



# The National Ataxia Foundation

*Dedicated to improving the lives of persons affected by ataxia through support, education, and research*

National Ataxia Foundation



## 2015 Annual Report



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# About the NAF

The National Ataxia Foundation (NAF) was founded in 1957 as a non-profit, charitable organization with a mission to find the cause and cure for all types of ataxia. The focus and purpose of the Foundation is to support promising research and provide meaningful programs and services to those affected by both dominantly and recessively inherited ataxia as well as sporadic ataxia and other closely related conditions.

The Foundation's objectives include:

## **Empowering ataxia families and persons at risk**

The NAF encourages a complete neurological examination to provide an early and correct diagnosis. The NAF maintains a current referral list of Ataxia and Movement Disorder Clinics and neurologists who are familiar with ataxia. The NAF provides assistance to start and sustain support groups and provides referrals to groups where available.

## **Increased awareness and education about ataxia**

The NAF assures that accurate information will be available through a variety of educational programs for those affected by ataxia, physicians, genetic counselors, physical therapists, other health professionals, and the public. Through literature, an in-depth quarterly news publication, and a comprehensive website, the NAF creates awareness and serves as a resource for current ataxia information

## **Prevention of ataxia**

At this time, there is no treatment available that can prevent ataxia from developing in a person who has an affected gene. The NAF encourages genetic counseling to help families make informed decisions about family planning and genetic testing.

## **Ataxia research activity**

The NAF continues to promote and fund world-wide ataxia research designed to better understand all types of ataxia, to find the genes that cause ataxia, and translate this information into treatment methods.

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More Information can be found on the National Ataxia Foundation's website [www.ataxia.org](http://www.ataxia.org)

# Message from the NAF

*Dear NAF members,*



**Michael Parent**

**NAF Executive Director**



**Bill Sweeney**

**NAF Board President**

*We are pleased to present to our members the National Ataxia Foundation's 2015 Annual Report. In this report you will find highlights of various activities conducted in 2015, a listing of funded Ataxia research studies, as well as financial information.*

*Since 1957, the vision of our original founders has been NAF's guiding light. In late 2015 the National Ataxia Foundation began work on a strategic plan to guide us over the next 3 – 5 years to further our founders' original vision to serve ataxia families through research, education, and service. We are thankful to all who have participated in this crucial planning process, particularly those members who provided valuable survey input. We expect this Strategic Plan to be completed and in place by mid-2016.*

*Our dedication to serve the needs of the Ataxia community is unwavering and our quest for treatments and a cure is unrelenting. In December 2015, the NAF Board of Directors approved funding for 20 promising Ataxia research studies. Additionally in 2015, NAF partnered with the American Academy of Neurology, American Brain Foundation as well as the Friedreich Ataxia Research Alliance (FARA) in funding other important ataxia research. In total, NAF committed nearly \$1 million dollars to research in 2015.*

*As vital research continues, NAF is also committed to publish up to date Ataxia information and provide essential programs and services to the Ataxia community. NAF delivers the latest information about Ataxia to the Ataxia community through NAF's quarterly newsletter "Generations", fact sheets, a constantly updated website, and contacts with individuals by phone and email. We communicate with clinicians, researchers, and the general public by participation at various medical conferences and Ataxia awareness events throughout the United States. Most importantly, NAF sponsored Support Groups, Chapters, and Ambassadors located throughout the United States provide a vehicle and setting to share, learn, and network.*

*Providing meaningful programs and supporting promising research requires the efforts of many. We are truly grateful to: our anonymous donor who generously committed another three-year, \$1.5 million research commitment, all who generously supported the 2015 Annual Ataxia Research Drive, our wonderful members and recurring gift members, to organizers, participants, donors, and sponsors of Walk n' Rolls and additional fundraisers, our corporate and foundation friends, those who contribute through their local CFC, and those who have included NAF in their estate plans. **YOU** are all making it possible to fund the best science in the world and to provide meaningful programs to Ataxia families.*

*While funding support is crucial, we would be at a loss without our amazing volunteers. We are grateful to our wonderful volunteers throughout the country who organize and participate in events, who staff information booths as Ability Expos, CFC functions, various medical conferences and who volunteer at NAF's Annual Ataxia Conference. We extend a special thanks to our support group leaders, chapter presidents, and ambassadors for providing vital support to their local Ataxia communities.*

*Lastly, we want to acknowledge the untiring work of the NAF staff. Their dedication not only aids the outstanding contributions made by the NAF Medical and Research Advisory Board and supports the leadership of the Board of Directors but serves as an example of the commitment NAF has to serving Ataxia families. The passion and commitment of so many is moving us forward to ending Ataxia. Thank you.*

*Respectfully submitted,*



**Bill Sweeney**  
President



**Michael Parent**  
Executive Director

# Research Today for a Hopeful Tomorrow

Ataxia research funding continued to be a high priority for the National Ataxia Foundation during 2015 with five research grant programs. The number of volunteer hours that world-leading scientists commit to the National Ataxia Foundation to ensure that the best research projects are selected to be funded is commendable. Dr. Harry Orr, Research Director, and Dr. Laura Ranum, Associate Research Director, led the grant applications peer-review process in 2015. Over 100 applications were submitted for review requiring a total of 212 individual reviews to take place. This required the commitment of 62 reviewers who were selected by Drs. Orr and Ranum for their expertise in progressive neurological disorders with a knowledge of the ataxias. The reviews were thorough and with the work of the reviewers, the National Ataxia Foundation's Board of Directors approved 20 research grants to be funded for FY 2016, having confidence that the best ataxia research was granted support. Below is a list of the research grants that were awarded funding at the December 2015 Board of Directors meeting.

