





































































the company out and perhaps have a representative come to your support group to demonstrate. He explained that two of the benefits of standing are health and independence. Health improves for wheelchair users who use a standing wheelchair by eliminating urinary tract infections, pneumonia, and decubitus ulcers. It also improves contractures and bone mass, as well as possibly preventing osteoporosis and lengthening tendons and muscles. Please check out this amazing company at [www.thestandingcompany.com](http://www.thestandingcompany.com) or by calling 1-800-STANDING.

**Northeast Florida Ataxia Support Group Update**

*By McGready Kelso*

The Northeast Florida Ataxia Support Group had another excellent meeting at Baptist Hospital South. Our meeting was held Aug. 13 with 36 members and visitors in attendance. Steve Brown introduced guest speaker Dr. Subramony, internationally known to the ataxia community for his cutting-edge research and locally known to many of our members as their neurologist. His presentation topic was "Moving Ataxia Research Forward."

Dr. Subramony briefly went over some of the basic research done in the past, including animal studies that are paving the way towards real neuroprotective treatment of ataxias such as switching the mutated gene off in some of the SCA's and replacing frataxin in Friedreich's ataxia. He then focused on how to speed up clinical research in the field including the need to obtain the proper funding. Ataxia is a rare disease affecting a small percentage of people, which creates a major challenge when competing for research funding. He discussed tools to identify and validate clinical outcome measures, possible biomarkers, and the need for national and international cooperative work to properly address the issues created by rare diseases such as the ataxias.

The recent initiatives in the United States with funding from NAF for the National Ataxia

Registry and the NIH Rare Disease Clinical Network (RDCRN) for studies in SCA 1, 2, 3 and 6 are examples of such collaboration. He also mentioned a recent trip to China by several ataxia investigators from the United States in an attempt to foster truly international collaboration. He strongly encouraged all members to register on the National Ataxia Registry and mentioned that within the next few months the consent process for the registry will become simpler. Currently he is looking for additional subjects with SCA 1, 2, 3 and 6 for the natural history study and for several other studies ongoing at the University of Florida, including research in Friedreich's ataxia. In closing he answered several questions from the members and visitors.



**The Northeast Florida Ataxia Support Group.**

After the meeting, all members of the group and visitors were invited to Applebee's to talk and enjoy the company of new and old friends, family and significant others. Our next meeting will be held Saturday Nov. 12, at 1:30 at Baptist Hospital South.

**Central MN Ataxia Support Group Update**

*By Marsha Binnebose*

At our August meeting we had 14 people in attendance. We didn't have a speaker scheduled so group members talked about the Walk n' Roll for IAAD and what everyone has been dealing with lately. We have a speech therapist, financial planner, estate planner, and sleep disorders doctor scheduled to speak at our upcoming meetings. In January or February we are planning for a visit from a local balance and coordination therapy group.



# We Must Be Our Own Advocate

By Deborah McClain

We have to learn to be our own advocates. “Never give up. Never surrender,” is a great phrase from the great movie “Galaxy Quest” (at least I thought it was a great movie). But what an awesome way to look at how we must fight for the things we need in this challenged walk.

My last appointment with my neurologist found me determined to get some attention and make some requests known. After all, what did I have to lose? They see me for 20 minutes once a year and make the determination that I am doing just fine. I see myself 24 hours a day, seven days a week, for 365 days a year. I know that I stumble, fall, choke because of swallowing problems, can no longer keep my house clean, and take all day to complete one task. So for me, it’s no question as to whether I have a right to ask for things from my doctor. I asked for Physical Therapy, Occupational Therapy, a drug known to increase my energy, and a prescription for a wheelchair. Know what? I got what I wanted from them – because I ASKED for it.

And after they “wrote it up” I was successful in actually obtaining three of the four requests. Not so bad.

No one knows our needs and desires better than we do. If I frequent a place and am continually frustrated that their bathroom does not

offer grab bars, what is wrong with asking them to add some? The least they could do is say no. If I grow weary of attending service at a church whose handicap ramp is not the safest, what harm is it in asking that it be made more safe and accessible? After all, I go there too. If I love shopping at the worlds’ most fabulous shoe store, and they don’t offer a single door that opens automatically, what’s wrong with me asking why they can’t install an automatic door? There’s nothing wrong with me asking. If I want to do my civic duty and vote, and my neighborhood poll place offers only an entrance with three steps and no railing, that warrants a call to the city (but that’s another post!).

