VOLUME 48, NUMBER 2

SPRING 2020

National Ataxia Foundation

GENERATIONS

THE OFFICIAL PUBLICATION OF THE NATIONAL ATAXIA FOUNDATION

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Please direct correspondence to:

National Ataxia Foundation
Connecting Ataxia families, researchers, clinicians and the community

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CFC #10752

Generations Schedule:

Issue	Spring	Summer	Fall	Winter
Mail Date	April	July	October	January

NAF Update:
Letter from the Executive Director

Andrew Rosen,
Executive Director

Hello NAF Members:

As I write this note at the beginning of April, the world around us has changed. In some ways, this edition of Generations is what you've come to know from NAF in the past – summaries of the research projects that NAF has recently funded, an update on our wildly successful Joint Mission Bataan (even though the actual event was canceled), and other items we hope you find valuable. But in other very important ways, this edition is like none other that NAF has ever produced. It's not the words that will appear here. It's the environment in which we're all living. I know that we will come out of this. I have no idea exactly when and under what conditions. What interests me most is the societal changes that will stem from our prolonged struggle with COVID-19, and how those changes will affect our Ataxia community. Will our understanding of how truly connected we all are change the way that those with disabilities are viewed and treated? Will all of this working from home and communicating virtually change the way the world conducts business and interacts? I don't know the answers, but I sure am curious.

One thing I do know – NAF is here for you. Whether it's helping our Support Group leaders manage virtual meetings, working with our Walk N' Roll leaders to think creatively about moving their events online, or granting generous time extensions to our research grant recipients who are dealing with temporarily closed labs and clinics, we are doing everything we can to make it "business as usual" for NAF. While we were extremely disappointed to cancel our research and patient conference (the first time that we will not have hosted a live AAC in over 60 years!), we know we made the right decision. I hope you've been able to join the webinars that are presenting the AAC sessions that would have happened. If not, they're available on our website at www.ataxia.org/webinars.

I'll sign off with a huge thank you to the many of you who have reached out with kind words of hope and support. Right back at you! I look forward to seeing you all soon...whether on Zoom or in person.

Support Groups and COVID-19

In a continued effort to protect our Ataxia community during the COVID-19 pandemic, NAF has advised our Support Group leaders to cancel in-person meetings and replace them with virtual meetings when possible. Many of our leaders have tried new virtual platforms, such as video chats and conference call services. We hope to see you join a virtual meeting and say hello!

Find a support group near you at www.ataxia.org/support-groups

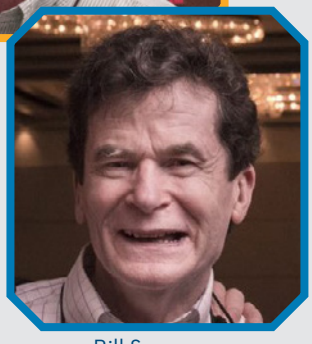
Find upcoming virtual meetings at www.ataxia.org/events

New Board Leadership for NAF

The NAF Board of Directors voted in a new Executive Committee in early March. The executive officers of the NAF Board of Directors are:

President: Sam Kirton
Vice President: Linda Snider-Sidwell
Treasurer: Camille Daglio
Secretary: John Mauro
Executive Committee at Large: Dave Brunnert

Sam Kirton



Bill Sweeney

The March meeting also saw Bill Sweeney's 5-year term as President at NAF come to an end. Thank you for your hard work and dedication to the Ataxia community, Bill! We'd also like to thank our board members who have moved to Emeritus status, which include Harold Crawford, Charlene Danielson, Marilyn Schut Lee, and Dave Zilles. A new member was elected to our board as well at the March Meeting. We would like to give a big welcome to new memeber, Peter Schnobrich. Welcome, Peter!

2018 NAF Funded Research

A No-Cost Extension was issued for the following 2018 NAF funded grant awards, resulting in printed lay summaries during this publication rather than the Fall edition.

RESEARCH SEED MONEY AWARD

Valeria Cavaliere, PhD | Universita di Bologna | Bologna, Italy

Investigating the Connection Between DNA Damage Repair and Nervous System Maintenance in a Drosophila Model of SCAN1 Disease

Spinocerebellar ataxia with axonal neuropathy-1 (SCAN1) is a rare hereditary form of ataxia. SCAN1 patients develop cerebellar ataxia and peripheral axonal motor and sensory neuropathy from late infancy to become wheelchair-bound with cerebellar atrophy at early adulthood. To investigate pathogenesis of SCAN1 we used the fruit fly Drosophila, a powerful model system to study human diseases since it shares remarkable conservation with human basic cellular and physiological properties. By using powerful molecular and genetic techniques available in this tiny organism we obtained flies expressing the human mutant protein related to the SCAN1 disease. Analyses of this fly SCAN1 model showed that expression of the human mutant protein in fly neurons causes alterations similar to those reported in cells from SCAN1 patients. Then, our deeper analyses of the fly SCAN1 model lead to the identification of altered cellular pathways that are relevant for many fundamental biological functions. This is a first relevant step toward the understanding of the pathogenic mechanisms of SCAN1 disease and the identification of candidate therapeutic targets for prevention and treatment of this disease.

2018 NAF Funded Research

YOUNG INVESTIGATOR AWARD

Claudio Melo de Gusmao, MD
Boston Children's Hopsital
Boston, MA

An edgotyping platform to stratify rare variants in ataxia

Since the release of the first reference sequences of the human genome, incredible advances have occurred in the identification of gene mutations that cause ataxia. Genes code for proteins, the building blocks of our cells. They are involved in chemical reactions, signaling, interactions with DNA and other proteins, as well as a host of other functions. When a genetic mutation occurs, it may impact any and/or all of these functions, causing cerebellar ataxia. Next-generation genetic sequencing is now inexpensive enough to bring this diagnostic capability to clinical practice. Achieving a precise genetic, or molecular diagnosis is the first step toward therapeutics because it allows patients to be stratified, counseled and for treatments to be matched to specific genetic lesions. Nevertheless, our diagnostic capacity has not improved at the same speed. Modern genetic diagnostic techniques are able to clinically detect relevant mutations in less than 50% of patients, with about ½ of patients whose genetic findings are uncertain (variants of unknown significance, or VUS). The ability to sequence genomes has outpaced the capacity to interpret the amount of data that is generated. Scientists have traditionally attempted to determine the impact of these VUS through studying the variant in a biological model (a process called functional validation), or using bioinformatic software prediction tools. The first approach is the most sensitive, but can be costly and time consuming. The second approach is commonly performed, but is prone to errors and inaccuracy. In this project, we chartered a new method developed to look at how a particular genetic mutation affects the mutated protein's interactions within a living cell. The premise of the project is the idea that no gene acts in isolation – rather, the gene product (protein) is often involved in several interactions in the cellular machinery. Symptoms of a genetic disease are therefore highly influenced by the degree and/or number of interactions that are affected by a particular mutation, a concept that has been widely accepted for benign and pathogenic mutations in the human genome.