**Young Investigator Award:** A one-year grant awarded to encourage a young investigator to pursue a career in the field of ataxia research.



**Ricardo Mouro Pinto, PhD**

Massachusetts General Hospital, Harvard Medical School  
Boston, MA

*Identification of Genetic Modifiers of Somatic GAA Instability in Friedreich Ataxia and in vivo CRISPR-Cas9 Genome Editing*



**Patricia Richard, PhD**

Columbia University  
New York, NY

*Role of the SETX/CHD3 Interaction in the DNA Damage Response and its Connection to AOA2*



**Percy Tumbale, PhD**

National Institute of Environmental Health Sciences, National Institutes of Health, Research Triangle Park, NC

*Expanded Roles for Aprataxin Mutations in Ataxia Oculomotor Apraxia 1 (AOA1)*

**Pioneer SCA Translational Research Award:** One year grants were awarded that will facilitate the development of treatments for the spinocerebellar ataxias.



**Laura Ranum, PhD**

University of Florida  
Gainesville, FL

*ASO Targeting of Bidirectional Transcripts and RAN Translation in SCA8*



**Wendy Raskind, MD, PhD**

University of Washington  
Seattle, WA

*Oligonucleotide-based Therapy in BAC-Mouse Models of SCA14*

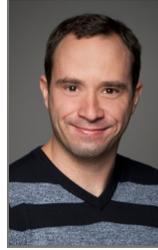
*In 2015, the NAF made a commitment through our partners and donors of nearly \$1,000,000 to fund promising world-wide research studies.*

## Research Today for a Hopeful Tomorrow (continued)

**Research Seed-Money Grants:** One-year grants which provide seed monies in early or pilot phases of studies that may attract future funding from other sources.



**Katia Aquilano, PhD**  
University of Rome  
"Tor Vergata", Italy  
*Study of the Role of Lipid  
Dysmetabolism in the Pathogenesis  
of Friedreich's Ataxia*



**Michael Downey, PhD**  
University of Ottawa  
Ottawa, Ontario, Canada  
*A New Look at Ataxia7 as a Regulator  
of Substrate Selection by the KAT2a  
Acetyltransferase*



**Liliana S. Mendonça, PharmaD, PhD**  
University of Coimbra  
Coimbra, Portugal  
*The Transplantation of Induced Plu-  
ripotent Stem Cells (iPSC)-derived  
Neural Stem Cells (NSC) in Machado-  
Joseph Disease (MJD)*



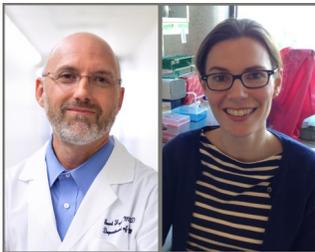
**Paul Rosenberg, MD**  
Duke University Medical Center  
Durham, NC  
*Contribution of Store-operated  
Calcium Entry to Calcium  
Dysregulation in Spinocerebellar  
Ataxias*



**Manolis Fanto, PhD**  
King's College London  
London, England, UK  
*RBfox Proteins as Critical  
Determinants for Cell Toxicity in  
DRPLA and Other Spinocerebellar  
Ataxias*



**Susan Perlman, MD**  
University of California  
Los Angeles, California  
*Ataxia Data Base*



**Brent Fogel, MD &  
Esther B.E. Becker, PhD**  
University of California, Los Angeles, California  
University of Oxford, UK  
*Development of a Cellular Model for the Functional  
Characterization of SCA41 Mutations*

**Young Investigator Award for SCA Research:** One year grants were awarded to encourage the following young investigators to pursue a career in spinocerebellar ataxia research:



**Sarah C. Goetz, PhD**  
Duke University  
Durham, NC  
*Exploring the Role of Primary Cilia in  
SCA11 Pathogenesis*



**Paul Rosenberg, MD**  
University of Chicago  
Chicago, Illinois  
*Role of SK Channels in Cerebellar  
Purkinje Cells in the Pathophysiology  
of Spinocerebellar Ataxia*

# Research Today for a Hopeful Tomorrow (continued)

## Young Investigator Award for SCA Research (Continued)



**Kenneth Scaglione, PhD**  
Medical College of Wisconsin  
Milwaukee, WI

*Investigation into Polyglutamine in Dictyostelium*



**Wei-Ling Tsou, PhD**  
Wayne State University School of Medicine  
Detroit, MI

*Mechanisms of Neuroprotection by DnaJ-1 in Spinocerebellar Ataxia Type 6*

**Post-Doc Research Fellowship Awards:** One-year Fellowship Grants are intended for researchers to spend a third year in a post-doc position to increase their chance to establish an independent ataxia research program.