We have to speak up for ourselves. Yes, it requires effort that we sometimes grow weary of. It requires a little bit of persistence. And sometimes it requires just plain anger. But we must advocate for ourselves and make our requests known. Whether the fight benefits only us, or also our disabled brother or sister who has no voice, we must continue to fight the fight.

Speak up! “Never give up, never surrender!”

*This article was adapted from Deborah McClain’s blog site with permission. More of Deborah’s blog postings can be found at [www.accessenabled.wordpress.com](http://www.accessenabled.wordpress.com).* ❖

## National Ataxia Registry Is Online Now

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.

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) 273-9194.

# NAF Directory of Chapters, Support Groups and Ambassadors

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

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

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

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### NAF FACEBOOK GROUP

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

### NAF FACEBOOK CAUSES

[www.causes.com/causes/368602?m=71bb3202&recruiter\\_id=52877151](http://www.causes.com/causes/368602?m=71bb3202&recruiter_id=52877151)

### NAF FACEBOOK FANS

[www.facebook.com/lshogren?ref=profile#!/pages/National-Ataxia-Foundation/227766109304](http://www.facebook.com/lshogren?ref=profile#!/pages/National-Ataxia-Foundation/227766109304)

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**— PENNSYLVANIA —****SOUTHEAST PENNSYLVANIA SUPPORT GROUP LEADER****Liz Nussear**

Norristown, PA  
 (610) 272-1502  
 E-mail: lizout@aol.com  
[www.ataxia.org/chapters/SEPennsylvania/default.aspx](http://www.ataxia.org/chapters/SEPennsylvania/default.aspx)

**PA AND DE SUPPORT GROUP LEADERS****Joseph DeCrescenzo**

Newark, DE



(302) 369-9287  
E-mail: [jdecr@comcast.net](mailto:jdecr@comcast.net)  
[www.ataxia.org/chapters/Rakshys/default.aspx](http://www.ataxia.org/chapters/Rakshys/default.aspx)

**Christina Rakshys**

Allentown, PA  
(610) 395-6905  
E-mail: [rakshys@ptd.net](mailto:rakshys@ptd.net)  
[www.ataxia.org/chapters/Rakshys/default.aspx](http://www.ataxia.org/chapters/Rakshys/default.aspx)

**— SOUTH CAROLINA —****AMBASSADOR****Cece Russell**

Easley, SC  
(864) 220-3395  
E-mail: [cecerussell@hotmail.com](mailto:cecerussell@hotmail.com)  
[www.ataxia.org/chapters/Carolinas/default.aspx](http://www.ataxia.org/chapters/Carolinas/default.aspx)

**— TENNESSEE —****MIDDLE TN AREA SUPPORT GROUP LEADER****Vicki Tyler**

Nashville, TN  
(615) 646-3024  
E-mail: [tylerv2@comcast.net](mailto:tylerv2@comcast.net)  
[www.ataxia.org/chapters/VickiTyler/default.aspx](http://www.ataxia.org/chapters/VickiTyler/default.aspx)

**— TEXAS —****CENTRAL TEXAS SUPPORT GROUP****Linda Crawley**

Liberty Hill, TX  
(512) 635-9478  
E-mail: [lcrawley57@gmail.com](mailto:lcrawley57@gmail.com)  
[www.ataxia.org/chapters/Linda/default.aspx](http://www.ataxia.org/chapters/Linda/default.aspx)

**HOUSTON AREA SUPPORT GROUP LEADER****Angela Cloud**

Houston, TX  
E-mail: [angelahcloud@aol.com](mailto:angelahcloud@aol.com)  
[www.ataxia.org/chapters/Houston/default.aspx](http://www.ataxia.org/chapters/Houston/default.aspx)

**NORTH TEXAS SUPPORT GROUP LEADER****David Henry Jr.**

Trophy Club, TX  
E-mail: [cheve11e@sbcglobal.net](mailto:cheve11e@sbcglobal.net)  
(817) 491-4573  
[www.ataxia.org/chapters/NorthTexas/default.aspx](http://www.ataxia.org/chapters/NorthTexas/default.aspx)

**AMBASSADOR****Dana LeBlanc**

Orange, TX  
(409) 883-5570  
E-mail: [tileasal@yahoo.com](mailto:tileasal@yahoo.com)  
Web: <http://ladyd1973.tripod.com/index.html>  
[www.ataxia.org/chapters/GoldenTriangle/default.aspx](http://www.ataxia.org/chapters/GoldenTriangle/default.aspx)

