be the first one to get tested, who in the family has been included, and who might not be communicated with? There’s ways of informing people but keeping your own results and your own decision private. How might decisions impact family members? I have fairly strong feelings about including a spouse or partner in the decision-making.

## **Pre-selection and unexpected results**

Pre-selection and unexpected results are particularly important. Two questions I’ll ask “are

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there ways you and your family already have organized your lives in relation to beliefs about your genetic risk?” And what would be the possible implications for you and your family if you get results or unexpected test results?”

**Accepting living with ataxia  
as a shared challenge**

I think of a physical burden and care-giving burden as forms of currency. The difficulty is for most people when they're worked up for a disease like an ataxia, and then the spouse or partner is not included, there is no “we” that is created. When people are worked up for a medical condition in a hospital, families are asked to step aside. And then when that disease is diagnosed, the treatment planning, it's all about the patient, because that's what hospitals and physicians do. So there's no “we” created, where the care-giving burden can be viewed as sort of an equal currency as the physical burden. Most of the problems I see in families or in couples as they live with chronic conditions, like ataxia is the imbalances that occur over time and they start when it's not viewed as a shared challenge. If we're a family and I say “it's my disease” I'm setting up an imbalance between us that over a period of years is going to take on a life of its own. As opposed to [understanding] the physical burden and care-giving are another form of currency, and if you can get families to view things that way, a lot of the difficulties I see psychosocially that families or couples are dealing with could be averted or certainly ameliorated and not be as severe.

When people are tested you do create two subgroups in a family, those that are tested that are positive, those that are tested that don't have a mutation, and those who are still at risk who haven't chosen to be tested. The ones who haven't chosen to be tested psychologically in some ways are a little closer to the person who

tested positive. They're not out of the woods. The people who found out “I don't have it” are free and clear of that. When part of the family does get tested that does create a kind of imbalance, and it does change the nature of relationships sometimes in a family. If you're at risk for a disease you're not getting regular medical attention. So often families get into difficulties later, either the psychology of living with a condition or even some of the care-giving difficulties that they're starting to have. Families will often say to me “we can handle it” and they find out it's more complicated. It's not like you're running a sprint, it is more like a century bike ride where you have to pace yourself.

**Communication and families**

Who is going to be included and excluded from conversations and why? What topics are off-limits and why? One of the things I do when I meet with a family or couple is ask them “what topics do you think about a lot but you don't bring up because you're afraid your spouse or other family members would be very upset if you tried to talk about that?” I have people make lists, and the overlap on those lists is over 80 percent. Usually what happens – families say “oh you want to talk about that too, I didn't know that.” So it's very useful to go home as a family and make a list of what things would you like to talk about but you feel you shouldn't because it would be too risky to your relationships.

Living with chronic diseases means stretching the envelope. I find families where they're often very tentative about talking it's not because they won't but because there's more to talk about (things you're not accustomed to talking about).

**Communication with children  
and adolescents**

There's no evidence that kids are hurt by age-appropriate information. If a kid asks a question I feel like they need some kind of an answer, not “we'll talk about that in eight years.” If a child or an adolescent has formulated a question it means they've got something on their ▶

mind. Certainly living in the day of the Internet, people have way more information, some of it inaccurate. Again, what is a problem in families is blocked communication that's associated with isolation, anxiety and depression for everybody.

If you come from a family where you come from a different ethnic or cultural background, often a chronic illness or living with genetic risk will bring up beliefs that you didn't know how different you were. Sometimes we say we live in a multi-cultural diverse society, where my spouse is from a different background and we enjoy eachothers' differences. In the face of chronic illness or when there's a health risk often those differences become like the Grand Canyon. One spouse might say "I don't want other people in the family to know about this" and the other spouse will say "well, I come from a family where we do all talk together." Who's allowed in as a caregiver, what kind of communication and who's included are often things that people haven't had to consider in the face of a chronic illness. Sometimes you're bringing in extended family members, and cultures are very different.

### **Living with uncertainty**

The bottom line is I think acknowledging the possibility of what may happen or future complications generally in my experience is a lot healthier than everybody sort of acting like there aren't any. Because people think about things, they often know them. So I think acknowledgment openly – that doesn't mean it's going to happen or we can't deal with it, usually is a lot healthier for families. Building flexibility into your life planning so whatever you're planning you also have a Plan B. So there's not just one way you can live your life. Because with genetic conditions there's a lot of uncertainty about how things might unfold, will they unfold, when will

they unfold.

I think it's important in families to discuss what can be done by the person with ataxia for themselves? What needs a family care-giver? What are the limits of all of that, and when would professional caregivers be needed? And what's the meaning to the relationship of being in a care-giver role? One of the things that's really hard for couples is you have your marital relationship or partnership and then you have sort of a care-giver/patient role. And those roles are very different – and how do you move from one to the other and how do you balance that is one of the main challenges for people dealing with these conditions.

### **Keeping ataxia in its place**

It's very important to keep ataxia in its place. I find it very useful for families to arrange a time to discuss ataxia-related issues. To find times that you can agree to talk about it, rather than "I have to talk about it right now." I'm a big advocate of family support-groups. Discussion groups where families can meet as families.

When ataxia develops or if there is genetic testing [performed], where are you in your life-cycle? What did you bring from your past to this situation? What's the impact on future planning? If I was meeting with you I would ask what kinds of illnesses you had in your family growing-up and how did you organize yourselves, what did you learn from these experiences? And what are the learned differences among key family members? For some of you who are couples, in the face of a chronic disease you may have learned very different things growing up about how to manage a chronic illness that wouldn't have been evident in your relationship before somebody had ataxia.

I like to think ahead about what transitions are



**Dr. John Rolland**

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coming up. Over the next three to five years are they any major family transitions or any individual transitions, for example if you have a kid who is a sophomore in high school, in two years they will be a senior in high school that's a major transition, often where sometimes adolescents will get into difficulties if there's a parent with a chronic illness or disability.

If you're planning to start a family, you're taking a very different perspective on life; you're making a 20-year plan. So if somebody might get an ataxia during those 20 years and it could be genetically transmitted, that's something that for a couple is a major thing to consider. Not what's the right or wrong decision, but you're no longer

doing a day-to-day relationship and you're thinking over a much longer term.

It's often during life transitions that your anxieties or concerns about threat and loss come up. I would ask you if there are things in your life that you won't do because you might have ataxia or because you will be developing ataxia at some point. Sometimes people over-step and cancel too many life plans, and some people underestimate.

Sometimes families make plans together about who's going to caretake whom, and you do that at one point in time. But in three or four years people's lives may change. I always say you need to go back every year, every two years, or any time there's a major change and re-discuss how that affects the decisions that you've made. ❖

## Generations Submission Guidelines

*Generations* is the official news publication of the National Ataxia Foundation (NAF). Produced quarterly, this 48-page newsletter contains a wide range of articles and information about ataxia and the activities of the National Ataxia Foundation.

Issues of *Generations* include:

- Articles about the latest ataxia research
- Information about ataxia therapies, treatments, and health strategies
  - A listing of NAF-supported ataxia support groups throughout the United States and abroad
  - Personal stories from readers
  - Updates and articles from ataxia support group leaders, researchers and the NAF staff
  - Information for caregivers
- Articles about accessibility products and services
  - Reports from the NAF office
  - A calendar of events
  - And much more!

If interested in submitting an article for possible publication in *Generations*, please refer to

the following guidelines for submissions:

### Guidelines for Submitting an Article

- Send your personal story or article to [liz@ataxia.org](mailto:liz@ataxia.org) or by mail to the following:  
National Ataxia Foundation  
Attention: Liz Werner  
2600 Fernbrook Lane, Suite 119  
Minneapolis, MN 55447
- Personal stories and articles should contain a title
- Submissions should not exceed 1,200 words
- Articles should be written in layperson language
  - Photos or relevant graphics are encouraged
  - Submissions may be edited for length and structure
  - The article's tone should be consistent with our organization's editorial style

Please note that articles are reviewed for content, clarity, readability, and relevance. All articles that are submitted are *not* guaranteed publication.

# Ataxia and Riding: Disability Does Not Equal Inability

By Adam Payne

As some of you know there is a small but growing group of ataxians who enjoy riding their bikes a lot longer and harder than people think they can. Some of us even consider ourselves bikers. I have no problem admitting that I am a member of this group. This article is meant to explain why I believe that my increased riding and the exercise that comes with it have bettered my life.

This disease could cause anyone to become depressed. When I was diagnosed 12 years ago I was depressed. My thoughts ran along the lines of, “You can’t do anything now. Oh well, 26 years was a long enough time.” Even with the wonderful advancements that we hear about at the annual convention, I find it easy to feel hopeless that we will ever find a cure. Most of the drugs we hear about are tested on mice, and last I looked I was not a mouse.

My treatment for the times when things aren’t working right is to go exercise. My preferred exercise is riding a bike but that’s not always possible. I live in New York City and even when the weather is perfect sometimes I just can’t go for a ride. That’s when I go to the gym.

My intensity level is pretty high. This winter a friend and I were talking about the number of centuries (100-mile rides) I’ve done and honestly I couldn’t say. It’s somewhere between 10 and 20. I live by the saying “disability doesn’t equal inability.” For me this means that I spend my life trying to disprove what people think a disabled person should do. I was diagnosed in ’97 and started doing AIDS Rides in ’99. AIDS Rides are

three- to four-day bike rides that cover many hundreds of miles. I also live by “whatever doesn’t kill me makes me stronger” and “no pain, no gain.” Every summer I ride in the five borough bike ride plus many other sponsored rides around NYC. I also rode in Ride Ataxia 3 from Portland to Seattle. Summer weekends usually find me off riding somewhere.

All of this riding has made my muscles stronger, which can only help fight the imbalance. It has also, unexpectedly, improved my outlook on life. After you work out you begin to look and feel better. Suddenly you find that things that were obstacles; things both mental and physical that had the power to stop you dead, aren’t obstacles any more.

It’s hard to describe the mental improvements, but I think it’s enough to say that I am currently a second year graduate student studying for my masters of social work. I will leave school with my degree in August.

Exercise isn’t a cure for ataxia. For that I will wait for doctors and I’m sure I will be falling down while I wait. Exercise is, however, something to do that will help to fight off the depression that comes with this life changing diagnosis.

Also, my style of exercising is just that: my style. You may not want to, or be able to, do what I do. That’s fine. All I’m asking is that you do *something*. Exercise and biking work for me but I’ve met ataxians who ride horses, who ski, who jump out of airplanes, or who go snowshoeing.

Remember this is about you, not anyone else. Disability does not equal inability! ❖



# NAF Needs Your Help

In these uncertain economic times, the National Ataxia Foundation more than ever appreciates your commitment and financial sacrifice in supporting the important work of the Foundation. Here are just a few ways in which you can help further the goals of NAF:

- Become an NAF Member and encouraging others to become members as well
- Support the NAF Annual Membership Meeting Fund
- Support the NAF Annual Ataxia Research Drive
- Stock Donations: Directly donate appreciated securities such as stock to NAF.
- Deferred Giving: Remember NAF in your will
- United Way Giving: Designate your United Way gift to NAF
- Employer Matching Gift Program: Ask your employer to match your gift to NAF
- Combined Federal Campaign (CFC): NAF's CFC number is 10752
- Vehicle Donations: Donate your car, truck, or van to NAF
- Shopping on the Web: Designate NAF as your charity of choice on the online shopping mall iGive.com and a portion of each purchase will be donated to NAF
- Surfing the Internet: Designate NAF as your charity of choice each time you search the internet through *iSearchiGive.com* or *GoodSearch.com* and a donation will be made each time you make a search online
- Memorials/Honor Of: Remember and honor family and friends
- Online Donations: You can become a member, support research, make a gift "In Memory Of" or "In Honor Of" support the NAF Annual Membership Meeting Fund and much more by going online at [www.ataxia.org](http://www.ataxia.org).
- Pledging: You can make monthly, quarterly,

or annual pledges to NAF

- Local Support: Ask your local civic groups to help support NAF
  - Host Your Own NAF Fund Raiser: Contact NAF or go online at [www.ataxia.org](http://www.ataxia.org) for a fund raising kit, guidelines, and an application form
  - Individual Donations: Make a donation in support of NAF programs
  - Family Funds: Families pool your money together to support NAF programs and research
  - Volunteer: There are many ways you can volunteer to help through your local NAF ataxia support group or chapter for various events and activities
  - Participate: Be part of a clinical trial or participate in a survey
  - Gift Membership: Give a Gift Membership to a friend or family member
  - Individual E-mail/Letter Writing Campaign: Email or write your friends, co-workers, family members and others to encourage them to support NAF
  - Individual Ataxia Awareness: Set a goal to tell one person each day about ataxia and NAF
  - Support NAF Walk N Rolls: For information go to [www.ataxia.org](http://www.ataxia.org)
  - Purchase and wear ataxia awareness apparel (see page 12 of this issue of *Generations*) to order
  - Designate NAF as a beneficiary on your insurance policy
  - Getting married? Register at [www.IDoFoundation.org](http://www.IDoFoundation.org) to designate NAF as the recipient of your charity registry
- These are just a few ways that you can help support the continuing efforts of the National Ataxia Foundation. If you have other ideas or opportunities to raise much needed funds for the Foundation or ataxia awareness, please let us know. NAF truly appreciates all that you doing in giving help and hope to the ataxia community. Thank you!



## From the Desk of the **Executive Director**

This year's theme for the National Ataxia Foundation's Annual Membership Drive is "I Am the Strength behind Ataxia." The theme was created by a very talented young woman, Lealan D.M. LaRoche, who won the NAF International Ataxia Awareness Day t-shirt contest. The theme means many things to many people: strength within our self, strength of family and friends, and strength of others. The strength behind ataxia can also be seen through volunteer efforts, letting people know about ataxia, getting involved with a local ataxia support group, conducting an NAF fundraiser, and through your NAF membership support.

What does it mean to be an NAF Member? Membership is really a partnership between you and the Foundation. As a member you are a stakeholder in the organization, investing in NAF's capacity to provide important programs and services.

An NAF Membership contribution allows the Foundation to continue its important work in serving the ataxia community.

Membership support helps pay for the printing of important ataxia publications, the maintaining of our website, and the developing of support groups and ataxia awareness programs. Membership donations also help with operational support of the day-to-day costs of doing business, such as office rent, supplies, database, postage, and staff.

As a member you are strengthening the organization's ability to help better serve ataxia families, bringing world-class researchers together through programs such as the NAF Ataxia Investigators Meeting (AIM), and offering a multi-day ataxia conference through the NAF Annual Membership Meeting. Member-

ship support also helps in the development, printing and distribution of *Generations* and the expansion of ataxia social networking sites.

Knowing that there is an organization just a phone call or e-mail away whose only purpose is to help is critical to ataxia families. Membership donations make a significant difference in NAF's ability to provide these and many other programs and services.

Current NAF members receive the quarterly 48-page news publication "Generations" and registration discounts in attending the NAF annual membership meeting.