**Rachael L. Cohen, DVM**  
Johns Hopkins University School Medicine  
Baltimore, MD

*Molecular Pathogenesis of Spinocerebellar Ataxia Type 12*



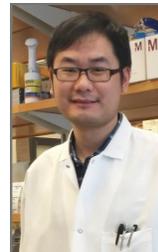
**Magda Matos Santana, PharmD, PhD**  
Center for Neuroscience and Cell Biology  
Coimbra, Portugal

*Advanced Induced Pluripotent Stem Cell-based Models of Machado-Joseph Disease*



**Pankaj Kumar Singh, PhD**  
Translational Medicine and Neurogenetics,  
IGMC  
Ellkirch-Strasbourg, France

*Unraveling Pathomechanism of Muscle Dysfunction in an Autosomal Recessive Cerebellar Ataxia 2 (ARCA2) Mice Model*



**Su Yang, PhD**  
Emory University  
Atlanta, GA

*Developing the MANF-based Therapeutic Approach for Spinocerebellar Ataxia 17*

## Clinical Research Training Fellowship in Ataxia Award:

The National Ataxia Foundation partnered earlier in 2014 with the American Brain Foundation to fund a two-year Clinical Research Training Fellowship in Ataxia award.



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

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



**Hélène Puccio, PhD**  
Institut de Génétique et de Biologie Moléculaire et Cellulaire,  
Strasbourg, France

*Development of Neuronal Gene Therapy Protocol for the Treatment of FA*

## The National Ataxia Foundation has partnered with FARA to fund a two-year study:

Additional research initiatives include a continuing partnership with the Coordination of Rare Diseases at Sanford and the CoRDS/Ataxia Patient registry. Working in partnership, CoRDS administers the ataxia patient registry, an important tool for recruiting participants to be involved in research studies or clinical trials. NAF continues to recruit individuals who are affected with ataxia, who are at risk for ataxia, and who are carriers of the ataxia gene to enroll in the registry which is a secure Velos eResearch Clinical Research Management System.

## Research Today for a Hopeful Tomorrow (continued)

As of December 10, 2015, 1,422 individuals are fully enrolled or in the screening process to complete enrollment. In addition to the administering the ataxia patient registry, CoRDS personnel attended the National Ataxia Foundation Annual Membership Meeting in 2015 and enrolled individuals on-site. They also host a monthly conference call with all of their patient advocacy partners, providing an excellent opportunity to learn of recruitment methods that have been successful and other best practices. CoRDS also provides a unique opportunity to raise awareness of ataxia and the work of the National Ataxia Foundation to an audience that the National Ataxia Foundation may have not had exposure.

The Brain Donation Program continues to be developed to serve those who wish to be a brain donor and provide important tissue to ataxia researchers at institutions across the United States. Dr. Arnulf Koeppen, at the VA in Albany, works with persons who have Friedreich Ataxia and wish to be a brain donor upon death. Dr. Laura Ranum is the lead investigator for brain donations for all other forms of ataxia. The National Ataxia Foundation honors seven individuals who passed in 2015 and donated their brain for ataxia research. There are 24 individuals who have completed all the necessary paperwork to be a brain donor and 30 individuals who have a plan pending. The NAF recognizes the courage and generosity of the donors and their families.

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The National Ataxia Foundation's research efforts include financial support of scientific meetings that have a direct relationship to a better understanding of the ataxias. In 2015, the National Ataxia Foundation provided support for the following meetings:

- 📄 Unstable Microsatellites and Human Disease
- 📄 International Ataxia Research Conference
- 📄 FASEB Mitochondrial Biogenesis and Dynamics in Health Disease and Aging
- 📄 CAG Triplet Repeat Disorders

The National Ataxia Foundation will continue to support important research initiatives with the goal of finding treatments for ataxia and ultimately a cure.

# Educational Services

As more ataxia genes are being discovered, as more options for genetic testing become available, and as basic science research continues to shed light on ataxia disease mechanisms moving the field into translational research, the National Ataxia Foundation is committed to providing education and the latest information to the ataxia community. This is done in a variety of ways, some of which are listed below:

**Generations**, the Foundation's quarterly newsletter, provides research updates, transcribed articles of the general sessions given at the Annual Ataxia Conference and the lay summaries of NAF-funded research grants and information on researchers who are recruiting research participants, in addition to other information pertinent to the ataxia community. NAF is grateful to the many volunteers who submit their personal stories on living with ataxia.

**Fact sheets** on the various types of ataxia and practical information such as physical therapy and preparing for a visit with the neurologist continue to be distributed. In 2015 the following fact sheets were updated: Episodic ataxia, Gene Testing for Hereditary Ataxia, Sporadic Ataxia and Multiple System Atrophy and Medications for Ataxia Symptoms. In 2015 over 5,000 paper copies of the NAF fact sheets were distributed. We are grateful for the assistance of ataxia specialists who volunteer their time to ensure that the materials from the National Ataxia Foundation are accurate and up-to-date.