**— UTAH —****UTAH SUPPORT GROUP LEADER****Dr. Julia Kleinschmidt**

Salt Lake City, UT  
(801) 585-2213  
E-mail: [julia.kleinschmidt@hsc.utah.edu](mailto:julia.kleinschmidt@hsc.utah.edu)  
[www.ataxia.org/chapters/Utah/default.aspx](http://www.ataxia.org/chapters/Utah/default.aspx)

**— VIRGINIA —****CHESAPEAKE CHAPTER PRESIDENT****Carolyn Davis**

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)

**AMBASSADORS****Donna Ring**

St. Stephens Church, VA  
(804) 769-3983  
E-mail: [ringwh@peoplepc.com](mailto:ringwh@peoplepc.com)  
[www.ataxia.org/chapters/Ring/default.aspx](http://www.ataxia.org/chapters/Ring/default.aspx)

**— WASHINGTON —****SEATTLE AREA SUPPORT GROUP LEADER****Milly Lewendon**

Kirkland, WA  
(425) 823-6239  
E-mail: [ataxiaseattle@comcast.net](mailto:ataxiaseattle@comcast.net)  
[www.ataxia.org/chapters/Seattle/default.aspx](http://www.ataxia.org/chapters/Seattle/default.aspx)

**AMBASSADOR****Linda Jacoy**

Spokane, WA  
(509) 482-8501  
E-mail: [linda4727@hotmail.com](mailto:linda4727@hotmail.com)  
[www.ataxia.org/chapters/Spokane/default.aspx](http://www.ataxia.org/chapters/Spokane/default.aspx)

## International Support Groups and Ambassadors

**— AUSTRALIA —****AMBASSADOR****Renee Moore (Nee McCallum)**

Hocking, W. Australia  
61-8-9404-7052  
E-mail: [moorear@bigpond.com](mailto:moorear@bigpond.com)  
[www.ataxia.org/chapters/ReneeMoore/default.aspx](http://www.ataxia.org/chapters/ReneeMoore/default.aspx)

**— CANADA —****AMBASSADORS****Susan M. Duncan**

Ottawa, Ontario  
(613) 820-7990  
E-mail: [smduncan1@sympatico.ca](mailto:smduncan1@sympatico.ca)  
[www.ataxia.org/chapters/SusanDuncan/default.aspx](http://www.ataxia.org/chapters/SusanDuncan/default.aspx)

**Prentis Clairmont**

Ottawa, Ontario  
(613) 864-8545  
E-mail: [prentis.clairmont@qmail.com](mailto:prentis.clairmont@qmail.com)  
[www.ataxia.org/chapters/PrentisClairmont/default.aspx](http://www.ataxia.org/chapters/PrentisClairmont/default.aspx)

**Terry Greenwood**

Winnipeg, Manitoba  
(204) 488-4155  
E-mail: [wpgmagic@shaw.ca](mailto:wpgmagic@shaw.ca)  
[www.ataxia.org/chapters/TerryGreenwood/default.aspx](http://www.ataxia.org/chapters/TerryGreenwood/default.aspx)

**— INDIA —****INDIA ATAXIA SUPPORT GROUP LEADER****Chandu Prasad George. CH,**

Secunderabad, India  
Phone: 0091-040-27961269  
Mobile: 0091-9949019410 Fax: 091-040-27971043  
E-mail: [sam\\_ataxiaindia@yahoo.com](mailto:sam_ataxiaindia@yahoo.com)  
[www.ataxia.org/chapters/Chandu/default.aspx](http://www.ataxia.org/chapters/Chandu/default.aspx)



# Calendar of Events

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

## SUPPORT GROUP MEETINGS

– Saturday, October 8 –

### Central Minnesota Ataxia Support Group Meeting

**Time:** 10 a.m. – noon

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

**Details:** Guest speaker Dr. Troy Payne will present on sleep and ataxia disorders. For more information contact Marsha Binnebose at [marshabinnebose@yahoo.com](mailto:marshabinnebose@yahoo.com) or (320) 240-9391. [www.ataxia.org/chapters/Binnebose/default.aspx](http://www.ataxia.org/chapters/Binnebose/default.aspx)

### Kansas City Area Ataxia Support Group Meeting

**Time:** 2 p.m. – 4 p.m.

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

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

### New England Ataxia Support Group Meeting

**Time:** Noon – 3 p.m.

**Location:** Mass General Hospital in the Yawkey Building on the 7th floor in room 980.

**Details:** The topic of this meeting will be fall prevention. For more information please contact Donna Gorzela at (978) 475-8072. [www.ataxia.org/](http://www.ataxia.org/)