We selected 115 variants in genes known to cause ataxia from a cohort of 85 patients from 2 ataxia centers; we excluded mutations with a biological impact that would not be replicated by this methodology such as repeat expansion alleles, synonymous mutations, indels, splice site mutations and mutations in mitochondrial genes. For each VUS, we also selected pathogenic and benign variants, from patient disease cohorts and populational databases. In the process of mapping these variants to the exisiting library of open reading frames (ORFeome) and establishing the protein interactors through the human interactome database, we began our experiment with a list of 245 variants in 11 ataxia genes, predicted to interact with 102 different proteins. The first step was to clone these variants (benign, pathogenic and VUS) into DNA from bacteria and then subclone the variants into round pieces of DNA called "expression plasmids". These code for the mutated protein of interest in combination with a fragment of another protein. This fragment is a part of a transcription factor, and it can be either the DNA binding ("bait") or the activating domain ("prey"). The plasmid is then inserted in a particular yeast strain. A similar process occurs for each of the variant's interactors. When both yeast strains are mated, co-expression of the variant of interest and the interactor allows for detection of an interaction. If the two proteins interact, it allows the formation of the full transcription factor ("bait+prey") through its hybrids with the variant of interest and the interacting protein. This transcription factor activates a reporter gene that allows the yeast to grow on restrictive media. We have so far subcloned all 245 variants into expression plasmids. We then performed pairwise testing on 11 "wild-type" gene products with their 102 interactors. We intend to finalize the experiments on all mutated alleles and select 1-2 variants that will be further subject to functional validation using a human-induced pluripotent stem cell model.

How to Qualify for Social Security Disability Benefits with Ataxia

Rachel Gaffney, Outreach Specialist at Disability Benefits Help

If you have Ataxia, you may experience a variety of challenges. Ataxia can be disabling, and if you are unable to work and earn a living because of the severity of the condition, you may qualify for disability benefits from the Social Security Administration (SSA).

Ataxia May Qualify Through Compassionate Allowances

The SSA introduced a program called the Compassionate Allowances Program (CAP) in 2008. This program has special guidelines which allows certain applicants for disability benefits to be approved for monthly disability benefits in less than a month. The CAP has 88 conditions that warrant faster claims processing, and Spinocerebellar Ataxia is on that list.

If you suffer from Spinocerebellar Ataxia, it is a genetic condition that causes a progressive degeneration of the cerebellum and spinal cord. There are many forms of the condition, which has been linked to more than 30 mutations of genes. The condition will cause progressive difficulty with their motor skills and coordination. The specific symptoms could vary significantly depending on the specific form of the disease and the condition's severity, but common symptoms include speech difficulties, swallowing problems, difficulty eating, and problems with controlling balance.

Ataxia Telangiectasia is also among those conditions that qualify for CAP. Ataxia Telangiectasia is sometimes called Louis-Bar Syndrome. The debilitating condition can affect multiple parts of the body, including a person's ability to fend off infections and the body's motor coordination control. If you have this condition, your chances of cancer or a respiratory disorder increases significantly.

Ataxia in the Blue Book

The SSA uses a medical guide, which is called the Blue Book, to determine if an individual qualifies for disability benefits. Section 11.00 of the Blue Book refers to neurological disorders and the criteria that an individual must meet to qualify for disability benefits. Listing 11.17 specifically covers neurodegenerative disorders of the central nervous system, which includes conditions including Friedreich's Ataxia and spinocerebellar degeneration.

To qualify according to the listing, you must have one of the following:
Disorganization of motor functioning in two extremities that causes extreme limitations in the ability to stand when getting up from a seated position, balance while walking or standing, or use the upper extremities OR have marked limitation in physical functioning as well as in one of the following:

- Adapting or managing oneself
- Understanding, remembering or applying information
- Interacting with others

It's best to review the Blue Book with your doctor or neurologist familiar with Ataxia to ensure you meet the Blue Book's requirement. Most claims are denied for lack of medical evidence, so working with your doctor to make sure you have enough medical support can help increase your chance of successful claim.

Filing Your Disability Claim

If you have Ataxia that has left you disabled, you should start the application process for Social Security Disability benefits. You can either go online to file your application or call 1-800-772-1213 to talk with a representative or to schedule an appointment at a field office. Medical evidence and supporting documentation are essential for a disability claim to be successful, so be sure to gather as much supporting evidence and documentation as possible, including all your medical records so they can be reviewed during the claims process.

For more information and helpful links visit: https://ataxia.org/how-to-qualify-for-social-security-disability-benefits-with-ataxia/

KNOW THE FACTS ABOUT SPINOCEREBELLAR ATAXIA AND A NEW CLINICAL STUDY

About Spinocerebellar Ataxia (SCA)

SCA is an inherited form of ataxia, a rare and progressive neurological disease that develops due to damage to the cerebellum, the part of the brain responsible for coordinating movement.

Ataxia affects nearly 150,000 people living in the U.S. of which an estimated 3,200–18,000 have SCA

Symptoms of SCA may include lack of coordination, trouble with balance, difficulty swallowing, slurred speech and/or deterioration of fine motor skills

The most common types of SCA are SCA1, SCA2, SCA3, SCA6 and SCA7 which are caused by specific genetic defects

People are typically diagnosed in their mid-30s but SCA can affect all ages, genders and race

There is no cure or FDA-approved treatment for SCA

Current treatment approaches focus on symptom management to improve quality of life

SCA Study Overview

The Phase 3 randomized, controlled study is designed to evaluate troriluzole, an investigational drug that modulates the brain chemical glutamate. Brain cells communicate with each another by using chemicals, such as glutamate.

Participants are enrolled in the study for 48 weeks*

** Participants who participate in the study will be eligible to continue for an additional 48 week phase where all participants receive troriluzole.*

Participants are randomized one-to-one on troriluzole or placebo and take two pills once daily

18+ More than 18 U.S. medical centers are participating in the study

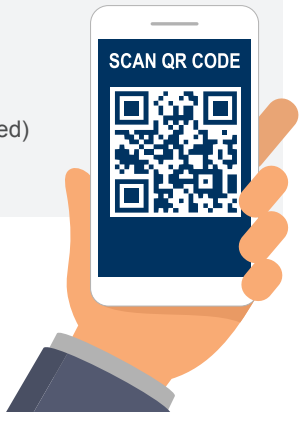
Mainly focus on disease-types SCA1 and SCA2

Study will measure if troriluzole can slow down and improve ataxia symptoms in people with SCA

Primary endpoint = measureable change in ataxia symptoms, including walking, standing, sitting and speech

Key Eligibility Criteria

- Known or suspected diagnosis of SCA1 or SCA2
- Confirmed clinical evidence of SCA diagnosis or willingness to have testing completed
- Ability to walk eight meters without human assistance (canes or other devices are allowed)
- Be physically able to complete the trial (adequate hearing, vision and language skills)



For more information about this study, visit
www.scatrial.org

The study is sponsored by Biohaven Pharmaceuticals.