**Michael Parent**

Each year NAF conducts an Annual Membership Drive in June and an Annual Ataxia Research Drive in October. There are distinct differences, however, between these drives and the use of funds received through these drives. Membership contributions help provide for the operational costs and many of the Foundation's programs and services. Research donations made through the annual ataxia research drive help support promising world-wide ataxia research. Each drive is extremely important in addressing key issues in the Foundation's ability to serve ataxia families. Your support of both of these drives is essential in maintaining and expanding the Foundation's efforts in funding vital ataxia research and providing meaningful programs and services.

NAF welcomes new, renewing, and pledging members. Today we invite you to become a member as we kick off the NAF Annual Membership Drive. You will be receiving a letter soon asking for your support through the annual membership drive or you can make a secure on-line membership donation today at [www.ataxia.org](http://www.ataxia.org). Thank you. ❖

# NAF Merchandise

## BOOKS

**There's Nothing Wrong with Asking for a Little Help: and Other Myths** by Dave Lewis  
A man's experiences living with Friedreich's ataxia. Proceeds support FA research. Paperback. \$15.95

**Summer Born** by Cheryl Wedesweiler  
Fictional story of a teenager who courageously faces cerebellar ataxia. Paperback. \$15.95

**Three Wheels** by Rebecca Cummings Baldwin  
True personal, heart-warming story of a woman with ataxia. A portion of the proceeds supports the NAF. Paperback. \$15.99

**Ten Years to Live** by Henry Schut  
The story of the Schut family's struggle with hereditary ataxia. Paperback, photos. \$8.75

**Living with Ataxia** by Martha Nance, MD  
Ideas on how to live with ataxia. See review on page 15. Paperback. \$14

**Healing Wounded Doctor-Patient Relationships** by Linda Hanner and contributor John J. Witek, MD  
Learn better ways to communicate with your medical care providers. Paperback. \$10

**Friedreich's Ataxia Research Cookbook**  
Julie Karjalahti published this cookbook to raise money for FA research. \$12

**Recipes and Recollections** by Kathryn Hoefler Smith  
Full of delicious recipes and recollections. Proceeds go towards FA research. Paperback. \$10

**Managing Speech & Swallowing Problems** by G.N. Rangamani, PdD, CCC-SLP  
A basic guide to understanding and managing speech and/or swallowing problems. \$7.50

**Evaluation and Management of Ataxic Disorders, an Overview for Physicians** by Susan L. Perlman, MD  
A guide for physicians treating ataxia patients. Paperback. \$5

| Description | Qty. | Size | Each | Total |
|-------------|------|------|------|-------|
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## 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**  
Continuation and expansion of "Together There is Hope." 50 minutes. VHS \$20 or DVD \$25

## SHIRTS / MISCELLANEOUS

**International Ataxia Awareness Day T-Shirt**  
Available in youth L, and adult S-XXXL. \$10

**2010 Annual Membership Meeting T-Shirt**  
Gray, long-sleeved with the "Winds of Progress" 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 M to XXX-large. *Womens* – Light blue w/ navy embroidered NAF logo. Sizes S 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

**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**

NAME: \_\_\_\_\_

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# 8th Annual All California Ataxia Research Meeting (ACARM)

The 8th Annual All California Ataxia Research Meeting (ACARM) will be held on Sunday, Dec. 12, 2010 at the Holiday Inn Northeast in Sacramento – 5321 Date Ave. Sacramento, CA 95841.

The day-long conference will be held in the Aviator Room and will include presentations from Drs. Heike Wull, Lisa Ellerby, Susan Perlman, Leslie Thompson, Theresa Zesiewicz, Jan Nolta, and David Schaffer.

This meeting is organized to provide hope for those with ataxia in California, the West Coast, and around the world. Attendees are encouraged to stay overnight at the hotel, although it is not required.

Arrangements have been made with the Holiday Inn Sacramento Northeast for Saturday, Dec. 11, 2010 for room accommodations at a special rate of \$79 per night. Ask for the ACARM meeting rate when contacting the hotel. If you need an ADA room please mention that when making your reservation. Contact the Holiday Inn Sacramento Northeast at (916) 338-5800 or visit their website [www.sacnortheast.com](http://www.sacnortheast.com). If you are unable to reserve an ADA room at this hotel, there are several motels in the area that should be able to accommodate this request.

Lift-equipped transportation to the airport is available. The following transportation services may be helpful:

- Super Shuttle – (800) 258-3826 (call at least

24 hours in advance)

- Direct Line – (916) 727-0403
- Med Star – (916) 561-5905
- Paratransit – (916) 429-2744 (local users must

pre-register with this service by calling (916) 557-4685. Registration may take up to 21 days. Out-of-town visitors may also use the service if they are registered with a similar service in their hometown. To make a reservation, call at least two days in advance.)

To register for the meeting, fill out the ACARM registration coupon below and return it and the non-refundable meeting payment of \$35 no later than Dec. 8, 2010 to Joanne Loveland, 1980 St. George Rd., Danville, CA 94526. Be sure to note your meal choice on the form.

You are invited to the “Get Acquainted” dinner on Saturday, Dec. 11, at the hotel’s restaurant. Please arrive at 6 p.m. for a \$7.95 – 16.95 per plate at-your-cost dinner.

The meeting begins on Sunday at 8:30 a.m. with check-in, coffee, and “mix and mingle” time. The first speaker is scheduled at 9:30 a.m. The meeting will end at 4 p.m. after an hour-long “Q and A session” with the presenters. Come and enjoy a day of research into the ataxias.

For more information contact Mike Fernandes at (925) 516-6906 or [fernandesml@comcast.net](mailto:fernandesml@comcast.net) or contact Joanne Loveland at (925) 735-7037 or [joanneloveland@gmail.com](mailto:joanneloveland@gmail.com).

## ALL CALIFORNIA ATAXIA RESEARCH MEETING (ACARM) REGISTRATION FORM

*Sunday, December 12, 2010 • Holiday Inn Sacramento Northeast – The Liberty Room*

|  |   |
|--|---|
| <p><b>Attendees’ Names (please print):</b></p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p>   | <p><b>Non-Refundable Payment Enclosed:</b></p> <p>Lunch &amp; Program (\$35 x number attending):      \$ _____</p> <p>Voluntary Donation:      \$ _____</p> <p><b>Check Total (payable to ACARM):</b>      \$ _____</p> |
| <p><b>Choose one lunch by checking one box:</b>    <input type="checkbox"/> Roast Turkey Sandwich    <input type="checkbox"/> Honey Baked Ham Sandwich</p> |   |

Mail registration coupon & check payable to **ACARM** (must be received by Wednesday, Dec. 8, 2010) to:  
**ACARM, c/o Joanne Loveland, 1980 St. George Rd., Danville, CA 94526**

# Ataxia Researchers: Searching for Answers at the Third Ataxia Investigators Meeting

By Sue Hagen, Patient Services Director at NAF

When researchers for any disease gather together, new knowledge and discoveries are presented that moves the entire field of study closer to understanding the cause of the disease. This type of collaboration is the basis for which treatments and cures can be discovered.

It is with this goal that the National Ataxia Foundation began facilitating the Ataxia Investigator's Meeting. In 2005 the first meeting, under the leadership of Dr. John Day, was held in Tampa, FL. Dr. Day organized the next meeting in 2008 in Las Vegas, NV. In March of this year, Dr. Christopher Gomez, member of NAF's Medical Research Advisory Board and Professor and Chair of the Department of Neurology at the University of Chicago was the lead organizer for AIM 2010 in Chicago. Each of these meetings has brought together junior and senior ataxia researchers from around the world.

The goals for the AIM 2010 were fourfold: to hold a conference on cutting-edge ataxia research, to facilitate common international approaches to ataxia research, to improve expo-

sure and training opportunities for junior ataxia investigators and to stimulate discourse and fruitful exchange by combining keynote speakers, senior investigators and junior investigators.

The 121 attendees of the meeting came from five continents and represented the following countries: the United States, Canada, Brazil, England, Germany, Italy, France, Belgium, Spain, Portugal, Japan, China and Australia.

The two-and-one-half day meeting included four high level keynote speakers, 25 presentations from senior investigators, four junior lecturers who were selected because of the quality of the abstracts that they had submitted for the poster session, and 35 posters presenters. Themes for the meeting were cerebellar function (and episodic) dysfunction, the molecular pathogenesis of autosomal dominant and recessively inherited ataxias and moving toward therapy: novel strategies and outcomes measures in ataxia.

According to Dr. Gomez, the high points of the meeting were the new junior investigators who will hopefully pursue careers in ataxia research, ►►



Participants at the Third Ataxia Investigators Meeting in Chicago

the recent ataxia news that was announced at the meeting (the discovery of four new ataxia genes), 21 presentations on potential therapies for ataxia and the genome-wide molecular genetic studies on multiple system atrophy (MSA), the most common sporadic ataxia.

Because of the many ataxia researchers who were present at this meeting, it provided the opportunity for two additional smaller meetings, which included the recently formed Clinical Research Consortium for the Spinocerebellar Ataxias and a meeting on cellular models and stem cell therapy for Friedreich's ataxia.

Important meetings like this could not happen without financial support from other Foundations and organizations. NAF is grateful for the support for the AIM 2010 from NINDS/NIH, ApoPharma, Athena Diagnostics, A-T Children's Project, Ataxia UK, Friedreich's Ataxia Society – Ireland, Bob Allison Ataxia Research Center, an anonymous private family ataxia research fund, FARA, Friedreich Ataxia Research Association (Australasia) and Santhera.

Members of the AIM 2010 Steering Committee included (left to right below) Stefan Pulst, MD; Harry Orr, PhD; Laura Ranum, PhD; Robert Wilson, MD, PhD; lead organizer Christopher Gomez, MD, PhD; Alexandra Durr, MD, PhD; and Henry Paulson, MD, PhD.

The NAF is grateful for the commitment of these researchers to move ataxia research forward to find answers to treating this disease. ❖



Members of the AIM Steering Committee

## Book Review: Living with Ataxia

By Martha A. Nance, MD  
for the National Ataxia Foundation

Originally published in 1997, the second edition of the book *Living with Ataxia*, was updated and printed in 2003. Although there have been new genes identified and more ataxia research done worldwide, this book continues to provide timely information to help those affected by ataxia and their family members understand what ataxia is and how it can affect a person physically and emotionally.

Important topics about ataxia are divided into three sections, which include "Understanding Ataxia," "You and Your Doctor" and "Managing Your Life with Ataxia."

This illustrated book is written in lay language and is useful for learning about the disease and positive ways to approach managing and coping with all forms of ataxia. It is also an excellent tool for building ataxia awareness for those who do not know what ataxia is or how it affects a person who has ataxia.

The following excerpt is from the introduction: "With or without ataxia, we all have good and bad experiences, joys and disappointments. The diagnosis of ataxia will most likely mean letting go of some prior goals and dreams. It might no longer be feasible to be captain of the football team or climb a mountain, but one can set new aspirations. People with ataxia can still be loving parents and friends, and active, contributing community members."

The National Ataxia Foundation has been providing this resource to those with ataxia and their families for over 10 years. This book continues to offer valuable information so that people understand that living a good life is an entirely reasonable aspiration, even with ataxia.

The book is \$14 plus shipping and can be ordered on-line at [www.ataxia.org](http://www.ataxia.org) or by using the order form on page 12 in this issue of *Generations*.

# Caregiver's Corner

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

## Home Safety – Kitchen & Bathroom

### *A Little Slip Can Ruin the Day*

Home Sweet Home can be a dangerous place. Falls, sprains, strains, and burns are a common source of injuries for older adults. In planning for home safety, follow a few simple guidelines, adapting them to your own needs:

**Smooth sailing.** Transitioning from outside the home to inside, from downstairs to upstairs, and from room to room should be as smooth as possible. Think level thresholds, nonskid flooring, and no loose rugs or carpeting to snag feet, walkers, canes, or wheelchairs.

**Light up.** Not only does ample lighting prevent falls, it deters crime. Well-lit pathways, entrances, and driveways scare off burglars.

**Level the playing field.** Keep work surfaces, frequently used drawers, tables, countertops, and storage areas at a comfortable height, to prevent the need to reach up high or bend down low to retrieve items or complete tasks.

### *The Kitchen*

The kitchen can be filled with booby traps for the unwary. Dangers include cuts from sharp knives, burns and scalds, and injuries from reaching and bending.

To keep safe handicapped or elderly people who enjoy helping in the kitchen, follow these tips:

### *Kitchen Safety Tips*

- Use an electric teakettle.
- Install microwave ovens at countertop height, not over-head, to reduce the chance of spills.
- Set the water-heater temperature below 120° F.
- Use a single-lever faucet that can balance

water temperature.

- Provide an area away from the knife drawer and the stove where the person in your care can help prepare food.
- Use a microwave oven whenever possible (but not if a person with a pacemaker is present).
- Ask the gas company to modify your stove to provide a gas odor that is strong enough to alert you if the pilot light goes out.
- If possible, have the range controls on the front of the stove.
- Provide a step stool, never a chair, to reach high shelves.

### *Kitchen Comfort and Convenience*

- Use adjustable-height chairs with locking casters.
- Install a Lazy Susan® (swivel plate) in corner cabinets.
- Set up cabinets to reduce bending and reaching.
- Put in a storage wall, rather than upper cabinets.
- For easy access, replace drawer knobs with handles.
- Place a wire rack on the counter to reduce back strain from reaching for dishes.
- Adapt one counter for wheelchair access.
- Remove doors under the sink to allow for wheelchair access; cover exposed pipes.
- Create different counter heights by putting in folding or pull-out surfaces.
- If bending is difficult, consider a wall oven.
- Install pullout shelves in cabinets.
- If possible, use a fridge that has the freezer on the bottom.
- Prop the front of the fridge so that the ►►

door closes by itself. (If needed, reverse the way the door swings.)

### **The Bathroom**

Many accidents happen in bathrooms, so check the safety of the bathroom that you will use for home care. Best safety improvements are:

- Shower chair
- An open-plan or walk-in shower stall with a low curb
- Nonskid flooring
- Grab bars

### **Bathroom Safety Tips**

- Cover all sharp edges with rubber cushioning.
- Install medicine cabinet lighting, so mistakes are not made when taking medicine.
- Remove locks on bathroom doors.
- Use nonskid safety strips or a nonslip bath mat in the tub or shower.
- Put a grab bar (instead of a towel bar) on the edge of the vanity.
- Remove glass shower doors, and replace them with unbreakable plastic or shower curtains.
- Install ground-fault interrupter (GFI) electrical outlets and use only electrical appliances with a GFI feature.
- Set the hot water thermostat below 120°F.
- Use faucets that mix hot and cold water, or paint hot water knobs red.
- Insulate (cover) hot water pipes to prevent burns.
- Install toilet guard rails, or provide a portable toilet seat with built-in rails.

### **Note**

To reduce the chance of falls, and to avoid reaching and bending, store frequently used items at a level between the shoulders and knees.

### **Falls**

According to the Centers for Disease Control

and Prevention (CDC), an older adult is treated in a hospital emergency room for a fall every 18 seconds, and every 35 minutes an older adult dies as a result of a fall-related injury. Among older adults, falls are the leading cause of injury deaths, and the most common cause of nonfatal injuries and hospital admissions for trauma.