**NAF Website** is an essential part of education and outreach. An internet search using the words "ataxia research" will usually put the National Ataxia Foundation's website at the top of the search list. The National Ataxia Foundation uses its website to answer frequently asked questions, provides downloadable fact sheets and ataxia booklets, posts research summaries, provides a news feed of national ataxia-related articles in addition to webpages dedicated to information on genetics, stem cells, Social Security disability information and other resources of value to those affected with ataxia and their families. NAF staff continually update the website with reliable and credible information.

**Email and phone calls** is another way that the National Ataxia Foundation provides information and education. Each and every day questions about treatments, research, and other aspects of living with ataxia come through the website or the [naf@ataxia.org](mailto:naf@ataxia.org) email box. Emails are answered as promptly as possible, (usually within the same day). Similarly, each weekday phone calls are made to the NAF office and a staff member is available to provide answers to ataxia-related questions. The National Ataxia Foundation is grateful to the members of the Medical Research Advisory Board members, who volunteer as an information resource.

**Meetings** continue to be a source of information and education for the ataxia community as well as the public. Meetings also educate NAF staff and volunteers on important issues related to ataxia. In addition to the Annual Membership Meeting held in March 2015, NAF had a presence at the following meetings and events:

**Rare Disease Day Minnesota State House event** was an event on February 24, 2015 to inform state legislators of the challenges of living with a rare disease. NAF partnered with the National Organization of Rare Disorders (NORD) and other rare disease advocacy groups to plan and execute this important meeting. The National Ataxia Foundation is grateful to our member who spoke at the event sharing his powerful story of living with ataxia.

**American Brain Foundation Brain Health Fair** in Washington, D.C. on April 18, 2015 which attracted hundreds of patients, families, and caregivers affected by a brain disease, as well as the general public interested in brain health. Thank you to local volunteers from the ataxia community for staffing the National Ataxia Foundation's exhibit table and answering questions from the attendees about ataxia.

## Education and Service (continued)

**American Academy of Neurology Annual Meeting**, also in Washington, D.C. from April 20-23, 2015. This annual meeting is attended by 1000s of neurologists. The National Ataxia Foundation staffs an exhibit table during the entire meeting making contacts with 100s of movement disorder specialists and other neurologists interested in ataxia. They learn about the services that the National Ataxia Foundation can provide for their patients and NAF's research grant program. A special "Thank you" to those who assisted in staffing the exhibit table.

**Progress through Partnership: NINDS Non-Profit Forum**, on September 8-9 was an opportunity for non-profit patient advocacy groups to meet with the NINDS staff to understand their research funding priorities, equip us to work effectively with NINDS and with industry in clinical trials. Thank you to local volunteers, for excellently representing the National Ataxia Foundation at this forum and reporting back the valuable information learned.

**Patient Engagement in Benefit/Risk Assessment** was a Drug Information Association conference on bringing the patient's voice into benefit-risk assessment throughout the research and approval process of medical products and how to best engage patients to incorporate their voices and identify next steps to overcome hurdles. The NAF was awarded a full travel support scholarship to attend this important conference.

**NORD's Rare Diseases and Orphan Products Breakthrough Summit**, October 21-22, 2015 brought the rare disease community together to discuss the patient's experience, advancing therapies, market accessibility to orphan drugs, and social media strategies for nonprofits in the rare space. NAF was awarded full travel support to attend the summit.

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The National Ataxia Foundation continues to explore the most current ways of communicating information in this digital world. NAF's social media spaces continue to not only provide support for the ataxia community, but also education and raise awareness.

# 58th Annual Membership Meeting

## “Soaring Mile High for a Cure”

Denver, CO March 6-8, 2015

The National Ataxia Foundation’s Annual Membership Meeting was held in Denver, CO in March. The meeting’s theme was “Soaring Mile High for a Cure.” The event was hosted by the North Central Region which includes the states of Colorado, Illinois, Iowa, Kansas, Minnesota, Missouri, Montana, Nebraska, North & South Dakota, Wisconsin and Wyoming.

Highlights of the 2015 meeting included:

- A well-received format change to the Birds of a Feather...sessions were divided and offered on Friday and Saturday afternoon. This new format allowed attendees to participate in other aspects of the conference such as visiting exhibit booths, bidding on the silent auction items, attending small group sessions like yoga, and more networking time with other attendees.
- For the first time attendees had access to an App for the meeting which allowed attendees to view the meeting schedule and session description, select sessions they wanted to attend and create their won schedule and reminders, interact with other attendees using the app, access exhibitor information , post pictures, and view maps of the meeting space and local area. Approximately 40% of the meeting attendees used the app and found this a great tool.
- The NAF was able to broadcast the General Sessions, on Sunday, live through a webcast for free to the public. The webcast was viewed 292 times and received great reviews from viewers that appreciated having access to these presentations.
- “I Am the Strength Behind Ataxia” awards were presented to Dr. Brent Fogel, The De Mint Family and Chanapangu Chandu Prasad George. Dr. Susan Perlman received an Outstanding Achievement award for her exceptional care to ataxia patients over the last 35 years and Dr. Lawrence Schut received a Lifetime Achievement award for his exceptional care to ataxia patients for more than 50 years.

Thanks to various fundraising efforts, the NAF was able to offer members a registration fee-at less than half the cost per person that is incurred to hold the meeting.