MICHIGAN MEDICINE
UNIVERSITY OF MICHIGAN

SPINOCEREBELLAR ATAXIA TYPE 3 (SCA3)

UNIVERSITY OF MICHIGAN RESEARCH OPPORTUNITY

Do you or a family member suffer from SCA3?

The Neurology Department of the Medical School is currently conducting a research study for the purpose of identifying new biomarkers useful for SCA3, and your help is needed!

We are looking for:

- Healthy individuals and individuals with known SCA3 over 18 yrs. of age
- Approximately 1 hour of your time
- Involves a single lumbar puncture and blood draw
- Paid incentive for participation

Some exclusions apply - contact us at

(734) 232-6247

NAF Funded Research

The National Ataxia Foundation's Board of Directors is excited to announce that *$955,000* of funding was approved for the highest quality Ataxia research grant applications. A total of 26 researchers were awarded funding focusing on: SCA1, SCA2, SCA3, SCA7, SCA8, SCA13, SCA28, SCAN1, SCAR20, SPAX5, and Friedreich's Ataxia. Nearly 60 applications were critically reviewed by the top Ataxia researchers in the US. The selected applications spanned the US and the following countries: Portugal, Spain, Italy, Canada, Poland, and Germany. Thank you to all the donors who participated in the NAF Annual Research Drive. Without your support, these studies could not have been funded. We wish all these researchers success as they continue to seek answers that will bring us closer to developing treatments for Ataxia. Listed below are the names, institutions and titles of the researches whom were funded. Full lay summaries of these studies are available at **https://ataxia.org/2020-naf-funded-research/**

Research Project Term – March 1, 2020 – July 1, 2021

Research Seed Money Grants

Margit Burmeister, PhD | University of Michigan | Ann Arbor, MI
Identification of a Novel Dominant Pure Ataxia Gene on Chromosome 13

Sara Duarte-Silva, PhD | University of Minho | Braga, Portugal
Studying the Effect of the Molecular Tweezer CLR01 in a Mouse Model of SCA3

Taner Akkin, PhD | University of Minnesota | Minneapolis, MN
Label-free Optical Imaging of Atrophy in SCA1 Mouse Models
- Funded in partnership with the Bob Allison Ataxia Research Center -

Roger Bannister, PhD | University of Maryland | Baltimore, MD
Using Zebrafish to Model Ataxic CaV2.1 Channelopathies

Francesca Maltecca, PhD | Ospedale San Raffaele | Milan, Italy
Targeting Altered Proteostasis in Cellular and Mouse Models of AFG3L2-related Cerebellar Ataxias (SCA28 and SPAX5).

Jacques Tremblay, PhD | Université Laval | Quebec, Canada
Using Extracellular Vesicles to Deliver Therapeutic Proteins for Various Ataxia

Gal Bitan, PhD | The Regents of the University of California | Los Angeles, CA
Developing Novel Biomarkers for Spinocerebellar Ataxia

Pedro Fernandez-Funez, PhD | University of Minnesota | Duluth, MN
Genetic and Molecular Mechanisms Mediating Congenital Deficits in SCA13

Dr. Sofia Araújo, PhD | Barcelona University | Barcelona, Spain
DNA Repair Failure and the Incidence of Ataxia in SCAN1 Patients

Pioneer SCA Translational Award

Maciej Figiel, PhD | Institute of Bioorganic Chemistry, Polish Academy of Sciences | Poznan, Poland
Allele Selective, CAG-targeted RNAi-based Strategy to Lower Mutant PolyQ Proteins in Polyglutamine Ataxias

Young Investigator – SCA Award

Alexandra Silva, PhD | Instituto de Biologia Molecular e Celular – IBMC | Porto, Portugal
Fighting Spinocerebellar Ataxia Type 3 at NanoScale

Jeannette Hübener-Schmid, PhD | University of Tuebingen | Tubingen, Germany
Development and Validation of a SIMOA-based Mutant Ataxin-3 Immunoassay for Biomarker Studies in SCA3

Dr. Jennifer Faber, MD | German Center for Neurodegenerative Diseases | Bonn, Germany
Implementation of a deep learning based neuroimaging pipeline for a fast and accurate automated parcellation of cerebellar lobuli and longitudinal volumetry in spinocerebellar ataxias (SCAs)

Chandrakanth Reddy Edamakanti, PhD | Northwestern University | Chicago, IL
GABAergic Inhibitory Interneurons as a Therapeutic Target for SCA1

Rita Perfeito, PhD | Center for Neuroscience and Cell Biology (CNCB) | Coimbra, Portugal
Intravenous Delivery of the Brain-Targeting AAV-PHPeB Encoding the Cholesterol Hydroxylase CYP46A1 into a Mouse Model of Spinocerebellar Ataxia Type 3: A Promising Non-Invasive Therapeutic Strategy

Nan Zhang, PhD | Houston Methodist Research Institute | Houston, TX
A DNAzyme that Targets the CAG Repeat RNA in Polyglutamine Diseases

Dr. Sharan Srinivasan, MD, PhD | Brigham and Women's Hospital, Inc. | Boston, MA
An Isogenic iPSC Model of SCA3 Examining Relative Loss and Gain of Ataxin-3 Function.

Post Doc Fellowship Awards

Dr. Raphael Benhamou, PhD | The Scripps Research Institute - Florida
Small Molecule Targeting of CAG repeats in Ataxias

Dr. Hannah Shorrock, PhD | Research Foundation of SUNY - University at Albany | Albany, NY
A CAG Expansion-Selective Small Molecule Screen for Multiple Spinocerebellar Ataxias

Yijing Zhou, PhD | The Children's Hospital of Philadelphia | Philadelphia, PA
Uncovering the Pathogenic Mechanisms of Cerebellar Atrophy with SNX14 Deficiency

Tiffany Thibaudeau, PhD | Northwestern University | Evanston, IL
Unraveling the Mechanisms of Impaired Protein Degradation Systems in Spinocerebellar Ataxia Type 3

Oleg Chertkov, PhD | Instituto de Biologia Molecular e Celular – IBMC | Porto, Portugal
Protein-Protein Interaction of Ataxin3

Young Investigator Awards

Collin Anderson, PhD | University of Utah | Salt Lake City, UT
Gene Therapy in the Shaker Rat Model of Cerebellar Degeneration and Ataxia

Angela Mabb, PhD | Georgia State University | Atlanta, GA
Resolving Sex Differences in the Onset of Motor Dysfunction in Gordon Holmes Syndrome

Elena Restelli, PhD | Pharmacological Research Institute Mario Negri | Milan, Italy
A Gene Therapy Approach for Marinesco-Sjögren Syndrome

Have you joined the Ataxia Patient Registry yet?

CoRDS is a centralized international patient registry for all rare diseases; it is based at Sanford Research. The goal of the CoRDS registry is to connect as many patients and researchers as possible to help advance treatments and cures for rare diseases. The CoRDS registry is free for patients to enroll and is available for researchers to access to recruit research participants.

Since 2013, NAF has partnered with CoRDS to enroll participants who have a diagnosis of Ataxia or are at-risk for Ataxia. Since that time, several researchers have accessed the Ataxia registry to help recruit research participants for their important studies.