To reduce falls in older adults, experts recommend a physical activity regimen with balance, strength training and flexibility components. Consult a health professional about getting a fall risk assessment and making sure the home environment is safe and supportive.

### **Bathroom Comfort and Convenience**

- If possible, the bathroom should be in a straight path from the bedroom of the person in your care.
- Put in a ceiling heat lamp.
- Place a telephone near the toilet.
- Provide soap-on-a-rope, or put a bar of soap in the toe of a nylon stocking and tie it to the grab bar.
- Try to provide enough space for two people at the bathroom sink.
- If possible, have the sink 32–34 inches from the floor.
- Use levers instead of handles on faucets.
- Provide an elevated (raised) toilet seat and place toilet paper within easy reach.

### **Taking Care of Yourself— Breathe Like a Baby**

Ever watch a sleeping baby? Babies breathe “from their bellies,” taking deep, lung-filling breaths that make their tummies rise and fall. Adults under stress, on the other hand, tend to take short, shallow breaths that use only the upper chest muscles. This shallow breathing means less oxygen for the body and brain, and can leave you feeling tired and unfocused.

Practice diaphragmatic breathing: When you

*Caregiver's Corner**Continued from page 17*

breathe in using your diaphragm – a thin, plate-like muscle lying deep inside your abdomen – your belly should round and fill like a balloon; as you exhale, your belly should slowly deflate. It's sometimes hard to remember to take deep, calming breaths when you're stressed, so keep a visual reminder on hand, such as a picture of a peaceful place with the word "Breathe" written on it.

**Quick Quiz**

Falls, sprains, strains, and burns are a common source of injuries for older adults. In planning for comfort and safety at home, think ahead. Have a plan that will be helpful and more accommodating to those who may want to stay in the home as they age or require care.

Read the article and answer True or False to the questions below to test your knowledge:

1) Dangers in the kitchen include cuts from sharp implements, burns and scalds, and injuries from reaching and bending. T F

2) Have level thresholds, nonskid flooring, and no loose rugs or carpeting to snag feet, walkers, canes, or wheelchairs. T F

3) A gas odor that is strong enough to alert you if the pilot light goes out is not helpful for kitchen

safety. T F

4) Either a step stool or a chair is equally safe to reach high shelves. T F

5) The water-heater temperature set at or below 120° F is safest to prevent scalds. T F

6) It is convenient to remove doors under the sink to allow for wheelchair access, but it is then especially important to cover exposed pipes. T F

7) Grab bars and nonskid flooring in the bathroom will prevent falls. T F

8) Among older adults, falls are the leading cause of injury deaths, and the most common cause of nonfatal injuries and hospital admissions for trauma. T F

9) If bending is difficult, a soap-on-a-rope or a bar of soap in the toe of a nylon stocking tied to the grab bar will make showering easier. T F

10) Removing the locks on the bathroom door will keep the person from accidentally locking himself in. T F

**KEY:** 1) T; 2) T; 3) F; 4) F; 5) T; 6) T; 7) T; 8) T; 9) T; 10) T.

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## Vehicle Donation

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

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

Thank you in advance for your donation.

## iSearchiGive

*iSearchiGive.com* is a search engine powered by Yahoo! Search and *iGive.com* is the internet's first online shopping mall where a portion of each purchase is donated to a charity of your choice.

Sign up today and indicate that NAF is your favorite cause. It is totally free with no hidden fees and provides support for the important work of the National Ataxia Foundation.

Thank you for searching and shopping.

## Book Release

# View from an Apple Tree: a Memoir of Courage

By Anna Sharon Logan

My name is Anna Sharon Logan; I have Friedreich's Ataxia. I was diagnosed in July 1959, at age 12, after a month's stay in the Philadelphia Naval Hospital, where I went through tests known to doctors at that time, a compilation of family history and a seemingly endless poking, prodding, and parading before a panel of highly skilled professionals.

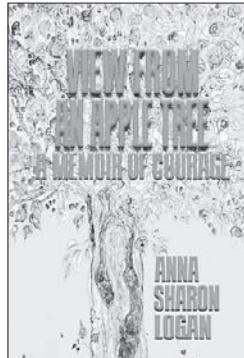
I am now 63 and defying all odds against my life. Though I can no longer drive a car or walk (I am in an electric wheelchair), I still go grocery shopping with help, to concerts, plays, parties, Starbucks, malls and visit friends by way of a specialized community transit. And too, I enjoy feeding the birds, working my vegetable and flower gardens, talking with neighbors and playing with my cat.

Living alone does not mean I am alone. I have my lifeline, a CNA (Certified Nursing Assistant) who comes in five days a week for two hours a day and friends and family who come over and call frequently. Also there is my writing. If I am not on my computer, I am on the phone.

For years I wrote about my life and kept the stories in a drawer. Aside from their value as a way of putting my tears on paper, they seemed to hold no real purpose. However, after my friend and I discussed the theory that our choices equal lessons to be learned, I went back to some of the papers, and realized how strong an influence those moments were in my growth. I saw my life growing in a series of stages; some stages bombarding me in rapid succession while others

took decades, but always coming to a full circle in the development of who I am. I had to write my story for myself, for you.

A little more than a year ago, my book, "View from an Apple Tree: a Memoir of Courage" was published by Alabaster Book Publishers in Kernersville, NC. The book has a one-paragraph introduction, a brief two-page outline of Friedreich's Ataxia, 16 chapters and an epilogue. It has 210 pages and is printed in 15-point type. My book has sold over 600 copies and is still generating quite a bit of interest, especially in libraries.



This book begins on the day of my birth and ends 17 chapters later in 2007. There have been adventures in my life, good and bad, and each has journeyed me into a world of different lights of understanding. I show how I have come to terms with many painful memories, and reached a point of

happiness. My book shows hope. It shows how I have dared to dream and fought to make those dreams come true, whether working, going to college, building flowerbeds or traveling to New York. My book shows how I have learned to hold my head high, and make no excuses for having a body that chooses to do its own thing. This uplifting memoir is a testament to the merit of perseverance that is in us all.

"View from an Apple Tree, a Memoir of Courage" is not meant to show the life of a person with special needs, but of the adventures

*Continued on page 20*

*View from an Apple Tree*  
Continued from page 19

of a person who is living her life to the fullest who has special needs. This life is not in spite of a body requiring consideration, instead a life form rejoicing in all that she is, because it is her makeup, teaching her lessons that make her who

she is, bad and good.

Books can be purchased on *amazon.com* or from Ms. Logan for \$15 plus \$3 S&H (please add \$0.75 for each additional book). Please mail to Anna Sharon Logan, 1714 10th St., Greensboro, NC 27405 and make check payable to Apple Tree. ❖

## Join the Contact Registry: Join in the Fight to Conquer Rare Diseases!

The Clinical Research Consortium for Spinocerebellar Ataxias (CRC-SCA) will advance ataxia research with your help.

The Rare Diseases Clinical Research Network (RDCRN) Patient Contact Registry is a method by which patients with rare diseases can register themselves with the RDCRN in order to be contacted in the future about clinical research opportunities and updates on the progress of the research projects. The contact registry is anonymous and free of charge.

You (or your child) are invited to participate in a research project that will develop a nationwide registry for patients.

Benefits of Joining the Contact Registry include:

- Communication of open recruitment for clinical studies of your disease
- Notice of opening of new clinical sites doing research on rare diseases
- Information on activities from affiliated awareness and advocacy groups
- And future opportunities to participate in research!

### Who Can Join the Contact Registry?

We encourage patients from all over the world to join the Contact Registry. Any patient with a confirmed diagnosis of Spinocerebellar ataxia

type 1, 2, 3 or 6 can register. Other types of degenerative ataxias will be added to the Registry in the future.

### How does the Contact Registry Work?

After you have read and agreed to the on-line Authorization, the Registry form will appear on your screen. This form asks you for information such as your (or your child's) name, address, birth date, place of birth, e-mail address, or items relevant to your (or your child's) disorders.

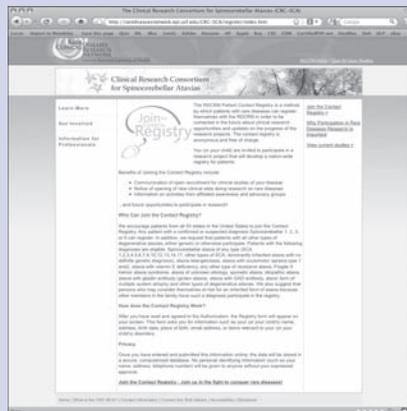
### Privacy

Once you have entered and submitted this information on-line, the data will be stored in a secure, computerized database. No personal identifying information (such as your name, address, telephone

number) will be given to anyone without your expressed approval.

Go to this web address now to register: <http://rarediseasesnetwork.epi.usf.edu/CRC-SCA/register/index.htm>

For more information, if you have difficulties registering, or if you do not have access to the Internet and prefer to register via phone or postal mail, please contact Sue Hagen, Patient Services Director, National Ataxia Foundation at (763) 553-0020 or [susan@ataxia.org](mailto:susan@ataxia.org).



RDCRN registration page

# Social Security Disability – Application Process Information

*The following article was prepared for the National Ataxia Foundation by Jon Rodis, a member of the National Marfan Foundation. Mr. Rodis serves as an informational resource for individuals who would like to learn more about the process of applying for Social Security Disability Benefits (SSD). His knowledge has been obtained through his own experience of applying for SSD and has been supplemented by information provided by his wife Kathleen Kane Rodis, an attorney with several years of experience with disability benefits issues.*

Below you will find answers to some common questions about the Social Security Disability program and eligibility requirements. Please use this guide for information-gathering purposes.

For more detailed information about Social Security Disability visit the Social Security Administration's website [www.socialsecurity.gov](http://www.socialsecurity.gov) or Tele-service at 1-800-772-1213. For vocational support visit [www.yourtickettowork.com](http://www.yourtickettowork.com) or call Maximus at 1-866-968-7842.

## ***Frequently Asked Questions and Topics***

**Q) What kind of evidence is needed to prove that a person is affected by the disease and is unable to work ... simply letters from a physician? Do you have to have letters from more than one doctor – and how recent do those letters need to be?**

*“My mother has ataxia and even though she has not had genetic testing, this disease sounds like hers. What is required by Social Security to validate the disease? Do you have to do genetic testing? She no longer sees her neurologist regularly.”*

A) Social Security does require that information be provided to show that the person has the condition for which they are applying. This does not mean they require a genetic test have been done (although it is very helpful) but that there is supporting documentation from a doctor stating that they have the condition. What is needed to prove that someone is unable to work requires a combination of support documentation such

as: A letter (or letters) from doctors stating that they are permanently disabled, detailed medical records through the years (there are exceptions to this based on financial/insurance status), letters of support from the foundation and medical experts, health logs and personal statements, etc. This information should be as up-to-date as possible.

**Q) What is the average timeline for approval of benefits?**

*“My sister’s neurologist has declared her as disabled and she has just applied for Social Security Disability Benefits which we understand may take some time to receive, since the system is so overwhelmed with applications.”*

A) Although the Social Security Disability system is a federal program, the time it takes for a decision to be made on a SSD claim is dependent on the case load of the individual state. A time range can be anywhere between 6-9 months or 1-2 years.

**Q) How is the amount of money a person receives on SS disability determined? What amount can individuals expect to receive – and how is that money distributed (i.e. one monthly payment)?**

*“I have Friedreich’s Ataxia that I was born with. I lost my job and only get social security disability of \$674.”*

A) The amount of money that a person

## *Social Security Disability* *Continued from page 21*

receives on Social Security disability is determined by how much an individual has put into the system (If applying for Social Security Disability) or an individual's financial income/assets (if applying for Social Security Income). Payments are made monthly for both programs. In addition to the SSD payments per month, any other financial help would be dependent on the state where the individual is from and what they offer within that state for assistance.

**Q) What if an individual has been marginally employed, or never worked a job – are they eligible for this program, or is there a different assistance program that they should look into?**

A) In this case, they would be applying for Social Security Income. This program is based on the the individuals financial income/assets.

**Q) How will the Compassionate Allowance impact applications?**

*“Now that spinocerebellar ataxia is listed on the compassionate allowance list, does this mean I can get more money with Social Security Income?”*

A) Having a condition that is on the Compassionate Allowance list, greatly improves the chances for quicker approval. Being on the list does not increase the amount of money that an individual would receive through Supplemental Security Income or Social Security Disability.

If you have questions about any of the information in this article, please visit Mr. Rodis' website [www.jrmarfan58.com](http://www.jrmarfan58.com) or e-mail him at [wsalmgcdjm@aol.com](mailto:wsalmgcdjm@aol.com). ❖

## National Ataxia Registry Sign-Up

The National Ataxia Foundation is pleased to announce that the web-based National Ataxia Registry (NAR) is up and running!

An essential component for rare disease research is the availability of people with these diseases to participate in drug trials and other research. This registry will be a valuable resource in the search for a cure for ataxia.

Even if you are registered on another patient registry, you are encouraged to sign-up on this NEW ataxia patient registry for individuals in the United States with any type of ataxia or who are at risk for ataxia.

Go to [www.nationalataxiaregistry.org](http://www.nationalataxiaregistry.org) to register. If you have questions or encounter problems, please contact the Research Coordinator by e-mail at [nationalataxiaregistry@neurology.ufl.edu](mailto:nationalataxiaregistry@neurology.ufl.edu) or leave a voicemail message with your name and phone number at (352) 273-9195.

For complete information on the Registry, please see the article on page 1.

## 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 many ataxia families it serves. These are people who have named NAF as a beneficiary in their will.

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

Over the years, individuals who have chosen NAF as a beneficiary have given anywhere from a few thousand dollars to nearly one million dollars. Their forethought and benevolence has enabled the Foundation to support promising ataxia research and provide meaningful programs and services to ataxia families. Their legacy lives on in the hope they have given ataxia families.

Perhaps this is the time to consider adding the National Ataxia Foundation in your will.

# “Survey Says...”

The National Ataxia Foundation would like your feedback about our quarterly newsletter, *Generations*. The following survey is designed to gather your opinions about the content, quality, and distribution of *Generations*.

Simply fill out the survey below and return it to the NAF office at:

National Ataxia Foundation  
Attn: Survey Results  
2600 Fernbrook Lane, Suite 119  
Minneapolis, MN 55447-4752

**Or you may visit the homepage of our website, [www.ataxia.org](http://www.ataxia.org), where you will find a link to the survey and complete it online.** All identified respondents will be entered to win selected Ataxia Awareness merchandise.

The National Ataxia Foundation appreciates your feedback and looks forward to better serving our *Generations* readership.

If you have any questions about this survey, please contact Liz Werner at [liz@ataxia.org](mailto:liz@ataxia.org).

Thank you!

## ★ Required

1) What is your overall satisfaction with *Generations*, NAF's quarterly newsletter?

- Very satisfied
- Somewhat satisfied
- Neutral
- Somewhat dissatisfied
- Very Dissatisfied

\*2) How much of our newsletter do you read?