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

### North Texas Ataxia Support Group Meeting

**Time:** 10 a.m. – noon

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

**Details:** Most of the meeting time is for sharing and asking questions about the difficulties and successes we have in our everyday life with ataxia. From time to time we do have an out-side speaker address some of our concerns from the caregivers, patients and families. For additional information please contact David Henry Jr. at [cheve11e@sbcglobal.net](mailto:cheve11e@sbcglobal.net). Please check the web site for updates. [www.ataxia.org/chapters/NorthTexas/default.aspx](http://www.ataxia.org/chapters/NorthTexas/default.aspx)

### San Diego Ataxia Support Group Meeting

**Time:** 1 p.m. – 3 p.m.

**Location:** Sharp Rehabilitation Center, 2999 Health Center Dr. on the East side of Hwy 163 between Genessee Ave. and Mesa College Dr. behind Sharp Memorial Hospital. There is plenty of free parking.

**Details:** For more information 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, October 12 –

### Willamette Valley Ataxia Support Group Meeting

**Time:** 11:30 a.m. – 1 p.m.

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

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

– Saturday, October 15 –

### Denver Area Ataxia Support Group Meeting

**Time:** 1 p.m. – 4 p.m.

**Location:** Swedish Medical Center, 501 E. Hampden Ave., Englewood, CO 80113. Meeting room: Spruce A & B.

**Details:** For more information 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) ►►

## 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](mailto:Arnulf.Koeppen@va.gov)

**Detroit Area Ataxia Support Group Meeting****Time:** 1 p.m. – 4 p.m.**Location:** Harper University, 3990 John R, Detroit, MI 48201. Wertz Classroom 1237. Near the main entrance off of John R.**Details:** For more information contact Tanya Tunstall at (313) 736-2827 or [tinyt48221@yahoo.com](mailto:tinyt48221@yahoo.com). [www.ataxia.org/chapters/Detroit/default.aspx](http://www.ataxia.org/chapters/Detroit/default.aspx)**Greater Cincinnati Area Ataxia Support Group Meeting****Time:** 1 p.m. – 3 p.m.**Location:** Meeting room of the Groesbeck Branch of the Cincinnati Public Library at 2994 W. Galbraith Rd., Cincinnati, OH 45239. Contact us at (513) 369-4454 or [www.cincinnatiilibrary.org/branches/groesbeck.html](http://www.cincinnatiilibrary.org/branches/groesbeck.html)**Details:** For questions contact Jennifer Mueller at [jenmu@yahoo.com](mailto:jenmu@yahoo.com). [www.ataxia.org/chapters/JenniferM/default.aspx](http://www.ataxia.org/chapters/JenniferM/default.aspx)**Maine Ataxia Support Group Meeting****Time:** Noon – 3 p.m.**Location:** TBD**Details:** For more information contact Kelley Rollins at [rollins@gwi.net](mailto:rollins@gwi.net). [www.ataxia.org/chapters/Maine/default.aspx](http://www.ataxia.org/chapters/Maine/default.aspx)**Orange County Ataxia Support Group Meeting****Time:** 1:30 p.m. – 4 p.m.**Location:** Orange Coast Memorial Medical Center (Breast Center Bldg., Room 1A), 9900 Talbert Ave., Fountain Valley, CA 92708.**Details:** 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****Time:** 10 a.m.**Location:** The Presbyterian Homes of Roseville at 1910 W. County Rd. D, Roseville, MN 55112.**Details:** 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)**– Saturday, October 22 –****DE/PA Ataxia Support Group Meeting****Time:** 10 a.m. – 1 p.m.**Location:** Christiana Care Hospital, 4755 Ogle-town-Stanton Rd., Newark, DE 19718. We will meet in Conference Room #1100 which is located directly off the main lobby, convenient for those with limited mobility.**Details:** For more information please contact JoeDeCrescenzo at (302) 369-9287 or [jdecr@comcast.net](mailto:jdecr@comcast.net) or Chris Rakshys at (610) 395-6905 or [rakshys@ptd.net](mailto:rakshys@ptd.net). [www.ataxia.org/chapters/DeCrescenzo/default.aspx](http://www.ataxia.org/chapters/DeCrescenzo/default.aspx)**– Saturday, October 29 –****Alabama Ataxia Support Group Meeting****Time:** 10 a.m. – 2 p.m.**Location:** Covenant Presbyterian Church, Homewood, AL**Details:** For more information please contact Becky Donnelly at (205) 987-2883 or [donnelly6132B@aol.com](mailto:donnelly6132B@aol.com). [www.ataxia.org/chapters/Birmingham/default.aspx](http://www.ataxia.org/chapters/Birmingham/default.aspx)**– Saturday, November 5 –****Central Texas Ataxia Support Group Meeting****Time:** 11 a.m. – 1:30 p.m.**Location:** The Dell Children's Medical Center of Central TX, 4900 Mueller Blvd., Austin, TX 78723. We will meet in Central Conference Room 4E.031 A & B (located between 4N & 4C) on the fourth floor. The medical center's main number is (512) 324-0000.**Details:** For more information contact Linda Crawley at (512) 635-9478 or [calebsnana2@msn.com](mailto:calebsnana2@msn.com). [www.ataxia.org/chapters/Linda/default.aspx](http://www.ataxia.org/chapters/Linda/default.aspx)**Greater Atlanta Ataxia Support Group Meeting****Time:** 1 p.m.**Location:** Emory Center for Rehabilitation Medicine, 1441 Clifton Rd., Room 101, Atlanta, GA 30322**Details:** 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)**West Central FL Ataxia Support Group Meeting and Thanksgiving Lunch****Time & Location:** TBD**Details:** 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)**– Wednesday, November 9 –****Willamette Valley Ataxia Support Group Meeting****Time:** 11:30 a.m. – 1 p.m.**Location:** Albany General Hospital, 1046 6th Ave. SW, Albany, OR 97321.**Details:** For more information contact Ivy Stilwell*Continued on page 44*