If you have not enrolled yet, you can register today to help researchers find more answers to Ataxia and to participate in research studies and clinical trials.

CoRDS
SANFORD RESEARCH

Enroll at www.sanfordresearch.org/SpecialPrograms/cords

Questions? Contact CoRDS at cords@sanfordhealth.org or (877)658-9192

BRAIN TISSUE DONATION PROGRAM

Ataxia researchers have made many discoveries because of donations of brain tissue from those affected with Ataxia. NAF's Brain Donation Program was established to allow those who desire to donate their brain upon death so that researchers can find more answers.

If you are interested in learning more about brain donation, you may contact Mary Ann Peterson, NAF Research Assistant, at ***mary@ataxia.org*** or **763-231-2750**.

A Letter on Social Distancing and Ataxia

Dr. Pravin Khemani - Swedish Neuroscience Institute & NAF Medical and Research Advisory Board Member

Hi folks! Social distancing is not social disengagement, so please stay as connected with your near and dear ones as possible...safely of course. Recruit your children or your tech-savvy friends and family to show you how to use technology to stay connected. Or if you are a tech-whiz share your knowledge with others.

Please visit Coronavirus Precautions for Ataxia Patients to get information on how to stay healthy and keep others healthy. Follow CDC guidelines and stay in tune with what's happening in your community through the Department of Health.

People who have chronic neurological disorders, including the Ataxias, are assumed to be at a higher risk of COVID-19, but the absolute risk is not known, therefore there is no reason for alarm and panic as long as you are following the health guidelines outlined by the CDC. People with respiratory compromise, high blood-pressure, diabetes, cardiovascular diseases, and other medical conditions that reduce immunity are the most commonly affected based on the scientific data available for review.

Use your time well while staying safe and healthy as we move closer to a cure for the Ataxias.

-Dr. Pravin Khemani

8 Things to Do While You Are Social Distancing

1. Enroll in CoRDS or if you have already enrolled, return to the registry and update your information. CoRDS hosts the Ataxia patient registry that is vital for Ataxia researchers.
2. Review General Session presentations from previous Annual Ataxia Conferences.
3. If you have a specific type of SCA, educate yourself more about it at Gene Reviews.
4. If you have Hereditary Ataxia, create a family tree indicating those who were or are affected.
5. Become educated on the clinical trial process. As we move into more pharma therapy development we will need to recruit participants into trials. Check out NAF's webinars on these topics.
6. Join the NAF Facebook page if you are not already a member.
7. Attend a virtual support group meeting. Check the NAF events calendar for the most up-to-date listing.
8. Join the National Ataxia Foundation, if you are not already a member. Membership is free!

Joint Mission Bataan to Cure Ataxia

Going the Extra Mile for Ataxia

Our Joint Mission Bataan to Cure Ataxia campaign and event had lots of participants this year. The Class of 2020 are living with Ataxia or family and friends of those living with Ataxia. We set goals. We created meaningful incentives. We delivered cool event specific items for participants use. They included backpacks, waterbottles, sunglasses and wide floppy hats to conquer the hot sun of the march. in the New Mexico Desert.

Unfortunately, the Joint Mission Bataan to Cure Ataxia had to be cancelled due to the coronavirus that is making its way across the country. The chance of meeting everyone face-to-face didn't happen. Their participation in something they had been training for was cancelled. The feeling of accomplishment by crossing the finish line was taken away. For some, not doing the 26-mile march wasn't an option and made the trek in their hometowns. Cathy Bethay, Georgia; Mark Alessi, New York; Mark Minkin, Wisconsin; Michael Cammer, Pennsylvania; Janel Doloiras, Massachusetts; Dana Mauro, Rhode Island; and Mike DeRosa, North Carolina. Congrats to you all!

Our Class of 2020 did some remarkable things. We had a "Best Burger" competition, another put on their own Super Bowl Tailgate Party to raise funds, and others had tremendous stories told of their efforts in their local media. All conducted meaningful online letter-writing campaigns to raise funds and educate more people about the ills of Ataxia. **To date, they have raised just under $221,000.**

Are you ready to join the class of 2021?

1. Cathy Bethay's JMB March
2. Cathy Bethay & supporter
3. Mark Minkin's JMB March

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biohaven pharmaceuticals

Biohaven is a proud sponsor of the AAC. Biohaven would like to express our gratitude to all clinical trial volunteers.Advances in the ataxia field would not be possible without your dedication.Our ataxia team continues to be inspired by the compassion and commitment of the entire ataxia community.

For more information on clinical trials visit: https://www.biohavenpharma.com/science-pipeline/resources/clinical-trials

CURE DRPLA

Connecting families, clinicians and researchers to further DRPLA research and work towards a treatment for DRPLA.

Website: www.cureDRPLA.org

Email: info@cureDRPLA.org

Twitter: #cureDRPLA

For DRPLA patients and caregivers: https://www.rareconnect.org/en/community/dentatorubral-pallidoluysian-atro

AAC 2020 Webinars Are Here!

The Annual Ataxia Conference in the Comfort of Your Home!

We are hard at work making sure you don't miss any of the great presentations we had planned for this year's conference. Stay tuned for future webinars. Below are the webinars we have already presented. You can find recordings of each one on our website.

Your Voice in Drug and Therapy Development
Dr. Jeremy Schmahmann

Ataxia Research Comes Full Circle
Harry Orr, PhD; NAF MRAB Research Director

Drug Development: Ataxia Drug Discovery Pipeline
Susan Perlman, MD and Vikram Shakkottai, MD, PhD

Patients as Research Collaborators
Panel Moderator: Pravin Khemani, MD
Panelists: David Brunnert, Sandy Read & Julie Geye

A Wholehearted Life: One Step at a Time
Theresa Chase, ND, MA, RN

Watch webinars here: https://ataxia.org/webinars/

Thank you to our generous sponsors

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Coronavirus Precautions for Ataxia Patients

The coronavirus (COVID-19) pandemic is affecting communities worldwide. The health and safety of the Ataxia community is a priority at NAF. We have consulted with our Medical Research Advisory Board, infectious disease specialists, the World Health Organization, and the Centers for Disease Control and Prevention to learn about the best ways that a person with Ataxia can protect themselves during this public health event. We'd like to help you understand what you can do to decrease your risk of contracting COVID-19.

Protect Yourself from Coronavirus

COVID-19 is thought to spread mainly from person-to-person. The best way to prevent illness is to avoid being exposed to the virus. Steps that you can take to limit your risk of exposure are outlined here.

Wash your hands often.

The Centers for Disease Control (CDC) recommends washing your hands with soap and water for at least 20 seconds, especially after visiting a public place, coughing, sneezing, or blowing your nose.

Avoid touching your eyes, nose, and mouth.

The World Health Organization (WHO) warns that your hands can pick up viruses when they touch surfaces. Once your hands are contaminated, touching your eyes, nose, or mouth can transfer the virus into your body. Wearing protective gloves does not protect you from COVID-19. You can still pick up the virus on rubber gloves. Wash your hands well before touching your face.