- 25% or less
- 25% - 50%
- 50% - 75%
- more than 75%
- 100%
- I do not read the newsletter

3) How many years have you been reading *Generations*? \_\_\_\_\_

4) Is there more than one person in your household/office/clinic who reads the newsletter?

- Yes (How many? \_\_\_\_\_)
- No

5) Would you prefer to receive the newsletter...

- More frequently
- Less frequently
- The same (quarterly)

6) How relevant do you find the information in the newsletter?

- Very relevant
- Somewhat relevant
- Neutral
- Somewhat irrelevant
- Very irrelevant

7) Would you be interested in receiving the newsletter electronically – either through an e-mail or a link on the NAF website?

- Yes
- No
- Maybe
- Don't Know
- I do not use the Internet

8) Rate your satisfaction with the following features of this newsletter (Very Dissatisfied, Somewhat Dissatisfied, Neutral, Somewhat Satisfied, Very Satisfied):

- Length \_\_\_\_\_
- Design \_\_\_\_\_
- Content \_\_\_\_\_
- Images \_\_\_\_\_
- Color \_\_\_\_\_

*Continued on page 24*

Survey

Continued from page 23

Layout \_\_\_\_\_

Comments \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

9) Please rank each part of the newsletter in order of importance to you (from 1 = most important to 10 = least important)

\_\_\_\_\_ News and Updates from NAF Chapters, Support Groups and Ambassadors

\_\_\_\_\_ Ataxia Research News, Updates, and Lay Summaries

\_\_\_\_\_ Personal stories

\_\_\_\_\_ Annual Membership Meeting Announcements and Articles

\_\_\_\_\_ Merchandise Order Form

\_\_\_\_\_ Calendar of Events

\_\_\_\_\_ Caregiver's Corner

\_\_\_\_\_ Fundraising Information

\_\_\_\_\_ Articles about Managing Ataxia (physically and emotionally)

\_\_\_\_\_ From the Desk of the Executive Director

10) Which section of the newsletter do you think needs most improvement?

News and Updates from NAF Chapters, Support Groups and Ambassadors

Ataxia Research News, Updates, and Lay Summaries

Personal stories

Annual Membership Meeting Announcements and Articles

Merchandise Order Form

Calendar of Events

Caregiver's Corner

Fundraising Information

Articles about Managing Ataxia (physically and emotionally)

From the Desk of the Executive Director

Comments \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

11) I think the research summaries in *Generations* are...

Much too technical

A little too technical

Just about right

A little too simplistic

Much too simplistic

12) Please rate your reaction to the following terms and phrases that are commonly used to describe those with ataxia (Strongly Dislike, Dislike, Neither Like nor Dislike, Like, Strongly Like):

Ataxians \_\_\_\_\_

Ataxans \_\_\_\_\_

Affected by ataxia \_\_\_\_\_

Afflicted by ataxia \_\_\_\_\_

Suffers from ataxia \_\_\_\_\_

Lives with ataxia \_\_\_\_\_

Ataxia families \_\_\_\_\_

Person with ataxia \_\_\_\_\_

Person with disabilities \_\_\_\_\_

Disabled \_\_\_\_\_

13) Do you like "Generations" as the title of the NAF quarterly newsletter? Please note if you have a suggestion for a different title.

Yes

No

Don't know

Comments \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

14) The thing I like best about *Generations* is...

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17) What would you like to see in future issues of *Generations*? (open-ended)

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15) The thing I would most like to change about *Generations* is...

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18) Thank you for taking part in this survey – your input is important. Enter your contact information below for a chance to win Ataxia Awareness apparel from NAF for participation in this survey.

First Name: \_\_\_\_\_

Last Name: \_\_\_\_\_

Home Phone: \_\_\_\_\_

E-mail Address: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_

State: \_\_\_\_\_

ZIP/Postal Code: \_\_\_\_\_

16) What do you suggest that would improve the quality, readability, and content of the newsletter? (open-ended)

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**GoodSearch**

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

*GoodSearch.com* is a search engine that donates 50 percent of its revenue to the charities and schools designated by its users. Simply go to the site's home page and follow the easy steps to make NAF your charity of choice.

Then use GoodSearch as you would any other search engine. You'll make a difference in the lives of those with ataxia!

# Events and Fundraisers for International Ataxia Awareness Day

For more details and links, please visit the NAF event calendar at [www.ataxia.org](http://www.ataxia.org).

## **NAF Virtual IAAD Walk n' Roll for Ataxia** Now through September 25, 2010

Sign-up for the first-ever "Virtual Walk n' Roll." Please join us in some fun and camaraderie as we raise awareness and funds together in support of ataxia research and other important NAF programs. Our goals are high, and participation is important. To participate, visit the following link: [naf.myetap.org/10VWnR/](http://naf.myetap.org/10VWnR/). There you will be able to register or donate to this fundraiser. The event will kick off on June 1 and conclude on International Ataxia Awareness Day (September 25) after we have crossed the continent. We will be touring Research Centers across the land, and would like to stop in and visit you too! All proceeds benefit the National Ataxia Foundation. For more information contact Lynda Howell at [MyLyndaHowell@yahoo.com](mailto:MyLyndaHowell@yahoo.com) or (909) 720-0634.

## **1st Annual Twin Cities IAAD Walk n' Roll** Saturday, September 18, 2010

Event will be held from 9 a.m. – noon at Wolfe Park, St. Louis Park, MN. For more information or to volunteer please contact Bill Sweeney at [wm.sweeney@yahoo.com](mailto:wm.sweeney@yahoo.com). To register or donate online please visit our event website at [naf.myetap.org/fundraiser/TCWnR/](http://naf.myetap.org/fundraiser/TCWnR/). All proceeds benefit the National Ataxia Foundation.

## **2nd Annual OC/LA, CA IAAD Walk n' Roll**

Saturday, September 25, 2010

8 a.m. at Shoreline Aquatic Park, Long Beach, CA. All proceeds benefit the National Ataxia Foundation. For more information please contact Daniel Navar at [dnavar@ucla.edu](mailto:dnavar@ucla.edu), or (323) 788-7751 or Cindy DeMint at (714) 329-4437

or [chatsdots@sbcglobal.net](mailto:chatsdots@sbcglobal.net). To register or donate online please visit our online event website at [naf.myetap.org/fundraiser/10OCLAWnR/](http://naf.myetap.org/fundraiser/10OCLAWnR/).

## **2nd Annual Central TX Joe Thell IAAD Walk n' Roll**

Saturday, September 25, 2010

9 a.m. at San Gabriel Park, Georgetown, TX. All proceeds benefit NAF. For more information or to volunteer please contact Linda Crawley at [calebsnana2@msn.com](mailto:calebsnana2@msn.com) or [linda@joethell.com](mailto:linda@joethell.com). To register or to donate online please visit [naf.myetap.org/fundraiser/10TXWnR/](http://naf.myetap.org/fundraiser/10TXWnR/).

## **Macy's Shop for a Cause**

October 16, 2010

Purchase a "Macy's Shop for a Cause" discount card today for \$5 and help the National Ataxia Foundation. Your special "Macy's Shop for a Cause" discount card gives you access to a special one-day-only sales event at Macy's stores nationwide on Saturday, October 16.

Card holders receive a 20% discount on regular, sale, and clearance items including clothing, jewelry, clearance furniture, mattresses, rugs and more. Exclusions may apply. Card holders also can participate in special events and entertainment, and register to win a \$500 Macy's shopping spree.

To purchase your discount card today, send a check made payable to the National Ataxia Foundation to 2600 Fernbrook Lane, Suite 119 Minneapolis, MN 55447. Write "Macy's Card" in the memo line. You may also call the NAF office for more information at (763) 553-0020.

## **2nd Annual Detroit, MI IAAD Walk n' Roll** Saturday, September 25, 2010

11 a.m. at Detroit's Tri-Centennial Park 1900 Atwater St., Detroit, MI. All proceeds benefit ►►

the National Ataxia Foundation. For more information or to volunteer please contact Tanya Tunstull at (313) 736-2827 or [tinyt48221@yahoo.com](mailto:tinyt48221@yahoo.com). To register or donate online please visit our event website at [naf.myetap.org/10Detroit/](http://naf.myetap.org/10Detroit/).

### **Ironman for Ataxia**

*Sunday, September 12, 2010*

NAF member Joe Golminas is once again training to complete an Ironman Triathlon (2.4-mile swim, 112-mile bike, 26.2-mile run) in an effort to raise money for the National Ataxia Foundation.

Joe is teaming up with Janus Funds, a sponsor of the Ironman Triathlons and a supporter of athletes who not only participate in the Ironman races, but who also raise money for their own favorite charities. Through the "Janus Charity Challenge" the top 50 fundraisers of each race will be awarded an additional donation of \$100 to \$10,000 by Janus for their charity. Last year with everyone's generosity, Joe raised enough money to win \$750 of "free" money for the National Ataxia Foundation from Janus Funds.

For more information visit [www.kintera.org/faf/donorreg/donorpledge.asp?ievent=330383&supID=275217384](http://www.kintera.org/faf/donorreg/donorpledge.asp?ievent=330383&supID=275217384).

### **1st Annual Omaha, NE – Amy LaPorte IAAD Walk n' Roll**

*Saturday, September 25, 2010*

Starts at 9 a.m. at Heartland of America Park – Downtown Omaha. All proceeds benefit the National Ataxia Foundation. For more information or to volunteer please contact Crystal Fink at [Omaha\\_Walkn\\_Roll@yahoo.com](mailto:Omaha_Walkn_Roll@yahoo.com) or (402) 208-5817. To register or donate online please visit our website at [naf.myetap.org/fundraiser/OmahaWnR/](http://naf.myetap.org/fundraiser/OmahaWnR/).

### **4th Annual San Diego, CA Charley McLaughlin IAAD Walk n' Roll**

*Saturday, September 25, 2010*

Event will be held at 8 a.m. at Tuna Harbor Park in downtown San Diego. No registration

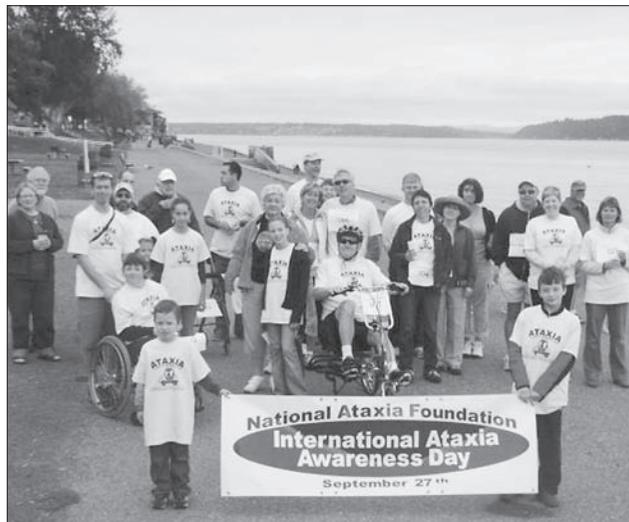
fee, donations only. All proceeds benefit the National Ataxia Foundation.

To volunteer or for more information please contact Earl McLaughlin at (619) 447-3753 or [sdasg@cox.net](mailto:sdasg@cox.net). To register or to donate online please visit our event website [naf.myetap.org/fundraiser/10sdwnr/](http://naf.myetap.org/fundraiser/10sdwnr/).

### **Dewayne's 2nd Annual 5K Walk, Run & Roll**

*Saturday, October 2, 2010*

Event will be held at 9 a.m. at First Baptist Church, 441 Lewie St., Gilbert, SC 29054. All proceeds benefit the National Ataxia Foundation. For more information please contact Anna Hite at (803) 532-2447 or [DocA35@ATT.net](mailto:DocA35@ATT.net). To register or donate online please visit our event website [naf.myetap.org/fundraiser/10DwayneWnR/](http://naf.myetap.org/fundraiser/10DwayneWnR/).



**The Seattle Ataxia Support Group at their 2008 Walk n' Roll event**

### **2nd Annual Seattle, WA IAAD Walk n' Roll**

*Saturday, October 2, 2010*

9 a.m. – 1 p.m. at Alki Beach Park, Seattle WA. To register or donate online please visit our event website [naf.myetap.org/fundraiser/10SeattleWnR/](http://naf.myetap.org/fundraiser/10SeattleWnR/). To volunteer or for more information please contact Milly and Tony Lewendon at [ojohnnie@charter.net](mailto:ojohnnie@charter.net). All proceeds benefit the National Ataxia Foundation. ❖

# Announcing the NAF 2010 International Ataxia Awareness Day T-Shirt Design Challenge Winner

Thank you to everyone who participated in the 2010 IAAD T-shirt Design Challenge. Over 4,500 votes were placed, and based on those votes Lealan D.M. LaRoche is the 2010 IAAD “Get to Know Ataxia” t-shirt design winner!

The National Ataxia Foundation would like to congratulate Lealan on her hard work and excellent design. Thank you to all the designers for their participation and enthusiasm to promote ataxia awareness.

The winning design is the official NAF 2010 IAAD t-shirt and is available for purchase through NAF’s website [www.ataxia.org](http://www.ataxia.org), or on the order form listed on page 12 of this issue of *Generations*.

Read on for more information about the winning designer and design as well as the other contest finalists.



## Lealan LaRoche

### Background:

I am an Architecture and City Planning graduate student at Georgia Tech. We are constantly building knowledge of design for not only function and form, but for presenting our ideas.

Over the past few years, I’ve picked up jobs designing t-shirts, announcements, signage, invitations, and event decor. This IAAD t-shirt design contest was calling my name.

I also have Friedreich’s Ataxia. I am 24 years old. I was diagnosed at age 20. I know FA will not stop me from a career in design. Being involved is crucial to experiencing what life has

to offer. Sometimes life hands you a curve ball. Life hands me a curve ball every day. From this, I have discovered how important it is for someone like me to be in the design field. I hope to direct my career towards consulting and designing, specializing in mobility and accessibility. I want to improve the lives affected by unforeseen life changes.

### About the Design:

Ataxia represents something very unfamiliar to most. What I hope it can represent is something positive, not something mysterious and scary. Ataxia does have positive changes on people. We need to focus on its STRENGTHS. Ataxia, to me, means support, hope, and STRENGTH. My family, friends, and I are the strength behind ataxia. I want to shout it! The ideas behind the design are just that simple. The color blue came from NAF. I knew no other color could do the design justice.

Behind the message is a composition of the words and graphics. It is understood more abstractly. I did not want to center everything on the shirt because asymmetry is more striking. And the message is so much more easily read. The circles on the back design represent the many forms of ataxia, yet they are all linked to each other. ▶▶



Lealan LaRoche’s winning t-shirt design front (left) and back (right)

On the back of the shirt I chose to beautify the word “Ataxia” by finding a font that brings out the beauty behind ataxia. I chose to take on this contest with honesty and passion, and I want the world to know the strength.

**Finalists**

*Designs by Danylle L. Kern*

My name is Danylle Kern and I am 22 years old. SCA7 runs in my family. About two years ago my sister and I began a t-shirt fundraiser to raise awareness and money for research of ataxia. Last year we raised more than \$2,000 with the selling of this shirt.