More than 375 attendees came for the three-day event. Attendees came from 42 U.S. states, Washington DC and from 4 additional countries including Canada, Denmark, India, and the United Kingdom.



Strength Behind Ataxia Awardees

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## Travel Grants Help Connect the Ataxia World

Through generous donations, the NAF was able to award 11 Travel Grants to help individuals with the costs associated with attending the meeting.

*“I have started going to the NAF meetings recently and have discovered hope within the words of the other members. Having become inspired by their words I long to go to these conventions and learn to further my role with NAF. “*

*“We were so fortunate and had the lovely opportunity in meeting all at Denver NAF meeting. We had a great time back there, all were so welcoming n made new friends, we learned a lot and experienced pleasant NAF, n frankly to say it was sooo hard to say goodbye to all. Back home ....we became celebrities due to NAF, don’t have words to express our joy.”*

# Building Ataxia Awareness



## Walk n' Roll for Ataxia:

In 2015, the NAF Walk n' Roll events raised more than \$285,000 for ataxia research and support of programs. The NAF support groups planned and organized a total of 12 unique Walk n' Roll events boasting more than 1,600 total participants.

The success of these events is a reflection on the efforts of the support group leaders, members, and event volunteers who dedicated their time and talents into making these events possible.

Pictures and videos from these events can be viewed at

[http://www.ataxia.org/events/walk\\_n\\_roll.aspx](http://www.ataxia.org/events/walk_n_roll.aspx)

The NCASG held its Walk n' Roll at a new location—Quarry Lakes Regional Park. Bill Sweeney, the NAF President joined them for the event. Ataxians from Sacramento to San Jose came to enjoy the festivities, food, games and comradery. The event raised almost \$15,000.

## International Ataxia Awareness Day

Each year individuals and communities throughout the world participate in events and activities to bring awareness to ataxia through International Ataxia Awareness Day (IAAD) which is recognized on September 25. In 2015 the NAF members, support groups, and ambassadors organized Walk n' Rolls for Ataxia events, fundraisers, information tables, and other activities to raise awareness about ataxia in their communities. A recap of the activities conducted in recognition of IAAD can be viewed at [http://www.ataxia.org/pdf/2015\\_Recognitions\\_of\\_IAAD.pdf](http://www.ataxia.org/pdf/2015_Recognitions_of_IAAD.pdf).



## Ataxia Awareness Tools

The NAF has some exciting awareness tools. For those giving talks to provide a greater understanding of ataxia in your communities the NAF has an [Ataxia Presentation](#) in Power-Point format for use in its entirety or to modify to be conducive to a variety of audiences and time constraints. For community members to distribute to media contacts with personal stories and/or share on social media spaces the NAF released a few [PSAs](#) to visually illustrate ataxia. These and other awareness tools including templates for [Press Releases](#) and [Proclamations](#) can also be found on the NAF website, [www.ataxia.org](http://www.ataxia.org).



# Building Ataxia Awareness, (continued)

The NAF E-blast list has grown to 8,500. In 2015, 96 E-blasts were sent out informing community members about upcoming support group activities, fundraising activities, the NAF funded research news, and the NAF Annual Membership Meeting notices.

## The NAF Website 2015 Statistics:

Visits/Sessions: 200,995

Page Views: 368,890

Returning Visitors: 55,026

Desktop: 111,639

Mobile: 62,765

Tablet: 26,592

## Demographics:

### Age:

18-24	27.5%
25-34	33.5%
35-44	15.5%
45-54	12.5%
55-64	5.5%
65+	5.5%

### Top 6 Countries (185 Countries):

United States	142,367	70.83%
United Kingdom	11,987	5.96%
Canada	9469	4.71%
Australia	7756	3.86%
India	3216	1.60%
Spain	1422	.071%

## Top Viewed Pages:

- 1: [www.ataxia.org/learn/ataxia-diagnosis.aspx](http://www.ataxia.org/learn/ataxia-diagnosis.aspx)  
Diagnosis of Ataxia, Being diagnosed with Ataxia
- 2: [www.ataxia.org/resources/publications.aspx](http://www.ataxia.org/resources/publications.aspx)  
Download our Facts Sheets
- 3: [www.ataxia.org/learn/ataxia-causes.aspx](http://www.ataxia.org/learn/ataxia-causes.aspx)  
Causes of Ataxia
- 4: [www.ataxia.org/research/naf-research-landing.aspx](http://www.ataxia.org/research/naf-research-landing.aspx)  
Home page > Research
- 5: [www.ataxia.org/index.org](http://www.ataxia.org/index.org)  
The National Ataxia Foundation Homepage
- 6: [www.ataxia.org/resources/generations.aspx](http://www.ataxia.org/resources/generations.aspx)  
"Generations" Newsletter Archive
- 7: [www.ataxia.org/connect/default.aspx](http://www.ataxia.org/connect/default.aspx)  
Home page > Support Groups
- 8: [www.ataxia.org/research/ataxia-research-grants.aspx](http://www.ataxia.org/research/ataxia-research-grants.aspx)  
Home page Research Grants and Applications
- 9: [www.ataxia.org/links/ataxia-clinics.aspx](http://www.ataxia.org/links/ataxia-clinics.aspx)  
Ataxia Research Studies Awarded Funding for FY 2014