*Calendar of Events**Continued from page 43*

at (541) 812-4162 or [istilwell@samhealth.org](mailto:istilwell@samhealth.org).  
[www.ataxia.org/chapters/Willamette/default.aspx](http://www.ataxia.org/chapters/Willamette/default.aspx)

**– Thursday, November 10 –**

**Tri-State Ataxia Support Group Meeting**

**Time:** 6 p.m. – 8 p.m.

**Location:** Beth Israel, Phillips Ambulatory Care Center (PACC), 2nd floor conference room #3, 10 Union Square, New York, NY.

**Details:** For more information 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, November 12 –**

**Central Minnesota Ataxia Support Group Meeting**

**Time:** 10 a.m. - noon

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

**Details:** Guest speaker, Nicole Zitzow will speak on motor speech therapy, assisted communication, and swallowing issues. For more information contact Marsha Binnebose at [marshabinnebose@yahoo.com](mailto:marshabinnebose@yahoo.com) or (320) 240-9391. [www.ataxia.org/chapters/StCloud/default.aspx](http://www.ataxia.org/chapters/StCloud/default.aspx)

**Los Angeles Area Ataxia Support Group Pizza Party**

**Time:** 2 p.m. – 4 p.m.

**Details:** For meeting location and general 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)

**North Texas Ataxia Support Group Meeting**

**Time:** 10 a.m. – noon

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

**Details:** Most of the meeting time is for sharing and asking questions about the difficulties and successes we have in our everyday life with ataxia. From time to time we do have an out-side speaker address some of our concerns from the caregivers, patients and families. For additional information please contact David Henry Jr. at [cheve11e@sbc](mailto:cheve11e@sbc)

[global.net](http://global.net). Please check the web site for updates. [www.ataxia.org/chapters/NorthTexas/default.aspx](http://www.ataxia.org/chapters/NorthTexas/default.aspx)

**Northeast Florida Ataxia Support Group Meeting**

**Time:** 1:30 p.m.

**Location:** Baptist Hospital South. Directions to Baptist South: From I-95, take exit 335, which is Old St. Augustine Rd. Go East. Follow the signs to the hospital. We are less than a half-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.

**Details:** For more information please contact Ann Mayo at [annwaynemayo@bellsouth.net](mailto:annwaynemayo@bellsouth.net) or (904) 471-4579. [www.ataxia.org/chapters/NortheastFlorida/default.aspx](http://www.ataxia.org/chapters/NortheastFlorida/default.aspx)

**Southeast PA Ataxia Support Group Meeting**

**Time:** 10 a.m. – 11:30 a.m.

**Location:** Mercy Suburban Hospital, Walkup Room on the second floor. The meeting is followed by lunch at Applebee's across the street.