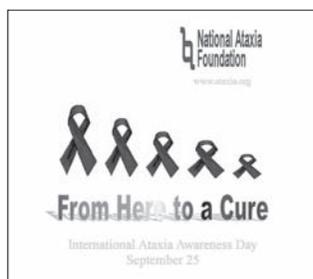
My second design consists of the contest “slogan” along with a definition of ataxia on the back. Within the definition I have placed the NAF logo in a separate color.



*Design by Caryn Benson*

My dad, who was one of my best friends, had spinocerebellar ataxia. He died this past June. It was a really hard time for me to watch my dad go through this; however, I am glad that I was able to spend as much time with him as I did.

I moved closer to



my dad 10 years ago when his disease starting getting worse. I started off having dinner with my dad once or twice a week. About two years before he passed away, I then started going over there three times a week.

About five months before he died, I spent every day with my dad. I was able to take care of him. He took care of me all my life and this was a very small way for me to show him just how much I loved him. We had always been close, but we bonded more than I could have ever believed. I kept wishing for a cure and that he would get better. I know that no one should ever have to endure what he went through, that is why I wanted to design a shirt in his memory.

The design of my shirt shows us having a ribbon supporting the cause and when we find a cure, we won't need the ribbons anymore. Let's find a cure!

*Design by Zack Stackle*

The design I came up with is fun, has a funky kind of feel, but is still educational in the sense that it gives someone wearing it an easy way to explain to people what ataxia is, and how it affects the brain. This helps others “Get to know Ataxia.” ❖



**TISSUE DONATION**

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

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

## Book Release and Review

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

By Lyn Culbert

My son, Dave Lewis, was actually relieved when he was diagnosed in 1983 with a rare degenerative neuromuscular disease, Friedreich's Ataxia. He was 14 years old and the diagnosis meant he no longer had to wear the dreaded back brace he had once thrown down the stairs piece by piece.

When he died 25 years later, he left us his memoir, "There's Nothing Wrong with Asking for a Little Help ... and Other Myths," the story of his life living with ataxia. Dave's editor calls him "a teacher with great life lessons to impart." In the editor's words, the story is "about a man with a progressively debilitating disease coming to terms with what's in and out of his control; about the nature of his spirit and dignity under these circumstances; about what's worth asking and refusing help for." Also, "his sense of humor defuses any potential awkwardness or melodrama ... amazingly deft writing and fun to boot."

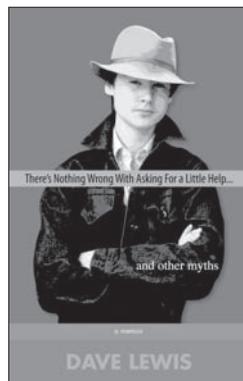
Beginning with a moment in time when Dave fell in the shower, he reminisces about his seemingly normal early years, the origin of his condition ("It seems that in the genetic crapshoot of life, I rolled snake eyes.") and his years of steady physical decline ("You know how people say, 'just like riding a bike, once you learn you never forget?' Well I seem to be the exception to that rule.") As he made choices about where and how he wanted to live, from college years at the University of New Mexico and the University of California – San Diego to teaching in Minnesota to designing software in the Washington D.C. area, self-sufficiency was always his primary goal.

Dave was once asked to address a senate subcommittee and physicians at a National Organization of Rare Diseases (N.O.R.D.) conference. Unlike the other speakers, who each described their disease and pleaded with Congress to devote more money to research, Dave addressed the "incomprehensible practice" of denying people with terminal illnesses access to experimental drugs because they might be "harmful."

Throughout the story he shares his emotional highs and lows – the challenges and the losses ("Of all the things I've lost I miss my voice the most.") sprinkled liberally with his unique sense of humor. Despite his failing health, Dave continually looked for new challenges. "You know I've always tried to push my limits," he once told me. Sometimes accused of being stubborn, he said he was simply doing what was needed to "make a life in the middle of a nightmare."

Dave spent the last three years of his life writing his memoir to provide information and inspiration to countless others. Throughout his life he continually assessed his abilities and made the most of them. He identified new skills, developed them and used them to move ahead. When a path closed down, he forged a new one. He found lots of joy in his life and became an inspiration to many people.

You can read more about Dave and his book at [www.bright-side-books.com](http://www.bright-side-books.com). It is also now available for purchase by using the NAF Merchandise page or by going to NAF's secure on-line store at [www.ataxia.org](http://www.ataxia.org). All proceeds from books purchased through NAF will be used to support research to find a cure for FA. ❖



# Our Experience(s) at Johns Hopkins

By Phyllis Skok

In 1997, a few years after my husband Jim was diagnosed as having ataxia at Penn State Hershey Medical Center, he made his first trip to Johns Hopkins. Jim saw an article in the National Ataxia Foundation newsletter that said Johns Hopkins was conducting a study of nystagmus. Jim called and was signed up for the study. We packed up his MRI and went to Johns Hopkins in the hope that we would also find some kind of help and hope for Jim. That did not happen. The doctors were obviously interested in their research and finding out more about this aspect of ataxia. But we left Johns Hopkins with the feeling that Jim was a piece of data.

Last February we decided to attend the Medical Meeting of the NAF Chesapeake Chapter. What an exciting day! After living with Jim's diagnosis for about 15 years, we were finally hearing that there might be some treatments on the horizon. And we heard enthusiastic statements about the Johns Hopkins Ataxia clinic. We decided to try again at Johns Hopkins.

The neurology resident at Hershey Medical Center and Jim's family doctor were both more than willing to help us with referrals and information to take to Johns Hopkins. Our appointment was set for months in the future. To our delight and amazement we began to be contacted by an amazing, helpful staff person from the clinic, Katie McGuire. From the first contact it was obvious that Katie understands what it is like to live with ataxia.

When the day for Jim's first appointment arrived, we made the 90-minute drive to Johns Hopkins not knowing what to expect. We were greeted in the waiting area by Katie and immediately began to feel comfortable. The first appointment was amazing! How often can anyone say he or she had the attention of his doctors for three hours? We were seen first by a resident

for an hour-and-a-half, and then by the resident, and then by Dr. Savitt for another hour-and-a-half. The tests for feeling, balance, strength, etc. were pretty familiar from Jim's yearly visits to his neurologists. But we were in a place where the doctors actually know the disease and spend time reviewing records and getting to know the patient. Jim is a patient here, not a piece of data.

The report forwarded to Jim's doctors at Hershey included recommendations for physical, occupational, and speech therapy as well as changes to various medications. We decided to follow up on the therapies here in Pennsylvania and alternate doctor visits between Hershey and Johns Hopkins. In that way we have a doctor closer to home, but we also have the benefit of having doctor who is expert in ataxia.

Dr. Savitt also talked to us about genetic testing, and this time we decided to pursue it. Unfortunately, it has not given us any clear answers. But we know that when treatments and answers come, the Ataxia Clinic at Johns Hopkins will be fully aware of them and will share them with its patients. ❖

## CFC Number

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

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

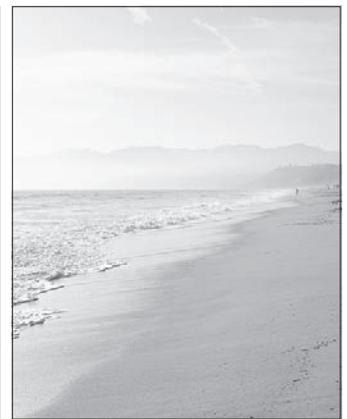
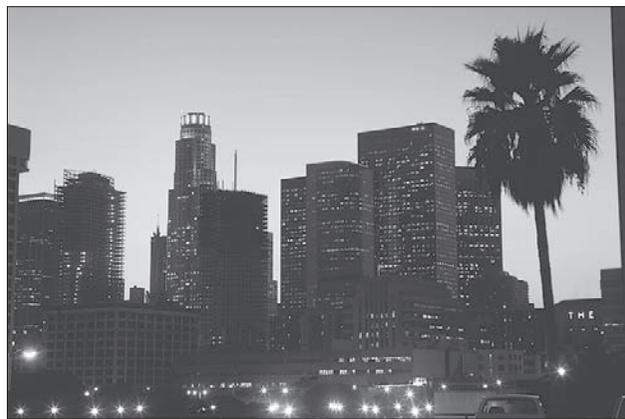
Please give as generously as you can and please ask your co-workers to also give to the National Ataxia Foundation.

*The NAF Board of Directors along with the Los Angeles, Orange County, and San Diego Support Groups would like to invite you to attend the*

## National Ataxia Foundation 54th Annual Membership Meeting “Bringing the Ataxia World Together”

### March 17-20, 2011

(Leadership Meeting, Fundraising Meeting & Reception March 17)



### *Join us in Los Angeles for the Annual Membership Meeting!*

The **Hilton Los Angeles Airport** is pleased to provide the facilities for the 2011 National Ataxia Foundation AMM. Rooms are available at the **special group rate** of \$100 per night. Please be sure to make your reservations by **March 1, 2011** in order to secure the special group rate. If rooms are available, the special group rate will be extended three days before and three days after the meeting dates.

**To inquire about the availability of an ADA room at the Hilton Los Angeles Airport you MUST contact the National Ataxia Foundation at 763-553-0020 or [naf@ataxia.org](mailto:naf@ataxia.org).**

If you need ADA equipment PLEASE be sure and mention this when making your room reservation. Shower chairs, tub bars, detachable shower heads, and toilet frames will be available on a first-come, first-serve basis by contacting the Hilton Los Angeles Airport Hotel front Desk upon check in.

To **book your stay online**, go to [http://www.hilton.com/en/hi/groups/personalized/LAXAHHH-NAF-20110312/index.jhtml?WT.mc\\_id=POG](http://www.hilton.com/en/hi/groups/personalized/LAXAHHH-NAF-20110312/index.jhtml?WT.mc_id=POG) or if you would prefer to make your reservations by phone, please call 1-800-445-8667 or (810) 410-4000 and ask for the **National Ataxia Foundation Conference special rate**.

Watch for the 2011 AMM Registration Form in the Winter 2010-11 issue of *Generations* and keep checking on our website, [www.ataxia.org](http://www.ataxia.org), for the latest information about the 2011 conference.

**We look forward to seeing you in Los Angeles!**

# I am Strength. I have Ataxia.

By Erin O'Kelley

I always considered myself an athlete. I was fit, quick, and strong. I competed in martial arts and mini-triathlons. I had a wonderful career as a clinical assistant professor in athletic training and physical therapy until suddenly one day at the age of 34 something changed. I had “zingers,” muscle twitches and cramps, I was speaking as if I was drunk, and I felt unstable. My colleagues’ concern grew for me as they watched me walk by keeping one hand lightly touching the wall and struggle with my speech and trunk jerks. Gee-whiz, this is one heck of a bug, I thought.

So off I went to the doctor. Then, off to the local neurologist. I was told “you either have a brain tumor or multiple sclerosis.” After four hours of MRIs, I was told that there were some “abnormalities” but no clear tumor or evidence of multiple sclerosis. I was told to come back in six months if I didn’t get better. I wanted an answer that was logical so I could use my mind and body and get a handle on it. So I went to several more specialists. One physician concluded that although my symptoms were real, my main problem was that I was suffering from post-traumatic stress disorder (PTSD) and suffering from severe depression. Well, she was correct. For about three hours after this horrific visit, I was very depressed and vowed never to see another doctor. So, I said, fine – I’ll fix myself! I started working out again.

I had already figured a couple of things out on my own. If I kept my stomach (core) tight and my legs tight by contracting my quadriceps and hamstrings at the same time by slightly bending my knees, my trunk didn’t jerk quite as wildly or

as noticeably. I could perform squats, push-ups and pull-ups and I felt better, more in control. I did have to monitor how aggressively I worked out as the after-shocks of over-doing it could make the next few days very difficult. Once again, however, my colleagues remained concerned. My speech was getting worse and they felt I was “compensating” to hide my symptoms. Partly just to prove them wrong (as I am notorious for doing) and partly because I knew somewhere deep inside of me that something was still not right, I acquiesced and saw one more doctor.



Erin O'Kelley

Genetic testing finally revealed the cause of my ataxia. With such a diagnosis, there is a huge incongruity both internally and externally in processing the information. While initially I was relieved to have an answer, those around me went into an immediate mourning phase for my future and the realization that the Erin they once knew wasn’t going to get better, but only worse. About the time they

were getting over the shock, I began to mourn. Sometimes, on some days, I return to mourning.

My initial reaction was to read everything I could about my condition to see what I could control. I was a bit frustrated that there didn’t seem to be very much information concerning exercise. As a physical therapist, I knew that having a good core strength level was important for everyone. I also knew that most people’s cores were poor. Even most of my Division One athletes couldn’t control their core as well as I could. Additionally, babies and toddlers are ataxic

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*I Am Strength. I Have Ataxia.*  
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because they haven't fully developed motor control and proprioceptive systems and because they don't have core strength. Their heads and bodies jerk when they learn to sit up, they wobble when they walk, and stumble when they reach for things. What changes? Well, they develop the system that is injured or diseased in ataxic patients and they get stronger in their core. It seems all too logical if we can't, to date, change the disease or injury to the system, we should absolutely keep strong.

While I realize that exercising does not stop the progression of ataxia, it may help mask some of the symptoms. My exercising is much more diverse today as it includes not only the previous mentioned exercises, but also yoga, weights, and cardiovascular training. Perhaps equally important, exercise releases endorphins (feel good neuro-transmitters) and gives me a sense of control.

I know so many have questions on how to start, how to choose good exercises, and how to find safe alternatives when you are wheel-chair bound or just plain scared. I hope, with the help of the National Ataxia Foundation, to soon provide some good examples. However, until then, be smart, first and always, consult your doctor. ❖

In loving memory of  
**Milan Cloud,**  
husband of  
Houston Support  
Group Leader  
Angela Cloud

Love  
Always & Forever



July 31, '60 - Feb. 6, '10

Birthday Benefit Celebration - August 1, 2010  
For more information visit  
[www.ataxia.org/chapters/Houston/default.aspx](http://www.ataxia.org/chapters/Houston/default.aspx)

## How will I dance?

By Sherry-Ann Brown

Now that you've taken away my balance  
How will I prance?

Now with this unsteadiness,  
How will I find happiness?

Now with this slur  
How will my voice be heard?

When my legs fail,  
Who will listen to my wail?

When I can't keep my gaze,  
Who will help me see through the haze?

When this ataxia threatens to take control,  
Will it take a toll

On me?

Perhaps it will affect the flesh of my body,  
But it will not deter what's inside of me.

Perhaps it will take away my voice,  
But it will not remove my choice

To decide  
How to abide.

Not in fear or anticipation,  
But in the knowledge of my dedication.

To the essence of who I am,  
To the essence of what I can

Achieve.

Although ataxia will try to rain on my parade,  
My will and gusto will form a motorcade,  
A barricade,  
A barrier.

My spirit will dance  
My heart will dance  
My mind will dance

And by golly,  
My voice will dance.

My voice is within.

