



2016 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.

More Information can be found on the National Ataxia Foundation's website www.ataxia.org

Message from the NAF



Joel Sutherland

NAF Executive Director



Bill Sweeney

NAF Board President

Dear Friends,

Sixty years ago, the National Ataxia Foundation was created to give voice for those living with a rare disease, Ataxia. The NAF mission was designed to improve the lives of those living with Ataxia and their families through research, support, and education.

Our new branding depicts this re-launch. The new logo and color scheme of the Foundation illustrates strength and leadership through the bold, navy blue letters calling out the NAF. Compassion for our community is communicated via the soft blue letter-

ing and hope is present in the form of the gold sphere incorporated in the logo. The sphere itself symbolizes the ever-present connectivity of our researchers, clinicians, and families. A new look to “Generations” and our monthly e-newsletter clearly represent a new NAF.

A motto that “money buys research and research finds answers” is to resonate and the results are clear. Revenues nearly doubled from 2015 to 2016 as the Foundation were recipients of several major, year-end donations. To supplement those gifts, efforts from our Walk n’ Roll campaign were record setting and new campaigns were initiated.

In 2016, the Foundation received more than 100 grant applications from 14 different countries. The results were more than \$1.1 million were distributed to researchers across the globe and Clinical Trial Readiness efforts are being initiated at 12 sites across the country.

The mission for years to come must be to continue to raise funds, build awareness, and to energize out community. By doing so we can increase the research efforts to find the answers we seek—first a treatment and then a cure for all those living with Ataxia.

Respectfully submitted,



Bill Sweeney
President



Joel Sutherland
Executive Director

Research - Proud Past...Focused Future

The National Ataxia Foundation (NAF) offered five research programs to provide direct funding of Ataxia research in basic science and translational studies to find treatments and a cure for hereditary and sporadic Ataxia.

The National Ataxia Foundation was pleased to announce that 27 groundbreaking Ataxia research studies were awarded funding at the December 2016 NAF Board of Directors meeting for fiscal year 2017. The grantees represented work from the United States, Canada, Germany, the Netherlands, Portugal and Australia.

The following is a list of the researchers who received funding:

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



Jill Butler, PhD

University of Alabama,
Birmingham, AL

Reduced Expression of Mitochondrial Aldehyde Dehydrogenases Contributes to Metabolic Stress in Friedreich's Ataxia



Vincenzo A. Gennarino, PhD

Baylor College of Medicine,
Houston, TX

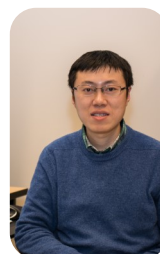
Pumilio1 Deficiency: Understanding a New Ataxia Gene and its Role in Cerebellar Dysfunction in Mice and Humans



Sathiji Nageshwaran, MD

Harvard University,
Boston, MA

Transcriptional Activation Using CRISPR/Cas Mutant Proteins as a Novel Therapy for Frataxin Gene Silencing

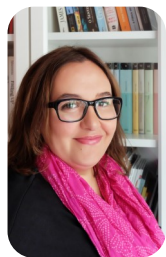


Bing Yao, PhD

Emory University,
Atlanta, GA

Epigenetic Modulation Mediated by RNA Binding Proteins in Neurodegeneration

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



Patricia Maciel, PhD

University of Minho,
Braga, Portugal

Testing the Therapeutic Potential of Mesenchymal Stem Cells and Their Secretome in an Animal Model of Spinocerebellar Type 3



Harry Orr, PhD

University of Minnesota,
Minneapolis, MN

Towards an ASO Therapy for Spinocerebellar Ataxia Type 1

In 2016, the NAF made a commitment through our partners and donors of more than \$1,000,000 to fund promising world-wide research studies.