**Details:** Attendees must RSVP to Liz Nussear by Friday before the meeting at (610) 272-1502 or [Lizout@aol.com](mailto:Lizout@aol.com). [www.ataxia.org/chapters/SEPennsylvania/default.aspx](http://www.ataxia.org/chapters/SEPennsylvania/default.aspx)

**– Saturday, November 19 –**

**Chesapeake Chapter Fall Picnic**

**Time:** 10 a.m. – 3 p.m.

**Location:** Glass Pavilion on the Johns Hopkins University Homewood Campus in Baltimore, MD.

**Details:** Bring your friends, family, and favorite dish! Please email any questions to Leela Chakravarti at [Ichakra1@jhu.edu](mailto:Ichakra1@jhu.edu) or contact Carolyn Davis at [ccnafpres@gmail.com](mailto:ccnafpres@gmail.com) or (703) 759-2008.

**Twin Cities Ataxia Support Group Meeting**

**Time:** 10 a.m.

**Location:** The Presbyterian Homes of Roseville at 1910 W. County Rd. D, Roseville, MN 55112.

**Details:** 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)

**– Sunday, November 20 –**

**Chicago Area Ataxia Support Group Meeting**

**Time:** 1 p.m.

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

**Details:** For more information contact Richard ►►

Carr at (847) 253-2920 or [caasg@aol.com](mailto:caasg@aol.com). [www.ataxia.org/chapters/Chicago/default.aspx](http://www.ataxia.org/chapters/Chicago/default.aspx)

– **Saturday, December 3** –

**Detroit Area Ataxia Support Group Meeting**

**Time:** 1 p.m. – 4 p.m.

**Location:** Harper University, 3990 John R, Detroit, MI 48201. Wertz Classroom 1237. Near the main entrance off of John R.

**Details:** For more information contact Tanya Tunstall at (313) 736-2827 or [tinyt48221@yahoo.com](mailto:tinyt48221@yahoo.com). [www.ataxia.org/chapters/Detroit/default.aspx](http://www.ataxia.org/chapters/Detroit/default.aspx)

– **Saturday, December 10** –

**Greater Atlanta Ataxia Support Group Holiday Party**

**Time:** 1 p.m.

**Location:** Emory Center for Rehabilitation Medicine, 1441 Clifton Rd., Room 101, Atlanta, GA.

**Details:** 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)

**Kansas City Area Ataxia Support Group Meeting**

**Time:** 2 p.m. – 4 p.m.

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

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

**North Texas Ataxia Support Group Meeting**

**Time:** 10 a.m. – noon

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

**Details:** Most of the meeting time is for sharing and asking questions about the difficulties and successes we have in our everyday life with ataxia. From time to time we do have an out-side speaker address some of our concerns from the caregivers, patients and families. For additional information please contact David Henry Jr. at [cheve11e@sbcglobal.net](mailto:cheve11e@sbcglobal.net). Please check the web site for updates. [www.ataxia.org/chapters/NorthTexas/default.aspx](http://www.ataxia.org/chapters/NorthTexas/default.aspx)

**Orange County Ataxia Support Group Meeting/Holiday Get-Together**

**Time:** 1:30 p.m. – 4 p.m.

**Location:** Orange Coast Memorial Medical Center (Breast Center Bldg., Room 1A), 9900 Talbert Ave., Fountain Valley, CA 92708.

**Details:** 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 Christmas Party**

**Time:** 1 p.m. – 3 p.m.

**Location:** 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. There is plenty of free parking.

**Details:** For more information 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, December 14** –

**Willamette Valley Ataxia Support Group Meeting**

**Time:** 11:30 a.m. – 1 p.m.

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

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

– **Saturday, December 17** –

**Greater Cincinnati Area Ataxia Support Group Meeting**

**Time:** 1 p.m. – 3 p.m.

**Location:** Meeting room of the Groesbeck Branch of the Cincinnati Public Library at 2994 W. Galbraith Rd., Cincinnati, OH 45239. Contact us at (513) 369-4454 or [www.cincinnati.library.org/branches/groesbeck.html](http://www.cincinnati.library.org/branches/groesbeck.html)

**Details:** For questions contact Jennifer Mueller at [jenmu@yahoo.com](mailto:jenmu@yahoo.com). [www.ataxia.org/chapters/JenniferM/default.aspx](http://www.ataxia.org/chapters/JenniferM/default.aspx)