The NAF exhibited, supported, and participated at meetings to raise ataxia awareness, educate healthcare professionals and the public about the NAF resources and inform ataxia investigators of the NAF's research programs. Those meetings included:

- **ASENT 17th Annual Meeting held at Georgetown University Hotel and Conference Center:**  
Washington, D.C. – February 19-21, 2015
- **Rare Disease Event at the Minnesota State Office Building:** St. Paul, MN – February 24, 2015
- **Brain Health Fair held at the Walter E. Washington Convention Center:**  
Philadelphia, PA – April 18, 2015
- **American Academy of Neurology Meeting held at the Walter E. Washington Convention Center:**  
Philadelphia, PA – April 20-23, 2015
- **New York Metro Abilities Expo held at Jersey Convention and Exposition Center:** Edison, NJ – May 1-3, 2015
- **Mobility Expo held at North Atlanta Trade Center:** Atlanta, GA – May 15-16, 2015
- **D-Backs Disability & Human Services Day held at Chase Field:** Phoenix, AZ – June 7, 2015
- **Peters Township Community Day held at Peterswood Park:** Venetia, PA – June 27, 2015
- **Abilities Expo held at NGR Center:** Houston, TX – July 31-August 2, 2015
- **Pasadena Senior Expo held at Pasadena Convention Center:** Pasadena, TX – August 12, 2015

# Building Ataxia Awareness, (continued)

The NAF continued:

- **Rivanna Station's CFC Kickoff Event held at the Rivanna Station James N Rowe Building:** Charlottesville, VA – September 8, 2015
- **NINDS Non-Profit Forum held at Natcher Conference Center:** Bethesda, MD – September 8-9, 2015
- **Abilities Expo held at Boston Convention & Exhibit Center:** Boston, MA – September 18, 2015
- **King County CFC Campaign Event held at the Jackson Federal Building:** Seattle, WA – October 7 and 8, 2015
- **Mid-Atlantic Ataxia Social Group 2nd Annual Wellness Day held at the Sheraton Columbia Town Center Hotel:** Columbia, MD – November 7, 2015
- **Abilities Expo held at Dulles Expo Center:** Chantilly, VA – December 4, 2015



## Social Media—



The NAF will continue to strengthen our connections with the ataxia community by participating in social media platforms.

	<u>2014</u>	<u>2015</u>
• <b>NAF Bulletin Board</b>	68,388 Members 9 Forum Discussions 2,202 Topics Posted	71,213 Members 9 Forum Discussions 3,162 Topics Posted
• <b>NAF Facebook Group</b>	4,443 Members	5,112 Members
• <b>NAF Facebook Page</b>	3,137 Likes	3,755 Likes
• <b>NAF Twitter Page</b>	886 Follows 951 Tweets	1,132 Follows 1,335 Tweets
• <b>NAF YouTube Channel</b>	98 Subscribers 8,127 Video Views	152 Subscribers 28,246 Video Views

# Administration & Fundraising

The National Ataxia Foundation (NAF) is dedicated to improving the lives of persons affected by ataxia through support, education, and research. NAF, a 501 (c) (3) nonprofit organization, has been serving ataxia families since 1957 and is able to do so only through the generosity of our donors. The following is a listing of sources which provided funding in 2015:

<i>Chapters/Support Groups</i>	<i>Fund Raising Events</i>	<i>Planned Giving</i>
<i>Combined Federal Campaign</i>	<i>Gifts of Stock/Assets</i>	<i>Recurring Gifts</i>
<i>Corporate Support</i>	<i>Group/Family/Individuals</i>	<i>Research Drive</i>
<i>Deferred Giving/Estates</i>	<i>IAAD Events</i>	<i>Social Networking</i>
<i>Employer Matching Gifts</i>	<i>Membership Support</i>	<i>Special Projects</i>
<i>Endowment Funds</i>	<i>Memorials/Honor Of</i>	<i>United Ways</i>
<i>Family Fund Raisers</i>	<i>Online Shopping Portals</i>	<i>Vehicle Donations</i>
<i>Foundation Support</i>	<i>Partnerships</i>	<i>Walk n' Rolls</i>

The National Ataxia Foundation gratefully acknowledges each of our donors. Every donor plays an essential role in fulfilling our mission to serve ataxia families. In addition, our amazing volunteers not only give of their precious time and extraordinary talents, but also significantly help in reducing the cost of NAF expenses, so more funds may be used to support promising research and important programs.

NAF gratefully acknowledges all of the generous donors who made a research donation during the 2015 Annual Ataxia Research Drive, making it possible to obtain the \$200,000 research match from a very generous anonymous donor. Thank you to all of our lead organizers, donors, sponsors, and volunteers across the country and beyond who have supported various NAF events, including the NAF Walk n' Rolls for Ataxia.

Thank you to those who contribute so generously through their local Combined Federal Campaign and United Ways. A special thank you to our members and to our recurring gift members. Thank you also to all who have donated to the Annual Ataxia Conference Silent Auction and to those who bid on those wonderful items. A heartfelt thank you to those who have included NAF in their wills...because of their selfless act, vital ataxia research has moved forward. We are grateful to our partners and the support we have received through our corporate and foundation friends. Thank you!