Research - Proud Past...Focused Future (continued)

Pioneer SCA Translational Research Award: (Continued)



Willeke M.C. van Roon-Mom, PhD
Leiden University Medical Center
Leiden, The Netherlands

Advancing the Therapeutic Potential of Exon Skipping for Spinocerebellar Ataxia Type 3

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.



Margit Burmeister, PhD
University of Michigan
Ann Arbor, MI

Role of VPS13D in Ataxia



Fang He, PhD
Texas A & M University
Kingsville, TX

Studying Spinocerebellar Ataxia Type 36 (SCA36) with Genetically Modified Fruit Flies



Martin Lavin, PhD
University of Queensland Centre for Clinical Research (UQCCR)

Assessing the Role of Senataxin in Cellular Inflammation, Gene Regulation, and innate Immunity in Setx -/- Mice and a Human Neuronal Model



Gülin Öz, PhD
University of Minnesota
Minneapolis, MN

Launching the US Europe Neuroimaging Partnership in SCA



Sandra de Macedo Ribeiro
Instituto de Biologia Molecular e Celular
Porto, Portugal

New Therapeutic Approaches for Machado-Joseph Disease: Chaperoning Protein Self-assembly



Susan Perlman, MD
University of California
Los Angeles, CA

Web-based National Ataxia Data Base



Ana Teresa Antunes Simões
University of Coimbra
Coimbra, Portugal

Calpain-mediated Proteolysis in Machado-Joseph Disease



Clara van Karnebeek, MD, PhD
University of British Columbia
Vancouver, BC, Canada

Whole Exome Sequencing (WES) in the Diagnosis and Management of Atypical Childhood Hereditary Ataxia Conditions

Research - Proud Past...Focused Future (continued)

Research Seed-Money Grants: (Continued)



Adam Vogel, PhD

Centre for Neuroscience of Speech
Parkville, Victoria, Australia

Intensive Home Based Speech Rehabilitation for Adults with Degenerative Ataxia

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.



Collin Anderson, PhD

University of Utah
Salt Lake City, UT

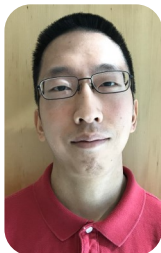
Development and Mechanistic Study of Deep Brain Stimulation of Dentate Nucleus for the Treatment of Degenerative Ataxia



Laura Bott, PhD

Northwestern University
Evanston, IL

Transcellular Regulation of the Proteostasis Network in Spinocerebellar Ataxia Type 3



Jonathan Chen, PhD

Scripps Florida
Jupiter, FL

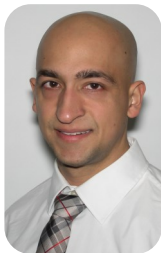
Rapid Structure-based Lead Optimization of a Small Molecule Drug that Targets c(CAG)^{exp}



Stephanie Seminara, MD

Massachusetts General Hospital
Boston, MA

Ataxia with Hypogonadotropic Hypogonadism due to Ubiquitin Ligase Dysregulation



Ravi Chopra, PhD

University of Michigan
Ann Arbor, MI

Identifying Dendro-protective Ion Channels in Cerebellar Ataxia



Joo Hyun (Joanne) Kim, PhD

University of Minnesota
Minneapolis, MN

The Role of Astrocytes in SCA1 via NF- κ B Pathway



James Orengo, MD, PhD

Baylor College of Medicine
Houston, TX

Unraveling the Mechanisms of Motor Neuron Degeneration in Spinocerebellar Ataxia, Type 1.