Maintain distance from others.

The WHO says that you should stay at least 3 feet away from anyone who is coughing or sneezing. It is also recommended to avoid shaking hands to limit your risk of exposure. Greet people with a wave or nod instead.

In addition, the CDC recommends that people at higher risk for complications, such as someone with Ataxia, should take additional preventative actions. These precautions include avoiding crowds and non-essential travel.

If you are at higher risk for complications and COVID-19 is spreading in your community, the CDC recommends that you stay home as much as possible.

Seek medical care early if you develop symptoms.

If you experience fever, cough, or difficulty breathing, call your health care provider immediately. They can tell you the next-steps you should take in your area. According to the CDC, emergency warning signs for adults are:

- Difficulty breathing or shortness of breath
- Persistent pain or pressure in the chest
- New confusion or inability to arouse
- Bluish lips or face

For Additional Coronavirus Resources Visit:
ataxia.org/coronavirus-precautions-for-ataxia-patients/

My Life with Ataxia

By Marina Lewycka

I'm better known for my first novel, called *A Short History of Tractors in Ukrainian*, which came out in 2005. My new book, my sixth, which came out on March is called *The Good, The Bad and the Little Bit Stupid*, and I can see from the patiently sympathetic look on people's face when I start to talk that they think the last bit applies to me - little bit stupid. You see it takes me a long time to get the words out, and by the time they're out they've been thoroughly mangled by my un-coordinated lips and tongue, so I sound as though I'm a little bit drunk – or a little bit stupid.

It's called dysarthria, and it's one of the effects of my condition, along with loss of balance so extreme that I stagger about like a drunk, and sometimes I fall down with a crash. If only I could be really drunk that would be some consolation, and it would wear off. There's probably a funny side to this, but if so I can't see it – I'm concentrating too hard on staying upright. The novel is not about Ataxia, it's about Brexit and Financial Fraud. In fact most of it was written before I became aware that something was wrong with me.

The doctor's description of this condition is Cerebellar Ataxia', which means brain-caused wobbliness. But despite numerous blood tests and brain scans she's still no nearer to working out what's gone wrong. Sometimes it's called 'idiopathic', which is a medical way of saying they don't really know. 'Never heard of it,' people say, 'What causes it?'

I wonder. Was it the zyklon-B gas which was sprayed so feely on my mother while she was pregnant with me, not enough to kill her but to kill the lice which inhabited everyone at the Displaced Persons Camp in Germany where I was born after the war? Or all those dental x-rays, or the mercury in the amalgam, or the downpour that drenched me on the 26 April 1986 laced with radiation from Chernobyl? Or whatever they sprayed on the crops in rural Lincolnshire? Or the stuff I spray to keep the moths down? Or the toxic spider-bite I had in my shoulder and the masses off antibiotics and painkillers I took to fight the painful infection? Or a fish-tapeworm picked up in Singapore, or Vietnam or Malawi? Or the sedentary lifestyle of the writer? Or the shingles jab I had when I turned 70? But all these hazards must have affected thousands of people. One doesn't get to 73 without having taken in some pretty dodgy things along the way.

Or perhaps it was none of these – perhaps it was a genetic fault - a build-up of rogue proteins like Parkinson's, Huntington's and Alzheimer's which all affect different parts of the brain. A chance mutation that happened in the DNA of an ancestor generations ago, among the vast forests of silver birch that covered much of what is now Ukraine, or hidden in the murky past of the Tsarist Empire - an ancestor who did not live long enough for the genetic fault to find expression: The Curse of the Tractor. After all, my father was pretty peculiar, and he had trouble swallowing. The Toshiba Apples were well peeled and the cores had to be removed.

"One of the very few advantages of this condition is that I get to see human beings at their best."

These thoughts keep me awake at night, and occupy hours of internet time. I have been tested for several types of Spinocerebellar Ataxia (SCA), vitamin and mineral deficiencies and gluten intolerance. I have tried Vitamins D, B, E, CoQ 10, trehalose sugar, zinc, and Red Bull (it contains Taurine), I go to the gym, but none seems to make any difference. Pilates helps balance but does not delay the relentless progression. I have had MRI brain scans and I've seen the black shadows galloping in on jagged waves of darkness from the sides where my cerebellum has atrophied, like the four horsemen of the apocalypse.

Somewhere in a faraway lab, some brainy person is even now working out ways to tweak or silence the rogue genes or to grow new ones. But my condition is too rare to attract the interest of major drug companies.

I have come to depend on friends and the kindness of strangers – the people who help me onto and off the bus or train, who give me a helping hand walking downstairs. One of the very few advantages of this condition is that I get to see human beings at their best. So many people are so very kind it seems to cut across all ages, genders, races and classes. I am no longer afraid to say 'Can you help me please?' when I have to cross a busy road. People's spontaneous kindness often brings tears to my eyes. Where did they learn it? Where

does it vanish to, in the knock-about of everyday life and politics? How can we bring it back un-monetised?

'But you can still write?' ask kind friends. Well yes I can, but more slowly. I often hit wrong keys, or the right keys, but not hard enough to register. Sometimes the mistakes can unleash new avenues of creative thought – for instance I might have a character who wears a red beet on her head instead of a red beret, or someone who perches on a hair. It keeps me smiling when there's not much else to smile about.

Marina Lewycka was born of Ukrainian parents in a German refugee camp after World War II and now lives in Sheffield, Yorkshire. T*he Good the Bad and the Little But Stupid* is her most recent novel. Marina's website is www.marinalewycka.com

Cobra with a Cane

By Mary Bird

A few years ago, based on a family history of SCA 6 and observation of symptoms in myself, I had my self-diagnosis confirmed by a DNA test. Fortunately, the downhill trend of my condition has been slow, so I figure, if I'm thinking of doing something, I had better do it now.

I had heard about Cordoba, Spain, its history, climate, architecture, food, pizzazz. So, I found a tourist apartment near Cordoba's main tourist sites, booked a plane, enticed a friend to join me for the second week of my trip, and went this October, 2019.

No longer do I seek a budget trip to the airport by a combination of buses, and trains. I arranged a taxi to pick me up at home and drop me by curbside check-in. Peter, the driver helped with my bags. I had a pocket full of small bills to tip wheelchair pushers.

Knowing I would have to drag my luggage at least short distances with one hand, while balancing with my cane in the other, I limited myself to one small suitcase and a tote bag. Even then, once I had been in Cordoba a week, I realized I could have gotten by with fewer things. Afterall, there was a clothes washer in my tourist apartment, and plenty of stores in Cordoba if I needed to buy something.

Another mistake I made was taking several library books. They were heavy and had to be returned. It would have been better to take used paperbacks I could leave behind, or take an electronic reader.

On the train from Madrid to Cordoba, my seat mate stored my suitcase in the overhead rack. When we arrived in Cordoba, he took it down, dragged it through the car, and out onto the platform. All with a smile. His kindness, and the kindness of other strangers made many aspects of travel alone, with a cane, possible.