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In 2015, the National Ataxia Foundation received Charity Navigator's four out of a possible four star rating. This is the third consecutive year NAF has received the four star rating, only 14% of the charities rated received at least 3 consecutive 4-star evaluations from Charity Navigator, America's premier charity evaluator. According to Charity Navigator, "Receiving four out of a possible four stars indicates that your organization adheres to good governance and other best practices that minimize the chance of unethical activities and consistently executes its mission in a fiscally responsible way."

The National Ataxia Foundation continues to evaluate current funding avenues and explores additional potential revenue streams to help in supporting important programs and services, while maintaining a high level of vigilance in the costs associated with these efforts.

As with other nonprofit organizations, there are various fund raising costs associated with securing needed funding, as well as administrative costs in maintaining the organization. The 2015 audited financial statements reflect fundraising costs were 4% of total expenditures and administrative costs were 8% of total expenditures. Program Services for 2015 totaled 88% of total expenditures, in other words, 88 cents out of every dollar spent was used to support research and programs. In the Program Services area, the highest expenditure was research, totaling 57% of all expenditures for fiscal year 2015.

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# Chapters, Support Groups, and Ambassadors

NAF 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. Leaders also help coordinate ataxia awareness activities and events. In 2014, the Foundation had 3 chapters, 41 support groups, and 23 ambassadors providing information, comfort, and support through their service to individuals throughout the United States and beyond.

## Chapters:

Chesapeake (VA)

Louisiana

Mississippi

## Support Groups:

Alabama

Iowa

Ohio (Greater Cincinnati, Cleveland Area)

Arizona (Phoenix Area)

Maine

Oregon (Willamette Valley)

California (Los Angeles, Northern California, Orange County, Palo Alto)

Maryland (Johns Hopkins)

Pennsylvania (Central, Southeast, Western)

Colorado (Denver Area)

Massachusetts (Central, Boston Area)

Rhode Island

Connecticut (Tri-State\*)

Michigan (Detroit, Western)

Tennessee (Middle TN)

Delaware

Minnesota (Twin Cities, Central)

Texas (Houston, North Texas)

Florida (Tampa)

Missouri (Kansas City, St. Louis Area)

Utah

Georgia (Greater Atlanta)

New Hampshire

Washington (Olympic, Seattle Area)

Illinois (Chi-Town, Metro Area)

New Jersey (New Jersey, Tri-State\*)

Wisconsin

Indiana

New York (Central, Tri-State\*)

North Carolina (Tarheel)