Research - Proud Past...Focused Future (continued)

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:



Manu Ben-Johny, PhD
John Hopkins University
Baltimore, MD

Aberrant Regulation of Voltage-gated Na Channels in the Pathophysiology of Spinocerebellar Ataxia 27



Marija Cvetanovic, PhD
University of Minnesota
Minneapolis, MN

Role of Astrocyte Calcium Signaling in the Pathogenesis of SCA1



Vikram Khurana, PhD
Brigham and Women's Hospital and
Harvard Stem Cell Institute
Boston, MA

Systematic Edgotyping of Ataxin Proteins in Cellular Systems from Yeast to Patient Neurons



Jana Schmidt, PhD
University of Tuebingen
Tubingen, Germany

Alleviation of Proteasomal Inhibition as a Therapeutic Approach for SCA3

As of December 31, 2016, 1,109 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 Ataxia Conference in 2016 and enrolled individuals on-site. They also host a quarterly 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 2016 and donated their brain for Ataxia research. There are 44 individuals who have completed all the necessary paperwork to be a brain donor and 38 individuals who are on the Living Donor Registry. The NAF recognizes the courage and generosity of the donors and their families.

The National Ataxia Foundation's research efforts include financial support and raising awareness of scientific meetings that have a direct relationship to a better understanding of the Ataxias. In 2016, the National Ataxia Foundation provided support or awareness for the following meetings:

- 📖 International Neurodegeneration Symposium
- 📖 Clinical Research Consortium for the Study of Cerebellar Ataxia
- 📖 Fifth International Meeting on Spastic Paraparesis and Ataxias
- 📖 The Tenth World Congress on Controversies in Neurology (CONy)

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 2016 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.

Evaluation and Management of Ataxic Disorders, an overview for physicians was updated by Dr. Susan Perlman, MD for the National Ataxia Foundation.

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 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 Ataxia Conference held in March, the NAF had a presence at the following meetings and events:

American Brain Foundation Brain Health Fair in Vancouver, BC, Canada on Friday, April 15, 2016 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. Eight individuals became new members of the Western Canada Ataxia Group.

American Academy of Neurology Annual Meeting, also in Vancouver from April 17-20, 2016. 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.

Educational Services (continued)

Progress through Partnership: NINDS Non-Profit Forum, on September 13-14, 2016 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 who attended part of the meeting.

NORD's Rare Diseases and Orphan Products Breakthrough Summit, October 17-18, 2016 in Arlington, VA brought the rare disease community together to discuss trending topics from the FDA, strategies to address patient challenges and breaking down the barriers to access to therapies and treatments for the rare disease patient.

American Society for Experimental Neurotherapeutics (ASENT), March 17-19, 2016 in North Bethesda, MD. The meeting is attended by leaders in academia, government, advocacy and industry to facilitate the process by which new therapies are made available to patients with neurological disorders. Thank you to our local volunteer who attended the meeting and reported back the important findings.

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.

59th Annual Ataxia Conference (AAC)

"THE MAGIC OF A CURE- DREAM IT. HOPE IT."

Orlando, Florida—April 1-3, 2016

The National Ataxia Foundation's Annual Ataxia Conference was held in Orlando, Florida. The conference's theme was "The Magic of a Cure-Dream It. Hope It." The event was hosted by the Southeast Region which includes the states of Alabama, Florida, Georgia, Tennessee, and North and South Carolina.

Highlights of the 2016 meeting included:

- The format of the program was well received. The General Sessions were scheduled in the mornings and the Birds of a Feather Sessions were divided and offered on either Friday or Saturday afternoon.
- With the Sixth Ataxia Investigators Meeting (AIM) dovetailing with the AAC, conference attendees had an opportunity to meet Ataxia researchers on Thursday afternoon to view scientific posters, interact and engage with Ataxia researchers and ask questions about their research efforts.
- The 2016 Ataxia Investigators Meeting (AIM) provided a forum for exchange of results and ideas during the scheduled scientific sessions as well as valuable opportunities for scientists to meet informally and to network. As a result of this meeting, five scientists from Germany, Portugal, and the U.S agreed to form an "Alliance to Fight SCA3."
- "I Am the Strength Behind Ataxia" awards were presented to Mike Cammer, Charlotte DePew, and Jane Jaffe. Dr. Harry Orr, PhD, received an Exceptional Service Award for his significant research accomplishments.
- The "Rose Lee Show" featured this year's conference in a segment of their show that aired in April. The segment included interviews with Michael Parent, NAF Executive Director, Cindy and Jerry DeMint, NAF Orange County Support Group Members.