**Twin Cities Ataxia Support Group Holiday Party**

**Time:** 10 a.m.

**Location:** The Presbyterian Homes of Roseville at 1910 W. County Rd. D, Roseville, MN 55112.

**Details:** 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)

**AWARENESS & FUNDRAISING EVENTS**

– **Saturday, October 1** –

*Calendar of Events**Continued from page 45***3rd Annual Central Texas****Walk n' Roll for Ataxia (NEW DATE)****Time:** 9 a.m.**Location:** San Gabriel Park, Georgetown, TX.**Details:** Registration is \$25 and includes an event t-shirt. If you have any questions, comments, or suggestions please contact Linda Crawley at [lcrawley57@gmail.com](mailto:lcrawley57@gmail.com) or (512) 635-9478. <https://naf.myetap.org/11TXWnR/>**Dewayne's 3rd Annual****5K Walk, Run n' Roll for Ataxia****Time:** Late registration starts at 7:30 a.m. Race starts at 8:30 with the 10K going first and followed a few minutes later by the 5K.**Location:** First Baptist Church, 441 Lewie St., Gilbert, SC 29054**Details:** Races are walk, run, and roll. Wheelchairs are encouraged. For more information, to volunteer, or to register for this event please contact Anna Hite at (803) 532-2447 or [doca35@att.net](mailto:doca35@att.net). [www.active.com/running/gilbert-sc/dewaynes-5k-10k-2011](http://www.active.com/running/gilbert-sc/dewaynes-5k-10k-2011)**– Saturday, October 15 –****8th Annual Lou Coletti Memorial Golf Tournament****Location:** The Belleair Country Club, Belleair, FL 33756.**Details:** All proceeds benefit the National Ataxia Foundation. To participation or for more information Please contact Scott Coletti at [scott.coletti@gmail.com](mailto:scott.coletti@gmail.com) or (727) 741-0838.**Tea Time for Ataxia****Time:** 11:30 a.m. – 1:30 p.m.**Location:** The Aubrey Rose Tea Room, 8362 La Mesa Blvd., La Mesa, CA.**Details:** Tea is \$40 per person. All proceeds benefit the National Ataxia Foundation. Please RSVP by Oct. 1 to Jane Jaffe at (619) 286-9745 or [sicilianmother@cox.net](mailto:sicilianmother@cox.net).**Sunday, November 6****ING New York City Marathon****Details:** Fighting Ataxia Together - Project Organizer, Kathleen is participating in the INC New York City Marathon in honor of her father, who has ataxia, to raise awareness and funds for ataxia. All proceeds benefit the National Ataxia Foundation. [www.crowdrise.com/ataxia/fundraiser/KathleenRichards](http://www.crowdrise.com/ataxia/fundraiser/KathleenRichards)**Friday, November 18****Butler Area School District Jeans Day for Ataxia****Details:** The Butler Area School District in Butler, PA is holding its Second Annual Jeans Day for Ataxia. All proceeds benefit the National Ataxia Foundation. For more information about this event contact Dena at [redjeep42@aol.com](mailto:redjeep42@aol.com).**– Sunday, November 20 –****Ironman for Ataxia****Details:** From Joseph Golminas "This year, in memory of my mother, Peggy Golminas, I will once again complete in an Ironman Triathlon, this time in Arizona on Nov. 20 to raise money and awareness for the National Ataxia Foundation." For more information, visit [www.ironmanarizona.com](http://www.ironmanarizona.com). <https://naf.myetap.org/fundraiser/Ironman/fundraiser/Ironman/> ❖

## Remembering NAF in Your Will

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

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

Over the years these individuals, who have

chosen NAF as a beneficiary, have given 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 to provide meaningful programs and services to ataxia families across the country.

Perhaps this is the time to consider adding the National Ataxia Foundation in your will For more information, please call NAF at (763) 553-0020 or e-mail [mike@ataxia.org](mailto:mike@ataxia.org).