I am slow. Most of my fellow passengers had disappeared into the terminal by the time I traversed the length of the platform from my train car to the moving ramp that would take me to street level. The slope was step enough that I had to hold tightly the banister with one hand, and my suitcase pull handle with the other. Would it be better to have the suitcase on the upslope in front of me where it might roll back and push me down, or have it on the downslope behind me where its weight could drag me backwards? A toss-up. After having worried through the "ramp experience" once, I sought out elevators to move between floors. On the return trip, my friend helped with my bags.

My tourist apartment was in a lovely old building with an interior patio: marble mosaic floors, marble columns, decorative tiles on the walls, and a small fountain. Charming but challenging. There was a deep step over the door sill from the street into the building's foyer, seven steps down to the patio level, then a small step up, a bigger step down, a marble patio to cross, and another step up to the apartment's foyer. With the combined use of a banister on the seven steps, holding marble columns for the steps to the patio, and grasping a pull handle on the door to the apartment, while switching my cane from one hand to the other or holding it under my armpit when I needed both hands free, I managed. Still, I expended a lot of mental and physical energy staying upright and being careful.

When I went out to explore the neighborhood, I encountered several more challenges: Cordoba is a hilly city. Many of the streets are paved with cobblestones. Some streets are so narrow, sidewalks and pavement are merely indicated by different types of stone, without curbs. But, to help with the challenges: many doors and windows had decorative security bars I could hold onto as a brake on steep hills. When sidewalks were crowded with diners, there were chairbacks to touch for balance. Pedestrians customarily took over the narrow streets, so cars and motorcycles moved slowly. At many corners, sidewalk and pavement

were level. Others had handicapped ramps. Every few blocks the path broadened into a church entry, small park or plaza with benches: good places to sit, rebalance, calm nerves, and enjoy the surroundings.

While still on my own, I bought a ticket for a hop on-hop off City Sightseeing bus with routes past key tourist sites. Other passengers helped me cross the gaps between the bus and the curb. Drivers waited until I was seated, helped set the audio to English, and pointed out spots of interest.

I also bought a pass for the public buses, so I could see some of the areas of Cordoba outside the tourist centers. Again, drivers and passengers made sure I got off near my destination, and helped me step down from the buses.

Cordoba is a walking city. On one pedestrian mall near Plaza de las Tendillas there was even a large sign showing the walking distances to various points. Walking with my cane, I looked at the ground a lot, so many of the snapshots from my trip show patterns of stone mosaic pavements. I leaned against buildings in order to look around at the people, architecture, fountains, steeples, clock towers, palm trees, school children in uniforms, and motorcycles. Only once in two weeks did someone jostle me.

The taxis in Cordoba were inexpensive, so if I wearied from walking too far afield, I asked for the nearest taxi stand and was soon home.

The Mezquita, a main Cordoba attraction, has ramps for entry and exit, with handrails. There was a small step, however, up to the ticket window. This 8th century mosque is vast, with few benches for resting around the outer edges. However, a cathedral was built in its center, with pews where tourists rest.

Another major tourist site, the 14th century Alcazar, was not handicapped accessible. I noticed a girl with crutches seated outside so asked the ticket salesperson if there were steps. "Some", she said. I managed the nine steps up to the first room on the tour, but refused to try the 15 steps without a hand rail down to the first garden. While my friend visited the gardens, I contemplated the Roman mosaics in the first room. My friend and a kind stranger helped me down the nine steps back to the entrance.

Another site with renowned gardens, Viana Palace, was more accessible with ramps and banisters between many of its patios and interior spaces. My friend, who had appointed herself my "sherpa", scouted out the most accessible routes for moving between them. Once I accessed some places, though, I had to be careful walking on gravel, skirting puddles, or avoiding the limbs of hedges bordering the narrow paths.

I'm glad I stayed in an apartment where I could rest between forays to tourist sites and the every-day city. I'm glad I was able to overcome my self-consciousness to adapt to the limitations of travel with SCA 6 and a cane. I'm glad I allowed my friend to help me, and accepted the kindness of strangers. I'm glad I didn't wait and visited Cordoba now.

Mary Bird has SCA6. Retired after 35 years working as a proposal writer and lawyer in Puerto Rico and Washington, DC, she lives with two cats in a CCRC in Bowie, Maryland. She has a special group of friends met through the ataxia support group sponsored by Johns Hopkins University. In 1969-70 she worked as a translator in Spain, and enjoyed visiting Cordoba for the first time last year.

For many with Ataxia, everyday tasks can become increasingly difficult. One person's shared tip might just be the help someone else needs. See what advice Ataxians are giving to make everyday tasks easier...

Ataxia Tips must be submitted by 6/01/20 to be eligible for inclusion in the next issue of *Generations*. Submit them via email to naf@ataxia.org.

1. I used to have what felt like shocks to my feet at night, causing me to lose sleep. I started doing leg lifts on my side on the floor and found that curling my toes upward while doing leg lifts both right and left , the shocks quit after a week. Apparently stretching the tendons in my feet was the answer for me. (Submitted by Ron Lucken)

Become an Ataxia Advocate

Visit our Advocacy webpage www.ataxia.org/advocacy for advocacy tools, events, and resources.

On the advocacy webpage you can:

- Download the Advocacy Toolkit
- Learn how to contact your local representatives to request a Proclamation for International Ataxia Awareness Day (IAAD).
- Check out advocacy events happening around the country.
- Get the latest news on legislative issues impacting the Ataxia community.

We want to hear from you if you have a relationship with a US Congressman or Senator to further support the legislative issues impacting the Ataxia community.

Contact Lori Shogren, Community Program and Services Director at **lori@ataxia.org.**

TO SEE THE LATEST ATAXIA NEWS:

-Research

-Support Groups

- Community Events

-Fundraising

-Membership

-NAF Updates

Visit:
ataxia.org/blog

REMEMBERING NAF IN YOUR WILL

Throughout the years, individuals have named the National Ataxia Foundation as a beneficiary in their wills. Their thoughtfulness and foresight has enabled NAF to provide more research studies, more services to patients and families and more education and Ataxia awareness to the public. We are grateful for the impact that has been made by these compassionate acts. If this is something you would like to consider, please contact Joel Sutherland at ***joel@ataxia.org*** or call (763) 231-2748.