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 500 attendees came for the three-day event. Attendees came from 38 U.S. states, Washington DC and from six additional countries including Canada, Denmark, India, Pakistan, Peru and the United Kingdom.



Doug Greener and Paul Blaes at the 2016 AAC

Travel Grants Help Connect the Ataxia World

Through generous donations, the NAF was able to award 31 Travel Grants to help individuals with the costs associated with attending the meeting.

"No matter how much you educate someone or tell them about what you're going through, no one really understands except someone who is experiencing something close to what you are. It is because of the NAF, allowing me to meet these wonderful people, to attend the conference with the help of a travel grant and discounted hotel rates, I have been able to meet with the doctors and hear the specialists in the field talk about the progress that is being made with scientific research. It helps me fight harder and to keep going to help them find treatments and cures for these diseases."

Building Ataxia Awareness

Walk n' Roll for Ataxia:

In 2016, the NAF Walk n' Roll events raised more than \$368,400 for Ataxia research and support of programs. The NAF support groups planned and organized a total of 13 unique Walk n' Roll events boasting more than 1,800 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.



The 9th Annual New England Walk n' Roll to Cure Ataxia was held at a new location this year on Saturday, September 10 at Bristol Town Beach in Bristol, RI. There was entertainment and a raffle following the walk. The event raised more than \$45,000 to benefit the National Ataxia Foundation.

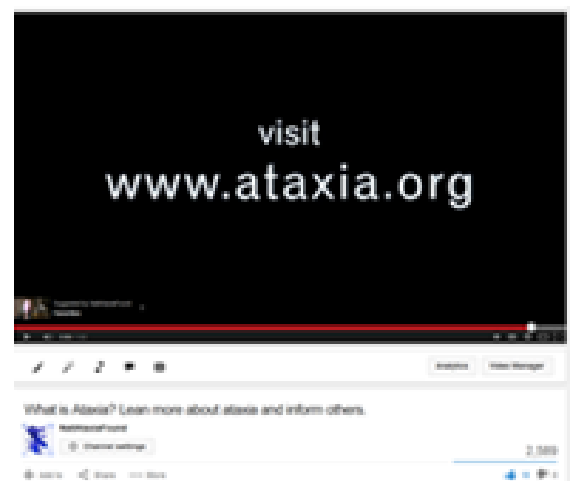
International Ataxia Awareness Day

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 2016 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.



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 PowerPoint 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.



Building Ataxia Awareness (continued)

The NAF E-blast list has grown to 9,500 . In 2016 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 Ataxia Conference notices.

The NAF Website 2016 Statistics:

Visits/Sessions: 225,958 **New Visitors:** 163,252 (72.2%) **Returning Visitors:** 62,706 (27.8%)

Desktop: 124,820 **Mobile:** 73,599 **Tablet:** 27,839

Demographics:

<u>Age:</u>		<u>Top 6 Countries (191 Countries):</u>		
18-24	13.24%	United States	164,341	72.48%%
25-34	20.61%	United Kingdom	11,830	5.24%
35-44	18.29%	Canada	10,675	4.72%
45-54	16.94%	Australia	9,166	4.06%
55-64	16.87%	India	3,468	1.53%
65+	14.06	Brazil	1,424	.063%

Page Views: 412,954

- 1: www.ataxia.org/learn/ataxia-diagnosis.aspx
Diagnosis of Ataxia, Being diagnosed with Ataxia
- 2: www.ataxia.org/resources/
- 3: www.ataxia.org/resources/publications.aspx
Download our Facts Sheets
- 4: www.ataxia.org/learn/ataxia-causes.aspx
Causes of Ataxia
- 5: www.ataxia.org/index.org
The National Ataxia Foundation Homepage