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

Cheryl Ackerman	Tal Dziengiel	Keiko Kain	Charity Ranger
Sherry Adams	Andrew Egeressy	Barry Karas	Jim Richards
Sharon Baggett	Philip Eisenhour	Mary Kolakosky	Kathleen Richards
Tracey Balis	Dick Eldredge	Sue Kremen	Janet Riley
Jeannie Ball	Robert Ellsperman	Marcella Kukelhan	DeNiece Roach
Lynn Ball	Daniel Eustache	Normand LaBarre	David Rollins
Jeannette Banta	Shirley Even	Leonilla Lake	Thomas Sanders
Ruby Barkhouse	Trinity Falk	Peter Lanzendorfer	Santa Croce Family
Karen Battles	Matthew Farrow	Gerald Laukhuf	Donald Santa Croce
Tom Bauder	Jill Flinn	Lorrie Laukhuf	Fred Santa Croce
Rick Bauder	Steve Flinn	Jennifer Leader	Rogene Schreiber
Luke Baxley	Jerry Frey	Dwayne LeBlanc	Derek Semler
William Baxley, III	Gregson Gann	Candi Leonard	Henry Skala, Jr.
Maria Beltran	John Gannon	Herriet Lewis	Marjorie Smiley
Sandee Berst	Rita Garcia	Richard Lewis	Adrian Smith
Joseph Black	Josephine Gheller-Brott	Phyllis Lindberg	Douglas Smith
Carol Brand	Tanya Goldman	Peggy Littlejohn	Mary Smith
Sam Bridgeman	Rosemary Golminas	Matt Machado	Waverly Smith
Molly Brooks	Fred Gooch	Caryn Mahaffy	Mikayla Spangler
David Brunke	Brenda Graner	Clarence Mahler	Stafford Family
Ruth Buckley	Lawrence Graner	Walter Mahler	Marilyn Stevens
Jessica Budreau	Richard Gregory	Brent Masserant	Vickie Sullivan
Ted Bulotti	Mary Griswold	Victor Masserant Family	Elizabeth Tanner
Martin Burke	Scott Griswold	Betty Mathine	Joe Thell
Kyle Bussas	Gladys Gruetzmacher	Bob McCleery	Fayne Thiel
Benjamin Cantor	Jackie Guercio	Frank McConville	Dr. Aymee
Irene Cantor	Denise Guercio-Higdon	Gloria McConville	Torres-Michels
Collin Capistrant	Ricardo Guerrero	Alisa McFarland	Louis Touns
Jenny Chang	Teresita Guerrero	Charley McLaughlin	Morton-Tribbett
Dave Chernoff	Annabel Guffin	Linda Meier	Wedding
Eileen Chernoff	George Guffin	Jennifer Moon	Roy Troutt, Jr.
M/M David Chernoff	George Hacke	Jack Moore	Kandy Turpin
Robert Coffey	Mary Hall	Jackie Moore	Terry Underwood
Eurance Collins	Donald Hardy	Willard Moore	Jacob Van Buren
Tiffinay Compiano	Jenice Harris	Carol Mullen	Rudy Van't Hoff
Rose Constance	Shirley Hayworth	Grace Mutschler	Janet Veal
Larry Cooley	Robert Healey, MD	Louis Neuendorf	Sharon Vinings
Russell Crystal	Richard Hinman	Jack Noonan	Shirley Wagner
Mary Danson	Johnny Hogan	Joan Noonan	Don Walker
DeMints Family	Lloyd Howell	Alayne Novalany	Carole Walters
Roman DiCroce	Lynda Howell	William Olesak	Barry Washburn
Betty Dienstfrei	Bill Huber	Debbie Omictin	Jeff Wentzell
Thomas DiPietro	A.J. Hughes	Norma Payne	Mike Williams
Fred Donnelly	Krista Humes	Frank Pellegrino	Lena Windhorst
Rick Donnelly	Howard Hunnius	Eric Peterson	Donald Womeldorf
Barbara Doogan	Robert Jackman	Alyn Platt	Margaret Working
Denise Drake	Lisa Jaffe	Scott Quinn	Elizabeth Wright





**National Ataxia Foundation**

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(763) 553-0020

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

**GIFT – HONOR – MEMORIAL**

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

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

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

My contribution is:

- In Memory    In Honor    Gift Membership

Name \_\_\_\_\_

Occasion \_\_\_\_\_

Send Acknowledgment Card to:

Name \_\_\_\_\_

Address \_\_\_\_\_

City/State/Zip \_\_\_\_\_

From:

Name \_\_\_\_\_

Address \_\_\_\_\_

City/State/Zip \_\_\_\_\_

**MEMBERSHIP**

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

- Lifetime membership                      \$500

*Annual memberships:*

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

Name \_\_\_\_\_

Address \_\_\_\_\_

City/State/Zip \_\_\_\_\_

Phone \_\_\_\_\_

E-Mail \_\_\_\_\_

- Yes, sign me up for NAF e-mails

**PAYMENT INFORMATION**

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

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

Total Amount Enclosed \$ \_\_\_\_\_

Credit Card:  Visa  MasterCard  Discover

Name on Card \_\_\_\_\_

Card # \_\_\_\_\_

Exp. Date \_\_\_\_\_ CVV # \_\_\_\_\_

Signature \_\_\_\_\_

Phone Number \_\_\_\_\_