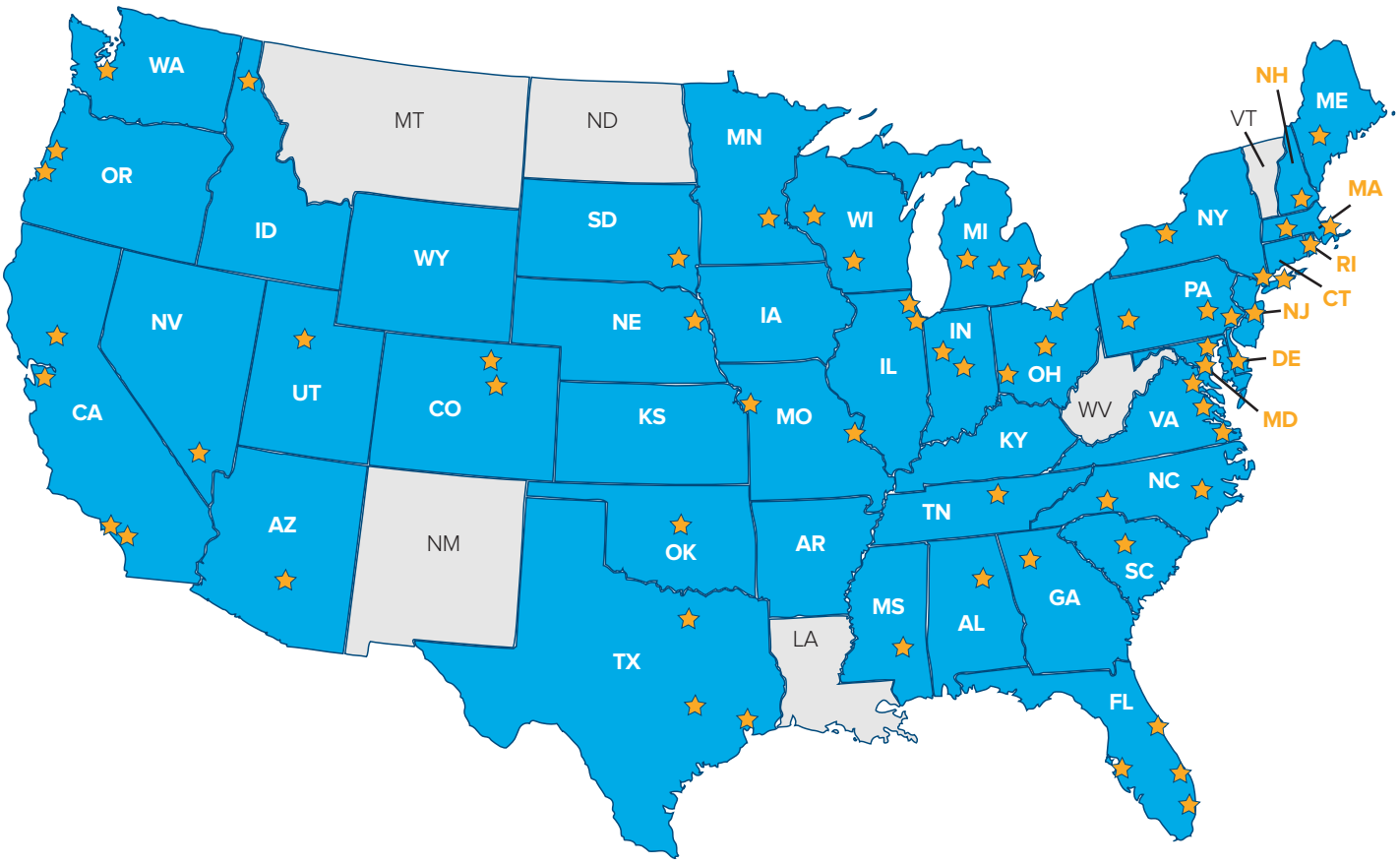
Support Groups

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

Support groups can remind us that we are not alone. Each person experiences Ataxia in a different way, but we still have many things in common. A benefit of attending a support group is having the chance to talk with others and learn how different people deal with the same disease.

If you or a loved one has been newly diagnosed with Ataxia, please contact the support group leader nearest you. If there is not a group in your area, we encourage you to visit our online social networks. You may also consider starting a support group in your area or becoming an NAF ambassador. If you are interested in these volunteer positions please contact Lori Shogren of the NAF staff at lori@ataxia.org or (763) 231-2743.

Come. Learn. Share. But most of all, know that you are NOT alone.



Join one of our Facebook Support Groups!

NAF Support Group	*www.facebook.com/groups/NAFmail*
Under 30 with Ataxia	*www.facebook.com/groups/under30withataxia*
Parents of Ataxia	*www.facebook.com/groups/ParentsOfKidsWithAtaxia*

Support Group News and Community Events

Welcome to our new support group leaders and ambassadors

Please join us in welcoming our new support group leaders. We have 5 new leaders who are volunteering their time to plan meetings and be there for you when you need to talk to others dealing with Ataxia.

Massachusetts : Donna Gorzela, 978-490-9552, Donna.gorzela@gmail.com

Doug Place, 781-307-0800, Douglas.place@comcast.net – Boston

New Hamphire: James Costa, 603-714-2550, costajames9@gmail.com

Ohio: Sue Moore, 614-395-9933, susanlmoore1@gmail.com – Central Ohio

Pennsylvania: Jason Armstrong, 215-378-3496, writeonfighton@gmail.com – Philadelphia

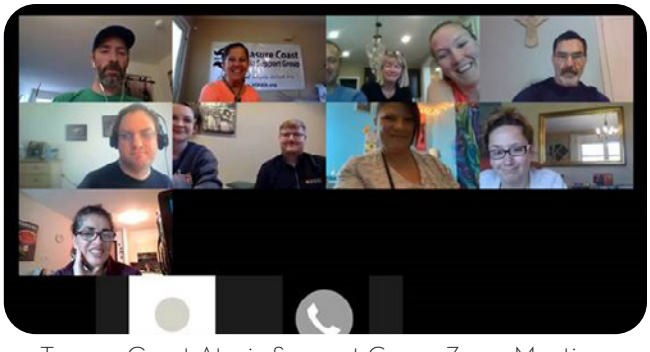
South Carolina: Simone Jasch, 803-704-0134, schild100@yahoo.com - Ambassador

Featured Support Group Update

Tresure Coast Ataxia Support Group

Submitted by: Kathi Yule

The weekly Zoom meeting of our Treasure Coast Ataxia Group opened on Saturday, April 25 at 11am. Lisa made introductions and announcements as well as showing terrific web sites, which are informative, helpful and available to us.