The dance is within.





# Chapter and Support Group News *from Around the Country*

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## **Northern California Ataxia Support Group**

*By Rebecca Douglass*

The NCASG met on April 10 at Our Savior’s Lutheran Church in Lafayette, CA. After “mix and mingle” time from 11:30 a.m. to noon, Mike Fernandes started the meeting with announcements, upcoming events, clinical trials and most important of all, welcomed new members. He also announced the cancellation of our speaker, David Cook, who was unable to attend. David will be with us, however, in July at our next meeting.

Lunch was served and then the group broke into breakout sessions, one of ataxians and one of caregivers. This type of program is popular with everyone.

Joanne Loveland, a new member this year, attended the NAF Annual Membership Meeting in Chicago as a substitute for Mike Fernandes. She wrote a comprehensive report which was read to the group. She cited awareness and fundraising as important goals for IAAD in September. Our group is planning a Walk n’ Roll with Joanne approaching a local Rotary club for sponsorship. She requested a committed core of workers from our group. The next meeting of NCASG is scheduled for July 9, same time, same place.

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## **Maine Ataxia Support Group Update**

*By Bev Lister*

The Maine Ataxia support group met at the Casco Bay (Freeport YMCA) on April 24. At 1 p.m. our speaker Jennifer Frank ESQ arrived she gave a fantastic talk and answer time on Elder

Law. We learned about living wills, special needs trusts, estate planning, DNR orders and nursing home planning. It is a subject that is difficult but needs to be discussed.

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## **Denver Ataxia Support Group**

*By Charlotte DePew*

The Denver Ataxia Support Group met March 17 at Swedish Medical Center. With four new members present, a total of 25 patients and family members attended. A wonderful potluck lunch was provided by all attendees.

The program included a presentation on care-giving issues and a report from the NAF Annual Membership Meeting held in Chicago in March. A registered nurse who has had extensive experience working with Parkinson’s families led us in a lively discussion covering patient and caregiver needs, responsibilities and concerns. Member feedback on her presentation was extremely positive.

Individuals who attended the 2010 NAF conference in Chicago shared their experiences and knowledge gained. All agreed that attending the conference is an experience that everyone should have at least once. Every attendee benefits by gaining knowledge, friendship and support.

The importance of ataxia patients signing up with registries was stressed. Registry information and web addresses were handed out and e-mailed to members not present at the meeting.

The next support group meeting will be on July 17.

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Chapter and Support Group News  
Continued from page 35

**Chesapeake Chapter News**

By Jillian R. Detherage and Carolyn Davis

The Outreach Group of the Ataxia Center at Johns Hopkins held a March meeting for spouses, significant others and family caregivers who have loved ones with ataxia. The topic of discussion was “Dealing with Stress and Sadness.” The discussion was led by Shanna Mislak, MSW, and Libby Labash, Vice President of the Chesapeake Chapter. This was a great opportunity for caregivers to connect with each other.

The next meeting of the Outreach Group will be July 24 from noon until 2 p.m. in the JHU Outpatient Center second floor conference room in Baltimore, MD. The topic will be “Legal and Financial Issues When One Has a Long-Term Medical Condition.” The discussion will be led by Rick Scholl, CPA. Rick has had ALS for over 10 years; as a result he can address this topic from a personal as well as professional point of view. This meeting is for patients, friends and family members. We invite and encourage all to attend. For additional information, please contact Jillian Detherage in Dr. Savitt’s office at (410) 955-4894 or by e-mail at [jdether1@jhmi.edu](mailto:jdether1@jhmi.edu).

The Chapter picnic, co-sponsored by the Ataxia Student Ambassadors at JHU, will be held Saturday, Sept. 25 on the Homewood Campus of Johns Hopkins in Baltimore, MD. Details will be available on the chapter website.

**Twin Cities Support Group**

By Lenore Healey Schultz

The Twin Cities Support Group is going to hold a Walk n’ Roll fundraiser on International Ataxia Awareness Day (IAAD) on Sept. 25. Thanks to Earl McLaughlin of the San Diego support group, who has written up a “how to guide” for organizing and running a Walk n’

Roll fundraiser. We plan to use his guide to do our own Walk n’ Roll.

At our May meeting, a representative from Wilderness Inquiry – a non-profit, outdoor adventure organization based in Minneapolis for people of all ages, backgrounds, and abilities – came to talk about their program and their many adventures available. The presenter mentioned that they do a day trip down the Mississippi River in 24-foot canoes. So in June, about 16 of us will gather on the banks of the Mississippi for a fun day-long adventure paddling down the river.

Influenced by what Dr. Gomez said at the NAF conference in March (where he urged researchers and those afflicted with ataxia to have more interactions), and since I knew that the Twin Cities is one of a handful of centers in the country who are doing ataxia research, I had an idea. I gave an open invitation to all researchers of ataxia to come anytime to our monthly support group meetings, just to listen. It is hoped that through this type of exposure, more awareness will be brought to the researchers about the day-to-day, moment-by-moment dealings of living with ataxia in one’s life.

**Orange County Support Group**

By Daniel Navar and Theresa Gonzales

For our holiday celebration on Dec. 12, 2009, the Orange County Support Group teamed up with participants from the Los Angeles Support Group for a luncheon at Mimi’s Café.

On Feb. 20 our group hosted massage therapist Terry Solomon and a few of his students. Daniel Navar briefly discussed tentative plans for the Annual Membership Meeting that will be hosted by the Orange County, Los Angeles, and San Diego Support Groups for 2011.

On April 9–11 our group hosted a NAF booth at the Abilities Expo. Representatives at our NAF booth passed out ataxia information and began promoting the San Diego, Orange County, and Los Angeles Walk n’ Rolls. The ►►

upcoming 2011 Annual Membership Meeting in Los Angeles was also promoted. Several Los Angeles, San Diego, and Orange County support group members helped staff the booth and had dinner on Saturday night where the group discussed upcoming events.

The Orange County Support Group is in the process of finalizing preparations for the Second Annual Walk n' Roll for Ataxia Awareness Day under the leadership of Cindy DeMint and Ana Moran. Last year's Walk was a great success, and we anticipate this year's will be as well. ❖

## Episodic Ataxia Research

Have you ever thought about participating in a research study? Do you wonder what it means to take part in one? In general there are two different types of studies: one that tests a new treatment for a disease, and one that gathers information about the natural course of the disease. The latter study, called a natural history study, allows scientist to gather enough data to better understand a disease and therefore have more information to develop worthwhile treatments. Without the information gathered from a natural history study it is difficult to know what aspects of the diseases to measure when conducting a trial of a new treatment.

Types of information gathered in a natural history study include people's individual experience of the disease, the degree and quantity of their symptoms, and how these symptoms might change over time. After data from a natural history study is collected, a study might be developed to test the effectiveness of a drug for treatment of the disease. This is known as a clinical trial. In a clinical trial a drug is compared to a placebo (sugar pill), or to another drug, to determine its safety and effectiveness.

One example of a natural history study is the *Episodic Ataxia: Genotype-Phenotype Correlation and Longitudinal Study*. This study is conducted by the Consortium for Clinical Investigators of Neurological Channelopathies (CINCH), and is funded by the National Institutes of Health. The primary objective of this study is to describe the range of EA and to increase knowledge about this condition by evaluating and following participants with EA. It requires participants to allow researchers to follow them for a period of two years. Only yearly visits are required to one

of the study's nationwide research sites.

At each visit the participant's medical history is reviewed, questionnaires regarding quality of life are filled out, and participants undergo a series of tests mainly focused on balance and coordination. If a person has not had a DNA test done this can be done, with a blood draw, at the first visit. Also at the first visit an EEG (electroencephalogram) is done to gather information about the health and functioning of the brain. Between visits, study participants are asked to track their symptoms for eight-week periods by calling into an automated telephone system. All of this information better allows researchers to understand the natural course of the disease and the differences among people's experiences of the symptoms.

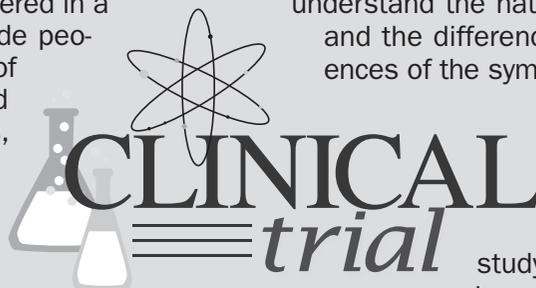
Before you decide if participating in a research study is right for you, be sure to get as much information you can. The

study doctor and the research team should be able to answer

any questions that you might have. There are several reasons why people volunteer for research studies but for most, it is the possibility to help themselves and to help others who may benefit from the development of a new understanding of a disease or a new medication for its treatment. Especially in the case of rare diseases, every participant counts.

If you would like more information about this and other studies of Episodic Ataxia you can view details at the Rare Diseases Clinical Research Network website: [rarediseasesnetwork.epi.usf.edu/](http://rarediseasesnetwork.epi.usf.edu/).

For general information regarding volunteering for research trials: [www.clinicaltrials.gov](http://www.clinicaltrials.gov). For more information on additional on-going trials in EA, contact Dr. Joanna Jen at [jjjen@ucla.edu](mailto:jjjen@ucla.edu).



# Chapters, Support Groups and Ambassadors

The following is a list of National Ataxia Foundation chapters, support groups and ambassadors. The use of these names, addresses and phone numbers for any purpose other than requesting information regarding NAF or joining a chapter or support group is strictly prohibited. We encourage you to contact the chapter or group nearest you.

## Social Networks

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### NAF BULLETIN BOARD

Moderator – Atilla

[www.ataxia.org/forum/toast.asp](http://www.ataxia.org/forum/toast.asp)

### NAF CHAT ROOM

Moderator – Della (blondie)

E-mail: [blondie.echat@gmail.com](mailto:blondie.echat@gmail.com)

[www.ataxia.org/connect/chat-rooms.aspx](http://www.ataxia.org/connect/chat-rooms.aspx)

### NAF FACEBOOK GROUP

[www.facebook.com/group.php?gid=93226257641](http://www.facebook.com/group.php?gid=93226257641)

### NAF MYSPACE GROUP

<http://groups.myspace.com/natlataxia>

### NAF TWITTER GROUP

[http://twitter.com/NAF\\_Ataxia](http://twitter.com/NAF_Ataxia)

## Chapters

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### Chesapeake Chapter

Carolyn Davis, President

Vienna, VA

(703) 759-2008

E-mail: [ccnafpres@gmail.com](mailto:ccnafpres@gmail.com)

[www.ataxia.org/chapters/Chesapeake/default.aspx](http://www.ataxia.org/chapters/Chesapeake/default.aspx)

### Louisiana Chapter

Carla Hagler, President

Slidell, LA

(985) 882-9830

E-mail: [ataxia1@earthlink.net](mailto:ataxia1@earthlink.net)

Web: [www.angelfire.com/la/ataxiachapter](http://www.angelfire.com/la/ataxiachapter)

[www.ataxia.org/chapters/Louisiana/default.aspx](http://www.ataxia.org/chapters/Louisiana/default.aspx)

### Mississippi Chapter

Camille Daglio, President

Hattiesburg, MS

E-mail: [daglio1@bellsouth.net](mailto:daglio1@bellsouth.net)

[www.ataxia.org/chapters/Mississippi/default.aspx](http://www.ataxia.org/chapters/Mississippi/default.aspx)

## Support Groups

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### Alabama

ALABAMA S.G.

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[www.ataxia.org/chapters/Birmingham/default.aspx](http://www.ataxia.org/chapters/Birmingham/default.aspx)

### Arizona

PHOENIX AREA S.G.

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[www.ataxia.org/chapters/Tucson/default.aspx](http://www.ataxia.org/chapters/Tucson/default.aspx)

### California

LOS ANGELES S.G.

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Web: <http://laasg-ca.info>

[www.ataxia.org/chapters/LosAngeles/default.aspx](http://www.ataxia.org/chapters/LosAngeles/default.aspx)

NORTHERN CA S.G.

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[www.ataxia.org/chapters/MikeFernandes/default.aspx](http://www.ataxia.org/chapters/MikeFernandes/default.aspx)

[www.ataxia.org/chapters/NorthernCalifornia/default.aspx](http://www.ataxia.org/chapters/NorthernCalifornia/default.aspx)

ORANGE COUNTY S.G.

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[www.ataxia.org/chapters/OrangeCounty/default.aspx](http://www.ataxia.org/chapters/OrangeCounty/default.aspx)

SAN DIEGO S.G.

Earl McLaughlin

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Earl's e-mail: [emclaugh@cox.net](mailto:emclaugh@cox.net)

Web: [www.geocities.com/ataxia\\_sdasg](http://www.geocities.com/ataxia_sdasg)

[www.ataxia.org/chapters/SanDiego/default.aspx](http://www.ataxia.org/chapters/SanDiego/default.aspx)



**Colorado****DENVER AREA S.G.****Charlotte DePew**

Aurora, CO

(720) 379-6887

E-mail: cldepew77@comcast.net

[www.ataxia.org/chapters/Denver/default.aspx](http://www.ataxia.org/chapters/Denver/default.aspx)**Connecticut**

See Tri-State S.G. under New York

**Florida****NORTHEAST FL S.G.****John Richwine**

Jacksonville, FL

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E-mail: sirichwine@aol.com

[www.ataxia.org/chapters/NortheastFlorida/default.aspx](http://www.ataxia.org/chapters/NortheastFlorida/default.aspx)**WEST CENTRAL FL S.G.****Cindy Steever-Ziegler**

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[www.ataxia.org/chapters/TampaBay/default.aspx](http://www.ataxia.org/chapters/TampaBay/default.aspx)**Georgia****GREATER ATLANTA AREA S.G.****Lynn Robinette**

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[www.ataxia.org/chapters/Chicago/default.aspx](http://www.ataxia.org/chapters/Chicago/default.aspx)**METRO AREA CHICAGO S.G.****Christopher "Topher" Marsh**

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<http://health.groups.yahoo.com/group/u-r-notalone/>[www.ataxia.org/chapters/ChrisMarsh/default.aspx](http://www.ataxia.org/chapters/ChrisMarsh/default.aspx)**Iowa****IOWA S.G.****Emily Medina**

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[www.ataxia.org/chapters/EmilyMedina/default.aspx](http://www.ataxia.org/chapters/EmilyMedina/default.aspx)**Louisiana**

See Louisiana Chapter

**Maine****MAINE S.G.****Kelley Rollins**

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[www.ataxia.org/chapters/Maine/default.aspx](http://www.ataxia.org/chapters/Maine/default.aspx)**Maryland**

See Chesapeake Chapter

**Massachusetts****NEW ENGLAND S.G.****Donna and Richard Gorzela**

Andover, MA

(978) 475-8072

[www.ataxia.org/chapters/NewEngland/default.aspx](http://www.ataxia.org/chapters/NewEngland/default.aspx)**Michigan****DETROIT AREA S.G.****Tanya Tunstull**

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[www.ataxia.org/chapters/Detroit/default.aspx](http://www.ataxia.org/chapters/Detroit/default.aspx)**WESTERN MI S.G.****Lynn K. Ball**

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[www.ataxia.org/chapters/LynnBall/default.aspx](http://www.ataxia.org/chapters/LynnBall/default.aspx)**Minnesota****TWIN CITIES AREA S.G.****Lenore Healey Schultz**

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[www.ataxia.org/chapters/TwinCities/default.aspx](http://www.ataxia.org/chapters/TwinCities/default.aspx)**Mississippi**

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**Missouri****KANSAS CITY S.G.****Jim Clark**

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*Chapters, Support Groups and Ambassadors*  
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[www.ataxia.org/chapters/KansasCity/default.aspx](http://www.ataxia.org/chapters/KansasCity/default.aspx)

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Columbia, MO  
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**New Jersey**

See Tri-State S.G. under New York

**New York****CENTRAL NY S.G.**

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[www.ataxia.org/chapters/Tri-State/default.aspx](http://www.ataxia.org/chapters/Tri-State/default.aspx)

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**Virginia**

See Chesapeake Chapter

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## International Support Groups

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## Ambassador Listing

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## Chapters, Support Groups and Ambassadors

Continued from page 41

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## Stay in Touch!