Top Viewed Pages:

- 6: www.ataxia.org/resources/generations.aspx
“Generations” Newsletter Archive
- 7: www.ataxia.org/connect/default.aspx
Home page > Support Groups
- 8: www.ataxia.org/research/ataxia-research-grants.aspx
Home page Research Grants and Applications
- 9: www.ataxia.org/links/ataxia-clinics.aspx
Ataxia Research Studies Awarded Funding for FY 2014
- 4: www.ataxia.org/research/na-f-research-landing.aspx
Home page > Research

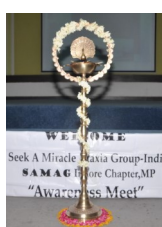
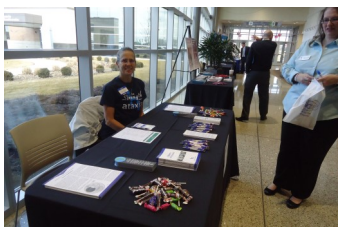
The NAF exhibited, supported, and participated at meetings to raise ataxia awareness, educate healthcare professionals and the public about the NAF resources and inform ataxia investigators of the NAF’s research programs. Those meetings included:

- **Abilities Expo held at the Los Angeles Convention Center:** Los Angeles, CA – February 5-7, 2016
- **Rare Disease Day event held at Parkview Mirro Center for Research and Innovation:**
Fort Wayne, IN – February 29, 2016
- **ASENT 18th Annual Meeting held at Bethesda North Marriott Hotel & Conference Center:**
Bethesda, MD – March 17-19, 2016
- **Brain Health Fair held at the Vancouver Convention Center:** Vancouver, BC – April 15, 2016
- **American Academy of Neurology Meeting held at the Vancouver Convention Center:**
Vancouver, BC – April 15-21, 2016
- **Mobility Expo held at North Atlanta Trade Center:** Norcross, GA – April 15-16, 2016
- **New York Metro Abilities Expo held at Jersey Convention and Exposition Center:** Edison, NJ – April 29-May 1, 2016
- **North Syracuse Family Festival Fundraiser and Awareness Event held at North Syracuse Community Center:**
North Syracuse, NY – May 28, 2016
- **Spastic Paraplegia Foundation Annual Conference held at the Renaissance Chicago O’Hare Suites Hotel:**
Chicago, IL – June 25-26, 2016
- **Abilities Expo held at Dulles Expo Center:** Chantilly, VA – December 2, 2016
- **D-Backs Disability & Human Services Day held at Chase Field:** Phoenix, AZ – August 6, 2016

Building Ataxia Awareness (continued)

The NAF continued:

- **Clinical Research Consortium for the study of Cerebellar Ataxia:** Bloomington, MN – August 30-31, 2016
- **NINDS Non-Profit Forum held at Lister Hill Auditorium:** Bethesda, MD – September 13-14, 2016
- **Abilities Expo held at Boston Convention & Exhibit Center:** Boston, MA – September 16, 2016
- **National Organization for Rare Diseases & Orphan Products Breakthrough Summit held at Courtyard by Marriott Crystal City:** Arlington, VA – October 17-18, 2016
- **Indo-US Rare Disease Conference held at The Commons Hotel:** Minneapolis, MN – November 18, 2016



Social Media—



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

	<u>2015</u>	<u>2016</u>
• NAF Bulletin Board	71,213 Members 9 Forum Discussions 3,162 Topics Posted	75,198 Members 9 Forum Discussions 3,208 Topics Posted
• NAF Facebook Group	5,112 Members	5,471 Members
• NAF Facebook Page	3,755 Likes	5,212 Likes
• NAF Twitter Page	1,132 Follows 1,335 Tweets	1,371 Follows 1,748 Tweets
• NAF YouTube Channel	152 Subscribers 28,246 Video Views	229 Subscribers 40,577 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 2016:

<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 2016 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!