## Ambassadors:

Alabama

Georgia

Minnesota

Arizona

Illinois

Missouri

Arkansas

Kansas

Texas

California

Kentucky

Washington

Connecticut

Maryland

Florida

## International:

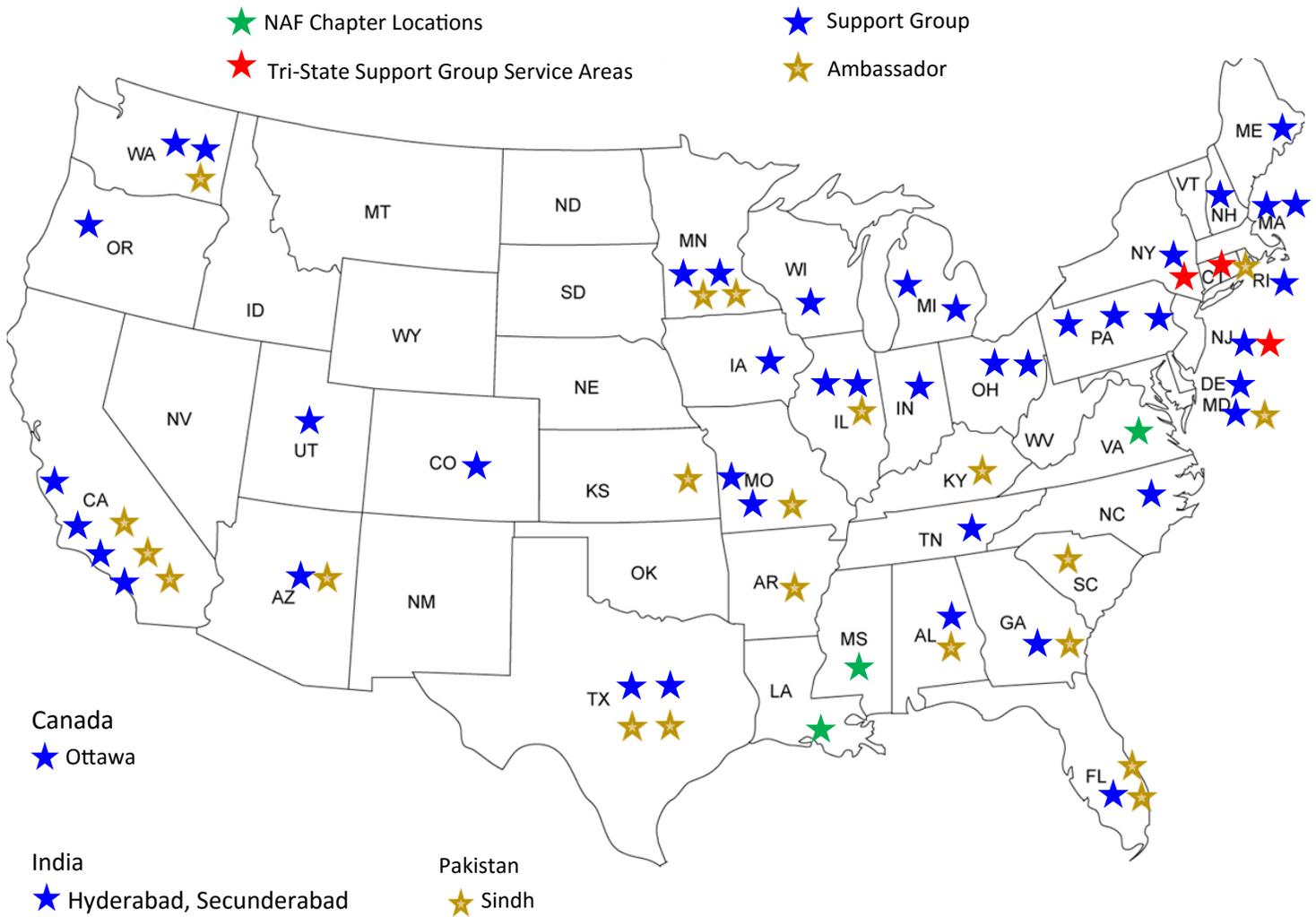
Canada

India—*Support Group*

Ontario—*Support Group*

Pakistan —*Ambassador*

# Chapters, Support Groups, and Ambassadors (Continued)



NAF has established more than 3 Chapters ★ and 43 Support Groups, ★ and appointed 20 Ambassadors ★ throughout the US

International Support groups: Canada (Ontario, Manitoba) & India  
★ Chapters: Louisiana, Mississippi, Chesapeake (MD, VA)

*“I feel like someone finally cares enough to help me”*

*“Thank you for sending me information about ataxia. The support group leader in my area is so friendly and helpful”*

The following is the National Ataxia Foundation's audited Balance Sheet for year ending December 31, 2015.

The 2015 CPA annual audited financial statements are available online at [www.ataxia.org](http://www.ataxia.org).

NATIONAL ATAXIA FOUNDATION, INCORPORATED  
BALANCE SHEET  
DECEMBER 31, 2014

	<u>Unrestricted</u>	<u>Temporarily Restricted</u>	<u>Permanently Restricted</u>	<u>Total</u>
<u>ASSETS</u>				
<u>Current Assets:</u>				
Cash and Cash Equivalents	\$451,587.34	\$ 294,796.11		\$ 746,383.45
Cash and Cash Equivalents-Clementz		3,479.04	\$ 69,607.45	73,086.49
Short Term Investments				-0-
Interest Receivable		233.01		233.01
Prepaid Expenses and Deposits	27,224.46			27,224.46
Other Receivables	<u>210.00</u>			<u>210.00</u>
Total Current Assets	<u>\$479,021.80</u>	<u>\$ 298,508.16</u>	<u>\$ 69,607.45</u>	<u>\$ 847,137.41</u>
<u>Property and Equipment:</u>				
Equipment	\$ 24,588.07			\$ 24,588.07
Less: Accumulated Depreciation	<u>24,588.07</u>			<u>24,588.07</u>
Net Property and Equipment	<u>\$ -0-</u>	<u>\$ -0-</u>	<u>\$ -0-</u>	<u>\$ -0-</u>
<u>Other Assets:</u>				
Stocks and Mutual Funds	\$ 66,370.34	\$ 330,371.36	\$ 530,392.55	\$ 927,134.25
Total Other Assets	<u>\$ 66,370.34</u>	<u>\$ 330,371.36</u>	<u>\$ 530,392.55</u>	<u>\$ 927,134.25</u>
TOTAL ASSETS	<u>\$545,392.14</u>	<u>\$ 628,879.52</u>	<u>\$ 600,000.00</u>	<u>\$1,774,271.66</u>
<u>LIABILITIES AND NET ASSETS</u>				
<u>Current Liabilities:</u>				
Accounts Payable	\$ 39,442.91			\$ 39,442.91
Accrued Payroll	14,252.14			14,252.14
Accrued Payroll Taxes	39.14			39.14
Accrued Vacation	17,742.57			17,742.57
Accrued Pension	<u>16,463.71</u>			<u>16,463.71</u>
Total Current Liabilities	<u>\$ 87,940.47</u>	<u>\$ -0-</u>	<u>\$ -0-</u>	<u>\$ 87,940.47</u>
<u>Net Assets:</u>				
Unrestricted	\$457,451.67			\$ 457,451.67
Temporarily Restricted:				
Research		\$ 452,823.17		452,823.17
Million Dollar Research Campaign		172,577.31		172,577.31
Clementz-SCA3		3,479.04		3,479.04
Permanently Restricted			<u>\$ 600,000.00</u>	<u>600,000.00</u>
Total Net Assets	<u>\$457,451.67</u>	<u>\$ 628,879.52</u>	<u>\$ 600,000.00</u>	<u>\$1,686,331.19</u>
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