News and photos covering your group's activities and updates about happenings in your area regarding education, support or awareness is important to our readers.

Please send stories, events and reports by e-mail to [liz@ataxia.org](mailto:liz@ataxia.org) or by mail to the NAF office address listed on page 2.

The deadline for the fall issue is August 13, 2010.

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# Calendar of Events

The most current event information is available on the NAF website, [www.ataxia.org](http://www.ataxia.org).

## **Saturday, June 26, 2010**

### **Central Texas Ataxia Support Group Meeting**

11 a.m. – 1:30 p.m. at the Dell Children's Medical Center of Central TX, 4900 Mueller Blvd., Austin, TX. We will meet in 4 Central Conference Room (located between Respiratory and Oncology on the 4th floor). The medical Center's main number is (512) 324-0000. For more information please contact Linda Crawley at (512) 635-9478 or [calebsnana2@msn.com](mailto:calebsnana2@msn.com). [www.ataxia.org/chapters/Linda/default.aspx](http://www.ataxia.org/chapters/Linda/default.aspx)

## **Saturday, July 3, 2010**

### **Middle Tennessee Ataxia Support Group River Rafting Retreat**

July 3-4 overnight in Ocoee, TN – Camping and river rafting (optional) retreat. For more information contact Vicki Tyler at (615) 646-3024 or [tylerv2@comcast.net](mailto:tylerv2@comcast.net). [www.ataxia.org/chapters/VickiTyler/default.aspx](http://www.ataxia.org/chapters/VickiTyler/default.aspx)

## **Friday, July 9, 2010**

### **Abilities Expo – Chicagoland**

July 9-11 at the Schaumburg Convention Center. [www.abilitiesexpo.com/chicago/index.html](http://www.abilitiesexpo.com/chicago/index.html)

## **Saturday, July 10, 2010**

### **Los Angeles Area Ataxia Support Group Annual BBQ**

We meet 2 – 4 p.m. bi-monthly on the second Saturday at the Westside Center for Independent Living (WCIL), 1201 Venice Blvd., Los Angeles, CA. Plenty of Accessible parking in back of WCIL. We meet in the community room. From the parking lot (in rear) enter through patio. For people with disabilities, mainly with some type of ataxia. For more information, please contact Sherry McLaughlin at (626) 791-1558. [www.ataxia.org/chapters/LosAngeles/default.aspx](http://www.ataxia.org/chapters/LosAngeles/default.aspx)

## **Northern California**

### **Ataxia Support Group Meeting**

11:30 a.m. – 3 p.m. at Our Savior's Lutheran Church, 1035 Carol Lane, Lafayette, CA. For more information contact Michael Fernandes at (925) 516-9606 or [fernandesml@comcast.net](mailto:fernandesml@comcast.net). [www.ataxia.org/chapters/NorthernCalifornia/default.aspx](http://www.ataxia.org/chapters/NorthernCalifornia/default.aspx)

### **San Diego Ataxia Support Group Meeting**

1 – 3 p.m. at Sharp Rehabilitation Center, 2999

Health Center Dr. on the East side of Hwy 163 between Genessee Ave. and Mesa College Dr. behind Sharp Memorial Hospital. Plenty of free parking. For more information please contact Earl McLaughlin at (619) 447-3753 or [sdasg@cox.net](mailto:sdasg@cox.net). [www.ataxia.org/chapters/SanDiego/default.aspx](http://www.ataxia.org/chapters/SanDiego/default.aspx)

## **Wednesday, July 14, 2010**

### **Willamette Valley Ataxia Support Group Meeting**

11:30 a.m. – 1 p.m. on the second Wednesday of every month at Albany General Hospital, 1046 Sixth Ave. SW, Albany, OR. For more information contact Malinda Moore, CCC-SLP at (541) 821-4162 or [malindam@samhealth.org](mailto:malindam@samhealth.org). [www.ataxia.org/chapters/Willamette/default.aspx](http://www.ataxia.org/chapters/Willamette/default.aspx)

## **Thursday, July 15, 2010**

### **Tri-State Ataxia Support Group Meeting**

6:30 p.m. at Beth Israel, Phillips Ambulatory Care Center (PACC), usually second floor conference rooms, 10 Union Square E. New York, NY. For more information please contact Denise Mitchell at (212) 844-8711 or [markmeghan@aol.com](mailto:markmeghan@aol.com). [www.ataxia.org/chapters/Tri-State/default.aspx](http://www.ataxia.org/chapters/Tri-State/default.aspx)

## **Saturday, July 17, 2010**

### **Denver Area Ataxia Support Group Meeting**

1 – 4 p.m. at the Swedish Medical Center, second Floor Meeting Rooms, 501 E. Hampden Ave., Englewood, CO. For more information please contact Charlotte DePew at (720) 379-6887 or [cldepew77@comcast.net](mailto:cldepew77@comcast.net). [www.ataxia.org/chapters/Denver/default.aspx](http://www.ataxia.org/chapters/Denver/default.aspx)

### **Twin Cities Ataxia Support Group Meeting**

10 a.m. every third Saturday of the month at the Presbyterian Homes of Roseville at 1910 West County Road D, Roseville, MN. For information contact Lenore Healey Schultz at [schultz.lenore@yahoo.com](mailto:schultz.lenore@yahoo.com). [www.ataxia.org/chapters/TwinCities/default.aspx](http://www.ataxia.org/chapters/TwinCities/default.aspx)

## **Sunday, July 18, 2010**

### **Chicago Area Ataxia Support Group Meeting**

1 p.m. at the Good Samaritan Hospital – White Oak Room, 3815 Highland Ave., Downers Grove, IL. For more information contact Craig Lisack at (847) 496-7544 or [caasg2@aol.com](mailto:caasg2@aol.com). [www.ataxia.org/chapters/Chicago/default.aspx](http://www.ataxia.org/chapters/Chicago/default.aspx)

*Continued on page 44*

*Calendar of Events**Continued from page 43***Saturday, July 24, 2010****Iowa Support Group Meeting**

1 – 3 p.m. at the Urbandale Library in Urbandale, IA. For more information contact Emily Medina at (515) 727-8713 or [emily061578@yahoo.com](mailto:emily061578@yahoo.com). [www.ataxia.org/chapters/EmilyMedina/default.aspx](http://www.ataxia.org/chapters/EmilyMedina/default.aspx)

**West Central FL Ataxia Support Group Meeting**

Noon – 3 p.m. at University of South Florida, Morsani Hall, Room A&B. For more information please contact Cindy Steever-Ziegler at (239) 878-3092 or [csteever@msn.com](mailto:csteever@msn.com). [www.ataxia.org/chapters/TampaBay/default.aspx](http://www.ataxia.org/chapters/TampaBay/default.aspx)

**Saturday, August 7, 2010****Middle Tennessee Ataxia Support Group Picnic**

Noon at Center Hill Lake. For more information contact Vicki Tyler at (615) 646-3024 or [tylerv2@comcast.net](mailto:tylerv2@comcast.net). [www.ataxia.org/chapters/VickiTyler/default.aspx](http://www.ataxia.org/chapters/VickiTyler/default.aspx)

**Saturday, August 14, 2010****Kansas City Area Ataxia Support Group Meeting**

2 – 4 p.m. on the second Saturday of each month at the Northeast Library, 65 Wilson Ave., Kansas City, MO. For more information please contact Lois Goodman at (816) 257-2428 or Jim Clark at [clarckstone9348@sbcglobal.net](mailto:clarckstone9348@sbcglobal.net). [www.ataxia.org/chapters/KansasCity/default.aspx](http://www.ataxia.org/chapters/KansasCity/default.aspx)

**Northeast Florida Ataxia Support Group Meeting**

1 p.m. at Baptist South Hospital. Directions to Baptist South: From I95, take exit 335 which is Old St. Augustine Rd.. Go East. Follow the signs to the hospital. We are less than a 1/2 mile off of the interstate. Directions to the conference rooms from the main entrance: Come in the main entrance and make a right. Go past the first hallway on the left and the Azalea, Begonia and Camellia conference rooms will be the next doors. All meetings will be in the Azalea and Begonia rooms. For more information please contact John Richwine at [sirichwine@aol.com](mailto:sirichwine@aol.com). [www.ataxia.org/chapters/NortheastFlorida/default.aspx](http://www.ataxia.org/chapters/NortheastFlorida/default.aspx)

**Sunday, August 15, 2010****Chicago Metro Ataxia Support Group Meeting**

1 p.m. at the University of Chicago Medical Center, 5758 S. Maryland (at 57th & Cottage Grove) Room 1402. For more information please contact Christopher Marsh at (773) 334-1667 or [cmash34@ameritech.net](mailto:cmash34@ameritech.net). [www.ataxia.org/chapters/](http://www.ataxia.org/chapters/)

[ChrisMarsh/default.aspx](http://ChrisMarsh/default.aspx)

**Saturday, August 21, 2010****Greater Atlanta Ataxia Support Group Meeting**

1 p.m. at Emory Center for Rehabilitation Medicine, 1441 Clifton Rd., Room 101, Atlanta, GA. For more information contact Dave Zilles at (770) 399-6710 or [dzilles@earthlink.net](mailto:dzilles@earthlink.net). [www.ataxia.org/chapters/Atlanta/default.aspx](http://www.ataxia.org/chapters/Atlanta/default.aspx)

**Orange County Ataxia Support Group Meeting**

Meets on the third Saturday of every other month from 1:30 – 4 p.m. at the Orange Coast Memorial Medical Center (Breast Cancer Building, Room 1A), 9900 Talbert Ave., Fountain Valley, CA. For more information contact Daniel Navar at [dnavar@ucla.edu](mailto:dnavar@ucla.edu). [www.ataxia.org/chapters/OrangeCounty/default.aspx](http://www.ataxia.org/chapters/OrangeCounty/default.aspx)

**San Diego Ataxia Support Group Picnic**

Time and location TBD. For more information please contact Earl McLaughlin at (619) 447-3753 or [sdasg@cox.net](mailto:sdasg@cox.net). [www.ataxia.org/chapters/SanDiego/default.aspx](http://www.ataxia.org/chapters/SanDiego/default.aspx)

**Twin Cities Ataxia Support Group Meeting**

10 a.m. every third Saturday of the month at the Presbyterian Homes of Roseville at 1910 West County Road D, Roseville, MN. For information contact Lenore Healey Schultz at [schultz.lenore@yahoo.com](mailto:schultz.lenore@yahoo.com). [www.ataxia.org/chapters/TwinCities/default.aspx](http://www.ataxia.org/chapters/TwinCities/default.aspx)

**Sunday, August 22, 2010****Seattle Area Ataxia Support Group Picnic**

2 – 4 p.m. at a local park TBD. For more information please contact Milly Lewendon at (425) 823-6239 or [ataxiaseattle@comcast.net](mailto:ataxiaseattle@comcast.net). [www.ataxia.org/chapters/Seattle/default.aspx](http://www.ataxia.org/chapters/Seattle/default.aspx)

**Friday, August 27, 2010****Abilities Expo – Houston**

August 27 – 29 at the Reliant Park Expo Center. [www.abilitiesexpo.com/houston/index.html](http://www.abilitiesexpo.com/houston/index.html)

**Saturday, August 28, 2010****Houston Ataxia Support Group Meeting**

Contact Angela Cloud for more information at [angelahcloud@aol.com](mailto:angelahcloud@aol.com) or (281) 693-1826. [www.ataxia.org/chapters/Houston/default.aspx](http://www.ataxia.org/chapters/Houston/default.aspx)

**Saturday, September 4, 2010****Central Texas Ataxia Support Group Meeting**

Meets on the first Saturday of every other month from 11 a.m. – 1:30 p.m. at the Dell Children's Medical Center of Central TX, 4900 ►►

Mueller Blvd., Austin, TX. We will meet in 4 Central Conference Room (located between Respiratory and Oncology on the 4th floor). The medical Center's main number is (512) 324-0000. For more information please contact Linda Crawley at (512) 635-9478 or [calebsnana2@msn.com](mailto:calebsnana2@msn.com). [www.ataxia.org/chapters/Linda/default.aspx](http://www.ataxia.org/chapters/Linda/default.aspx)

### **Wednesday, September 8, 2010**

#### **Willamette Valley Ataxia Support Group Meeting**

11:30 a.m. – 1 p.m. on the second Wednesday of every month at Albany General Hospital, 1046 Sixth Ave. SW, Albany, OR. For more information contact Malinda Moore, CCC-SLP at (541) 821-4162 or [malindam@samhealth.org](mailto:malindam@samhealth.org). [www.ataxia.org/chapters/Willamette/default.aspx](http://www.ataxia.org/chapters/Willamette/default.aspx)

### **Saturday, September 11, 2010**

#### **Los Angeles Area Ataxia Support Group Meeting**

We meet 2 – 4 p.m. bi-monthly on the second Saturday at the Westside Center for Independent Living (WCIL), 1201 Venice Blvd., LA, CA. Plenty of Accessible parking in back of WCIL. We meet in the community room. From the parking lot (in rear) enter through patio. For people with disabilities, mainly with some type of ataxia. Any type of disability tends to isolate us. This is a place to meet people, socialize, and support each other. We all have something in common, our disabilities. Together we can make life easier, more comfortable, supportive, and productive. For more information please contact Sherry McLaughlin at (626) 791-1558 or [ccherilynmc@yahoo.com](mailto:ccherilynmc@yahoo.com). [www.ataxia.org/chapters/LosAngeles/default.aspx](http://www.ataxia.org/chapters/LosAngeles/default.aspx)

#### **West Central FL Ataxia Support Group Meeting**

Noon – 3 p.m. at University of South Florida, Morsani Hall, Room A&B. For more information please contact Cindy Steever-Ziegler at (239) 878-3092 or [csteever@msn.com](mailto:csteever@msn.com). [www.ataxia.org/chapters/TampaBay/default.aspx](http://www.ataxia.org/chapters/TampaBay/default.aspx)

### **Saturday, September 18, 2010**

#### **1st Annual Twin Cities IAAD Walk n' Roll**

9 a.m. – noon at Wolfe Park, St. Louis Park, MN. For more information or to volunteer please contact Bill Sweeney at [wm.sweeney@yahoo.com](mailto:wm.sweeney@yahoo.com) or (612) 821-2072. To register or donate online please visit our event website at [naf.myetap.org/fundraiser/TCWnR/](http://naf.myetap.org/fundraiser/TCWnR/). All proceeds benefit NAF.