In 2016, the National Ataxia Foundation received Charity Navigator's four out of a possible four star rating. This is the fourth consecutive year the 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 2016 CPA annual audit reflects fundraising costs were 4% of total expenditures and administrative costs were 8% of total expenditures. Program Services for 2016 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 56.75% of all expenditures for fiscal year 2016.

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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 2016, the Foundation had 2 chapters, 41 support groups, and 25 ambassadors providing information, comfort, and support through their service to individuals throughout the United States and beyond.

Chapters:

Chesapeake (VA)

Mississippi

Support Groups:

Alabama

Arizona (Phoenix Area)

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

Colorado (Denver Area)

Connecticut (Tri-State*)

Delaware

Florida (Tampa, Port St. Lucie)

Georgia (Greater Atlanta)

Illinois (Chi-Town, Metro Area)

Maine

Maryland (Johns Hopkins)

Massachusetts (Central, Boston Area)

Michigan (Detroit, Western)

Minnesota (Twin Cities, Central)

Missouri (Kansas City, St. Louis Area)

Nebraska

New Hampshire

New Jersey (New Jersey, Tri-State*)

New York (Tri-State*)

North Carolina (Tarheel)

Ohio (Cleveland Area)

Oregon (Willamette Valley)

Pennsylvania (Central, Southeast, Western)

Rhode Island

Tennessee (Middle TN)

Texas (Greater Houston Area, North Texas)

Utah (Salt Lake City)

Washington (Western)

Wisconsin

Ambassadors:

Alabama

Arizona

Arkansas

California

Florida

Georgia

Illinois

Indiana

Iowa

Kansas

Kentucky

Maryland

Minnesota

Missouri

Texas

Washington

International:

Canada

Ottawa, Ontario — *Support Group*

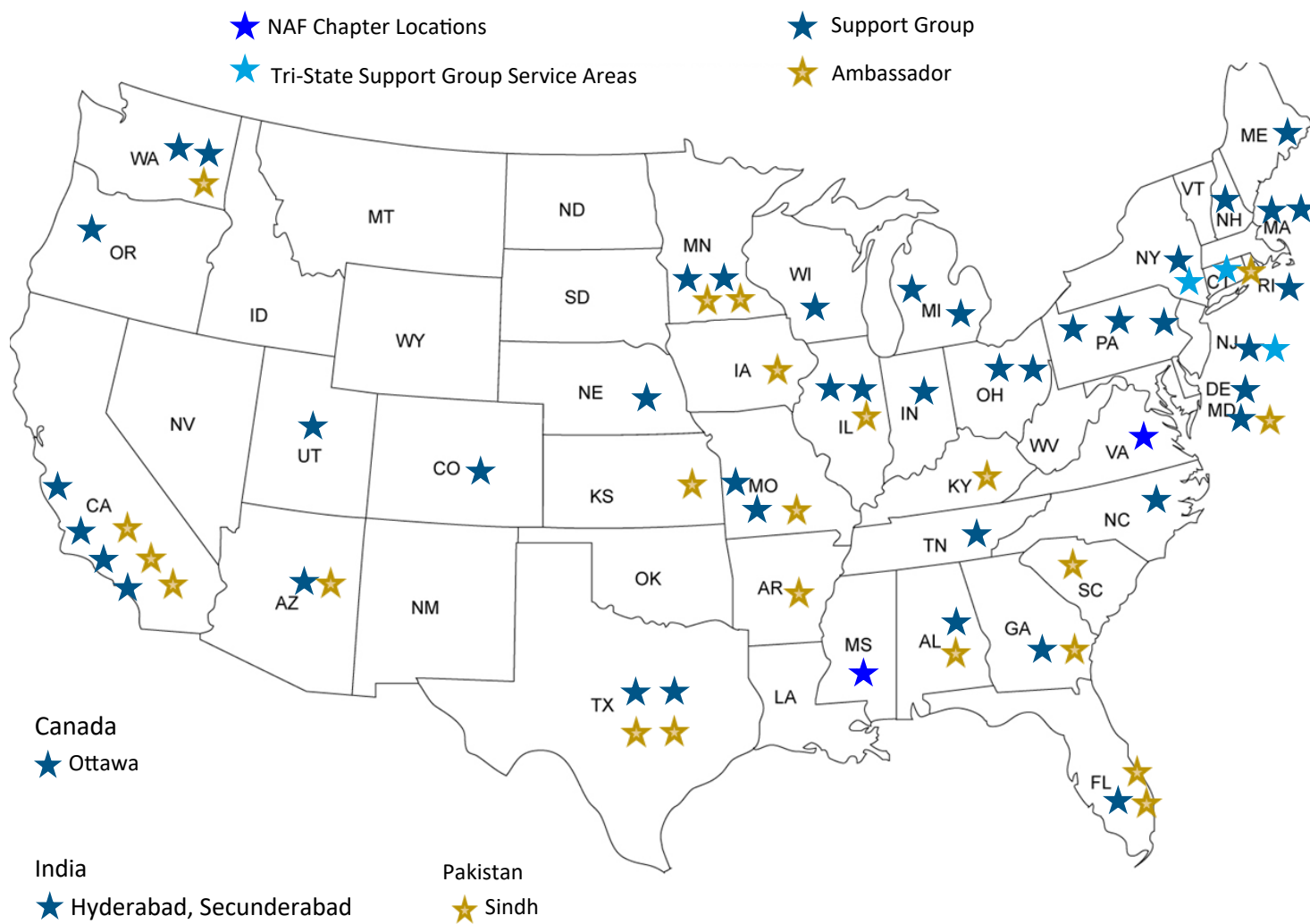
India

Hyderabad, Secunderabad — *Support Group*

Pakistan

Karachi — *Ambassador*

Chapters, Support Groups, and Ambassadors (Continued)



NAF has established more than 2 Chapters ★ and 41 Support Groups ★ and appointed 25 Ambassadors ★ throughout the US

International Support groups: Canada (Ontario, Manitoba) & India

★ Chapters: Mississippi and Chesapeake (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”

NAF FINANCIALS

The following is the National Ataxia Foundation's audited Balance Sheet for year ending December 31, 2016.

The 2016 CPA annual audited financial statements are available online at www.ataxia.org.

NATIONAL ATAXIA FOUNDATION, INCORPORATED
BALANCE SHEET
DECEMBER 31, 2016

	<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	\$1,470,517.23	\$ 69,741.29		\$1,540,258.52
Cash and Cash Equivalents-Clementz		8,092.78	\$ 46,546.92	54,639.70
Short Term Investments				-0-
Interest Receivable				-0-
Prepaid Expenses and Deposits	22,184.08			22,184.08
Other Receivables	6,974.70			6,974.70
Total Current Assets	<u>\$1,499,676.01</u>	<u>\$ 77,834.07</u>	<u>\$ 46,546.92</u>	<u>\$1,624,057.00</u>
<u>Property and Equipment:</u>				
Equipment	\$ 24,588.07			\$ 24,588.07
Less: Accumulated Depreciation	24,588.07			24,588.07
Net Property and Equipment	<u>\$ -0-</u>	<u>\$ -0-</u>	<u>\$ -0-</u>	<u>\$ -0-</u>
<u>Other Assets:</u>				
Stocks and Mutual Funds	\$ 85,037.58	\$344,301.77	\$553,453.08	\$ 982,792.43
Total Other Assets	<u>\$ 85,037.58</u>	<u>\$344,301.77</u>	<u>\$553,453.08</u>	<u>\$ 982,792.43</u>
TOTAL ASSETS	<u>\$1,584,713.59</u>	<u>\$422,135.84</u>	<u>\$600,000.00</u>	<u>\$2,606,849.43</u>
<u>LIABILITIES AND NET ASSETS</u>				
<u>Current Liabilities:</u>				
Accounts Payable	\$ 106,764.38			\$ 106,764.38
Accrued Payroll	15,234.49			15,234.49
Accrued Payroll Taxes				-0-
Accrued Vacation	36,903.36			36,903.36
Accrued Pension	16,022.44			16,022.44
Total Current Liabilities	<u>\$ 174,924.67</u>	<u>\$ -0-</u>	<u>\$ -0-</u>	<u>\$ 174,924.67</u>
<u>Net Assets:</u>				
Unrestricted	\$1,409,788.92			\$1,409,788.92
Temporarily Restricted:				
Research		\$235,414.98		235,414.98
Million Dollar Research Campaign		178,628.08		178,628.08
Clementz-SCA3		8,092.78		8,092.78
Permanently Restricted			\$600,000.00	600,000.00
Total Net Assets	<u>\$1,409,788.92</u>	<u>\$422,135.84</u>	<u>\$600,000.00</u>	<u>\$2,431,924.76</u>
TOTAL LIABILITIES AND NET ASSETS	<u>\$1,584,713.59</u>	<u>\$422,135.84</u>	<u>\$600,000.00</u>	<u>\$2,606,849.43</u>

NAF FINANCIALS

The following is the National Ataxia Foundation's audited Statement of Activities for year ending December 31, 2016. The 2016 CPA annual audited financial statements are available online at www.ataxia.org.

NATIONAL ATAXIA FOUNDATION, INCORPORATED
STATEMENT OF ACTIVITIES
FOR THE YEAR ENDED DECEMBER 31, 2016

	<u>Unrestricted</u>	<u>Temporarily Restricted</u>	<u>Permanently Restricted</u>	<u>Total</u>
<u>Revenues, Gains & Other Support:</u>				
Contributions, Memorials & Honorariums	\$1,369,384.49	\$1,241,068.15		\$2,610,452.64
Memberships	73,181.90			73,181.90
Annual Meeting/AIM	323,903.02			323,903.02
Investment Earnings	3,653.82	36,563.51		40,217.33
Market Adjustment	22,114.82	17,733.47		39,848.29
Royalties	260.00			260.00
Sales	6,635.50			6,635.50
Net Assets Released from Restrictions:				
Satisfaction of Research Program Restrictions	<u>1,399,558.32</u>	<u>(1,399,558.32)</u>		<u>-0-</u>
Total Revenues, Gains & Other Support	<u>\$3,198,691.87</u>	<u>\$ (104,193.19)</u>	<u>\$ -0-</u>	<u>\$3,094,498.68</u>
<u>Expenses:</u>				
Program Services:				
Education	\$ 287,308.84			\$ 287,308.84
Service	320,764.84			320,764.84
Research	<u>1,380,364.03</u>			<u>1,380,364.03</u>
Total Program Services	<u>\$1,988,437.71</u>			<u>\$1,988,437.71</u>
Supporting Services:				
Administration	\$ 146,198.34			\$ 146,198.34
Fund Raising	<u>91,544.73</u>			<u>91,544.73</u>
Total Supporting Services	<u>\$ 237,743.07</u>			<u>\$ 237,743.07</u>
Total Expenses	<u>\$2,226,180.78</u>			<u>\$2,226,180.78</u>
CHANGE IN NET ASSETS	\$ 972,511.09	\$ (104,193.19)	\$ -0-	\$ 868,317.90
NET ASSETS - BEGINNING OF YEAR	<u>437,277.83</u>	<u>526,329.03</u>	<u>600,000.00</u>	<u>1,563,606.86</u>
NET ASSETS - END OF YEAR	<u>\$1,409,788.92</u>	<u>\$ 422,135.84</u>	<u>\$ 600,000.00</u>	<u>\$2,431,924.76</u>



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