### **Sunday, September 19, 2010**

#### **Chicago Area Ataxia Support Group Meeting**

1 p.m. at the Good Samaritan Hospital – White Oak Room, 3815 Highland Ave., Downers Grove,

IL. For more information contact Craig Lisack at (847) 496-7544 or [caasg2@aol.com](mailto:caasg2@aol.com). [www.ataxia.org/chapters/Chicago/default.aspx](http://www.ataxia.org/chapters/Chicago/default.aspx)

### **Saturday, September 25, 2010**

#### **Chesapeake Chapter IAAD Fall Picnic**

On the Homewood Campus of Johns Hopkins University, Baltimore, MD. Co-sponsored by the Ataxia Student Ambassadors at JHU. For more information contact Carolyn Davis (703) 759-2008 or [ccnafpres@gmail.com](mailto:ccnafpres@gmail.com). [www.ataxia.org/chapters/Chesapeake/default.aspx](http://www.ataxia.org/chapters/Chesapeake/default.aspx)

#### **1st Annual Omaha – Amy LaPorte Walk n' Roll**

9 a.m. at Heartland of America Park in downtown Omaha. All proceeds benefit the National Ataxia Foundation. For more information or to volunteer please contact Crystal Fink at [Omaha\\_WalknRoll@yahoo.com](mailto:Omaha_WalknRoll@yahoo.com) or (402) 208-5817. To register or donate online please visit our website at [naf.myetap.org/fundraiser/OmahaWnR/](http://naf.myetap.org/fundraiser/OmahaWnR/).

#### **2nd Annual OC/LA, CA IAAD Walk n' Roll**

8 a.m. at Shoreline Aquatic Park, Long Beach, CA. All Proceeds benefit the National Ataxia Foundation. For more information please contact Daniel Navar at [dnavar@ucla.edu](mailto:dnavar@ucla.edu) or (323) 788-7751, or Cindy DeMint at (714) 329-4437 or [chatdots@sbcglobal.net](mailto:chatdots@sbcglobal.net). To register or donate online please visit our event website at [naf.myetap.org/fundraiser/100CLAWnR/](http://naf.myetap.org/fundraiser/100CLAWnR/).

#### **2nd Annual Central TX**

##### **Joe Thell IAAD Walk n' Roll**

Event will be held at 9 a.m. at San Gabriel Park, Georgetown, TX. All proceeds benefit the National Ataxia Foundation. For more information or to volunteer please contact Linda Crawley at [calebsnana2@msn.com](mailto:calebsnana2@msn.com) or [linda@joethell.com](mailto:linda@joethell.com). To register or to donate online please visit our event website at [naf.myetap.org/fundraiser/10TXWnR/](http://naf.myetap.org/fundraiser/10TXWnR/).

#### **Arts for Ataxia**

**What** – “Arts for Ataxia” is a dynamic new event, featuring a collaborative performing arts show involving student groups and members of the ataxia community. Proceeds will go to National Ataxia Foundation efforts in supporting patient registries [www.ataxia.org/research/patient-registry.aspx](http://www.ataxia.org/research/patient-registry.aspx).

**When** – The event will be held at the Johns Hopkins University Homewood Campus on September 25th. **Why** – The Johns Hopkins University Ataxia Ambassadors will raise ataxia awareness throughout the undergraduate and local commu-

*Calendar of Events**Continued from page 45*

nities. Ultimately our goal is to support progress in the field of ataxia research. **How can I help?** 1) Vote early, vote often. Help us win a \$5,000 Pepsi Refresh grant for seed money. From May 1 to June 30 go online at [www.refresheverything.com/ataxia](http://www.refresheverything.com/ataxia) to vote and make your voice heard! Tell your friends and family, and vote daily. 2) Become a Movement Ambassador. If you're passionate about the arts and ataxia, write [artsforataxia@gmail.com](mailto:artsforataxia@gmail.com) to be partnered with an undergraduate student arts group. We need your help to make "Arts for Ataxia" a reality. Please visit [www.jhu.edu/ataxia](http://www.jhu.edu/ataxia) for more information, and to track our progress! [www.jhu.edu/ataxia](http://www.jhu.edu/ataxia)

**Detroit MI 2nd Annual IAAD Walk n' Roll**

11 a.m. at Detroit's Tri-Centennial Park, 1900 Atwater St., Detroit, MI. All Proceeds benefit the National Ataxia Foundation. For more information or to volunteer please contact Tanya Tunstull at (313) 736-2827 or [tinyt48221@yahoo.com](mailto:tinyt48221@yahoo.com). To register or donate online please visit our event website at [naf.myetap.org/10Detroit/](http://naf.myetap.org/10Detroit/)

**Greater Atlanta Ataxia Support Group Annual IAAD Picnic**

1 p.m. at Lake Lanier – West Bank Park at Buford Dam. Join us to celebrate International Ataxia Awareness Day. To RSVP please contact [atlantaataxia@gmail.com](mailto:atlantaataxia@gmail.com) or (404) 822-7451. [www.ataxia.org/chapters/Atlanta/default.aspx](http://www.ataxia.org/chapters/Atlanta/default.aspx)

**Maryland IAAD Yard & Bake Sale**

7 a.m. – noon at Friendship United Methodist Church, 10537 Friendship Rd., Berlin, MD. All proceeds benefit the National Ataxia Foundation. For more information or to purchase a space to sell your own items please contact Dana Simpson at (410) 251-2478 or [danalynn16@comcast.net](mailto:danalynn16@comcast.net).

**Northeast Florida Ataxia Support Group Meeting**

1 p.m. at Baptist South Hospital. Directions to Baptist South: From I95, take exit 335 which is Old St. Augustine Rd. Go East. Follow the signs to the hospital. We are less than a 1/2 mile off of the interstate. Directions to the conference rooms from the main entrance: Come in the main entrance and make a right. Go past the first hallway on the left and the Azalea, Begonia and Camellia conference rooms will be the next doors. All meetings will be in the Azalea and Begonia rooms. For more information please contact John Richwine at [sirichwine@aol.com](mailto:sirichwine@aol.com). [www.ataxia.org/chapters/NortheastFlorida/default.aspx](http://www.ataxia.org/chapters/NortheastFlorida/default.aspx)

[NortheastFlorida/default.aspx](http://www.ataxia.org/chapters/NortheastFlorida/default.aspx)

**San Diego 4th Annual Charley McLaughlin IAAD Walk n' Roll**

8 a.m. at Tuna Harbor Park in downtown San Diego. No registration fee – donations only. All proceeds benefit the National Ataxia Foundation. 8 a.m. at Tuna Harbor Park in downtown San Diego. To volunteer or for more information please contact Earl McLaughlin at (619) 447-3753 or [sdasg@cox.net](mailto:sdasg@cox.net). To register or to donate online please visit our event website [naf.myetap.org/fundraiser/10sdwnr/](http://naf.myetap.org/fundraiser/10sdwnr/).

**Friday, October 1, 2010****San Diego Ataxia Support Group Meeting**

1 – 3 p.m. at Sharp Rehabilitation Center, 2999 Health Center Dr. On the East side of Hwy 163 between Genessee Ave. and Mesa College Dr. behind Sharp Memorial Hospital. Plenty of free parking. For more information please contact Earl McLaughlin at (619) 447-3753 or [sdasg@cox.net](mailto:sdasg@cox.net). [www.ataxia.org/chapters/SanDiego/default.aspx](http://www.ataxia.org/chapters/SanDiego/default.aspx)

**Saturday, October 2, 2010****Dewayne's 2nd Annual 5K Walk, Run & Roll**

Event will be held at 9 a.m. at First Baptist Church, 441 Lewie St., Gilbert, SC. All proceeds benefit the National Ataxia Foundation. For more information please contact Anna Hite at (803) 532-2447 or [DocA35@ATT.net](mailto:DocA35@ATT.net). To register or donate online please visit our event website [naf.myetap.org/fundraiser/10DewayneWnR/](http://naf.myetap.org/fundraiser/10DewayneWnR/).

**2nd Annual Seattle, WA IAAD Walk n' Roll**

Event will be held at Alki Beach Park, Seattle, WA. To register or donate online please visit our event website [naf.myetap.org/fundraiser/10SeattleWnR/](http://naf.myetap.org/fundraiser/10SeattleWnR/). To volunteer or for more information please contact Milly and Tony Lewendon at [ojohnnie@charter.net](mailto:ojohnnie@charter.net). All Proceeds benefit the National Ataxia Foundation. To register or donate online please visit our event website [naf.myetap.org/fundraiser/10SeattleWnR/](http://naf.myetap.org/fundraiser/10SeattleWnR/).

**Saturday, October 9, 2010****Kansas City Area Ataxia Support Group Meeting**

2 – 4 p.m. on the second Saturday of each month at the Northeast Library, 65 Wilson Ave., Kansas City, MO. For more information please contact Lois Goodman at (816) 257-2428 or Jim Clark at [clarckstone9348@sbcglobal.net](mailto:clarckstone9348@sbcglobal.net). [www.ataxia.org/chapters/KansasCity/default.aspx](http://www.ataxia.org/chapters/KansasCity/default.aspx)

**Northern California Ataxia Support Group Meeting**

11:30 a.m. – 3 p.m. at Our Savior's Lutheran Church, 1035 Carol Lane, Lafayette, CA. For more information contact Michael Fernandes at (925) 516-9606 or [fernandesml@comcast.net](mailto:fernandesml@comcast.net). [www.ataxia.org/chapters/NorthernCalifornia/default.aspx](http://www.ataxia.org/chapters/NorthernCalifornia/default.aspx)

### **Sunday, October 10, 2010**

#### **Seattle Area Ataxia Support Group Meeting**

2 – 4 p.m. at Madison House Retirement Center. This meeting's focus will be House Safety. For more information please contact Milly Lewendon at (425) 823-6239 or [ataxiaseattle@comcast.net](mailto:ataxiaseattle@comcast.net). [www.ataxia.org/chapters/Seattle/default.aspx](http://www.ataxia.org/chapters/Seattle/default.aspx)

### **Wednesday, October 13, 2010**

#### **Willamette Valley Ataxia Support Group Meeting**

11:30 a.m. – 1 p.m. on the second Wednesday of every month at Albany General Hospital, 1046 Sixth Ave. SW, Albany, OR. For more information contact Malinda Moore, CCC-SLP at (541) 821-4162 or [malindam@samhealth.org](mailto:malindam@samhealth.org). [www.ataxia.org/chapters/Willamette/default.aspx](http://www.ataxia.org/chapters/Willamette/default.aspx)

### **Thursday, October 14, 2010**

#### **Tri-State Ataxia Support Group Meeting**

6:30 p.m. at Beth Israel, Phillips Ambulatory Care Center (PACC), usually second floor conference rooms, 10 Union Square E. New York, NY. For more information please contact Denise Mitchell at (212) 844-8711 or [markmeghan@aol.com](mailto:markmeghan@aol.com).

[www.ataxia.org/chapters/Tri-State/default.aspx](http://www.ataxia.org/chapters/Tri-State/default.aspx)

### **Saturday, October 16, 2010**

#### **Denver Area Ataxia Support Group Meeting**

1 – 4 p.m. at the Swedish Medical Center, second Floor Meeting Rooms, 501 E. Hampden Ave., Englewood, CO. For more information please contact Charlotte DePew at (720) 379-6887 or [cldepew77@comcast.net](mailto:cldepew77@comcast.net). [www.ataxia.org/chapters/Denver/default.aspx](http://www.ataxia.org/chapters/Denver/default.aspx)

#### **Orange County Ataxia Support Group Meeting**

Meets on the third Saturday of every other month from 1:30 – 4 p.m. at Orange Coast Memorial Medical Center (Breast Cancer Building, Room 1A), 9900 Talbert Ave., Fountain Valley, CA. For more information Contact Daniel Navar at [dnavar@ucla.edu](mailto:dnavar@ucla.edu). [www.ataxia.org/chapters/OrangeCounty/default.aspx](http://www.ataxia.org/chapters/OrangeCounty/default.aspx)

#### **Twin Cities Ataxia Support Group Meeting**

10 a.m. every third Saturday of the month at the Presbyterian Homes of Roseville at 1910 West County Road D, Roseville, MN 55112. For more information contact Lenore Healey Schultz at [schultz.lenore@yahoo.com](mailto:schultz.lenore@yahoo.com). [www.ataxia.org/chapters/TwinCities/default.aspx](http://www.ataxia.org/chapters/TwinCities/default.aspx)

#### **Macy's Shop for a Cause**

Purchase a \$5 "Macy's Shop for a Cause" discount card today and help the National Ataxia Foundation. For more information, please see the boxed article on page 26. ❖

## 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 April 2010. 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.

|                   |                  |                      |                    |                   |
|-------------------|------------------|----------------------|--------------------|-------------------|
| Remo Agostini     | Trinity Falk     | Eileen Jubina        | William Mugford    | Cynthia Shannon   |
| Bethel Church     | Donald Farquhar  | R. Jurasek           | Charity Ranger     | Kevin Shannon     |
| Women             | Sharae Felder    | Denis Kelly          | Sue Robinson       | Walter Sieradzki  |
| Anna Betland      | Donna Gorzela    | Annie Kleiber        | Don Royer          | Michael Skowronek |
| Fred Blasberg     | Carol Greenblatt | Ed Lee               | Merrill Rushin     | Charlotte Strong  |
| Tina Blasberg     | Paschal Guercio  | Harriet Lewis        | Ethel Sankey       | David Thummel     |
| Courtney Cardinal | Brent Hertzfeldt | Claire Lutz          | Don & Roberta      | Bonnie Tucker     |
| Fred Cook         | Homer Hilner     | John Matthews        | Santa Croce        | Carol West        |
| Janet Coyne       | Carrie & David   | Richard McGlinchey   | (50th Anniversary) | Tom Williams      |
| Archie Curtit     | Hanson (Wedding) | Earl McLaughlin, Jr. | Josephina          | Ken Yousten       |
| Valeria Cuthbert  | Richard Hinman   | Patrick Moore        | Schembre-McCabe    | Kenneth Yousten   |
| Mary Donahue      | Eugene Hoffman   | Dolores Morello      | David Seidel       | Toshiko Ziemann   |
| Troy Duda         | Elaine Jennings  | John Mugford         | Collin Shannon     |                   |





# National Ataxia Foundation

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## GIFT – HONOR – MEMORIAL

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

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

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

My contribution is:

- In Memory    In Honor    Gift Membership

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Occasion \_\_\_\_\_

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## 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

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## PAYMENT INFORMATION

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

- Check. Please make payable to the  
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Total Amount Enclosed \$ \_\_\_\_\_

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