Tresure Coast Ataxia Support Group Zoom Meeting

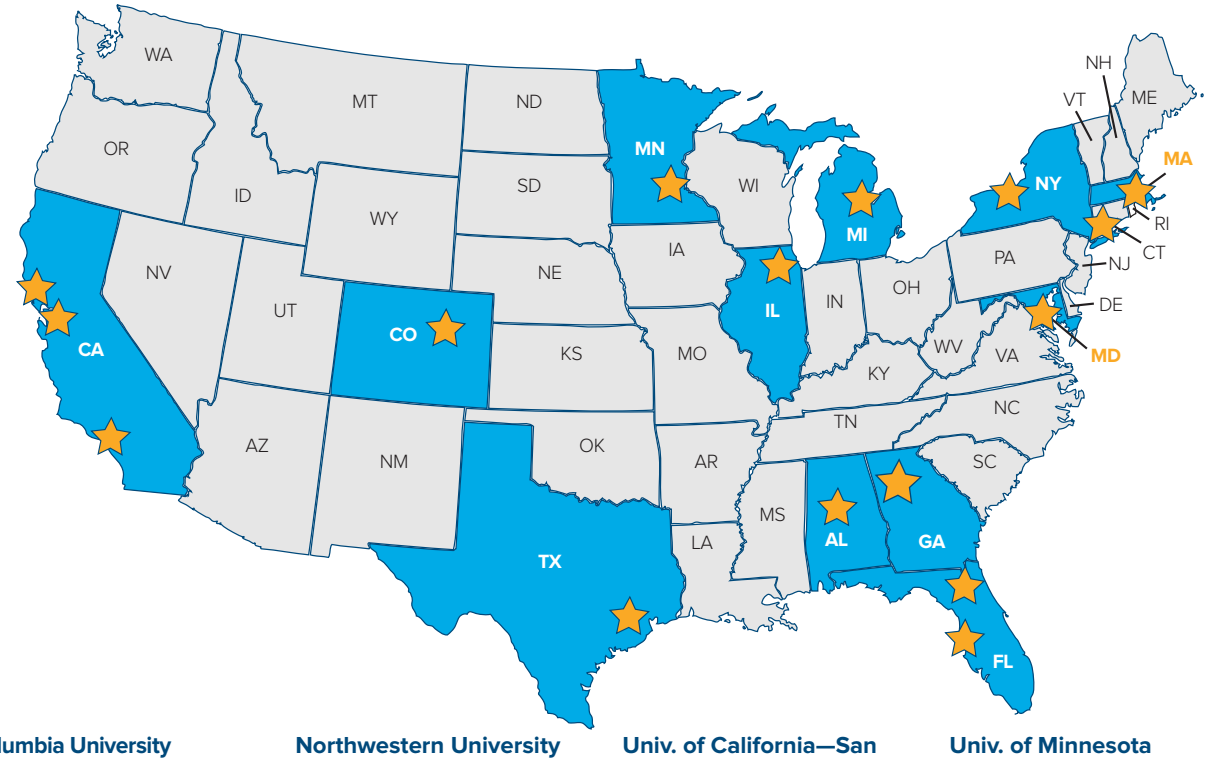
Lisa introduced our feature presenter, Kyle Bryant, author of Shifting Into High Gear. Kyle shared his understanding and eloquently discussed our understanding and expressions of our main thread of Ataxia, as our personal situations vary. He suggested we look at Ataxia as an opportunity to make a difference. His story is one of "pursuing adventure in the face of adversity" Kyle showed his home and how he has made accommodations for himself. Certainly Kyle is an enlightening hero who inspires so many. Questions were asked and answered. Interactions from many areas were great.

All of the latest support group news and events are posted at:

https://ataxia.org/category/support-groups/support-group-news/

READISCA Observational Study for SCA 1 & 3

Looking for participants with SCA1 and SCA3 to help with the READISCA study at any of the sites across the US. One of the main goals of this study is to get ready for treatment trials. READISCA does not involve medication or treatment therapy, but it will collect crucial data that will help future clinical trials. The main goals of this study are to establish the world's largest group of early stage and symptomless SCA1 and SCA3 individuals.



Columbia University
New York, NY

Emory University
Atlanta, GA

Houston Methodist Hospital
Houston, TX

Johns Hopkins University
Baltimore, MD

Mass General Hospital (Harvard)
Boston, MA

Northwestern University
Chicago, IL

Stanford University
Palo Alto, CA

Univ. of Alabama—Birmingham
Birmingham, AL

Univ. of California—Los Angeles
Los Angeles, CA

Univ. of California—San Francisco
San Francisco, CA

Univ. of Chicago
Chicago, IL

Univ. of Colorado—Denver
Denver, CO

Univ. of Florida
Gainesville, FL

Univ. of Michigan
Ann Arbor, MI

Univ. of Minnesota
Minneapolis, MN

Univ. of Rochester
Rochester, NY

Univ. of South Florida
Tampa, FL

★ Indicates location of Clinical Trial Site

For more information on READISCA contact:

Houston Methodist Research Institute

Tetsuo Ashizawa, MD—Contact PI/PD

Phone: 346-238-5021 • Email:U01SCA1&3@houstonmethodist.org

Memorials and In Your Honor

NAF is grateful to those who have made contributions in memory of or in honor of their friends and families whose names are listed below. This list reflects contributions made in December 2019 - March 2020.

Adam Main
Albert Frei
Alex Alessi
Alexandra DeSantis
Aly Bourbeau
Amy Cantrell
Amy Lynn Bac
Amy Messigian-Legault
Andrea Kiess
Andy Moss
Arlo Drury
Art Walsh
Barbara Schneidmiller
Bart Beck
Bert Lahr
Betty Brophy
Bettylou McIntosh
Beverly Henry-Terry
Beverly Niedzialkowski
Bill Moore
Bonnie Dunkelberg
Brett Masserant
Brian 'Turk' McCall
Carol Haukos
Carol Larson
Carol Stabenow
Carole Brown
Carole Keniley
Catherine O'Brien
Edge
Cathy Bethay
Charlie and Mary Ruehl
Charlotte Depew
Cheri Bearman
Cheri Morse
Chris Richardson
Chuck Norman
Cindy & Jim Bean
Cindy Brown-Moss
Cindy Pridy
Cindy Smith Grady
Claire Cooper
Cletus Brunnert
Clyde and Denise Jackson
Courtney Hicks
Craig Lisack
Dan Macken
Daniel Eustache
Darlene Harris
David Alessi
David Hunt
David J. Kalamas
David Wiedeman
Debi Adair
Deborah Taylor-Omictin
Debra Charlesworth
Debra Covington
Denise Claire Drake
Denver Ataxia Support Group
Derek Semler
Diane Ballard
Dick Brown
Dirk Desserault
Don Anderson
Donna Brown
Dorothy Drelick
Doug Brunnert
Dr. Debbie Hildreth
Dr. James E. Skok
Dr. John Schut
Dr. Kenneth Canter
Dr. Rudolph Schweizer
Dr. Willis Brown
Dustin Breeden
Ed Brand
Ed Schwartz
Edith Chille
EF Rezendes
Elizabeth Lawton
Ella Edwards
Erin Peterson
Ernest and Margaret
Evan Serrano
Evan Sharpe
Fola Odegbami
Frank Coffey, Joe Coffey, Colleen Coffey Yosick
Frank O'Connor
Franklin Delano Patton
Frei Family
Frugal Fannie's Family
Gail Rose
Gary Duff
Gary Peterson
Gertrude Macintyre
Giecel Gruezo
Glen Shooks
Gordon Hoffmann
Hannah Xu
Harold Smith
Heather Nicole Dulany
Henry Schut
Hinman Family
Hortense Oberndorf
Hugh Hohe
Ikue Pollak
Jacqueline DeVito
Jacqueline Gray
Jacqueline Williams
Jalean Retzlaff
James Carr
James Richards
Jan Dohn Clay
Jan Primeaux
Jane G. Shaw
Janel Doloiras
Janet Coyne and Stacy Coyne Leger
Janice Haworth
Jason Hinkle
Jason Michael Aiello
Jean Hardy
Jeanne Lee Hernandez
Jeannette Martinho Viveiros
Jeff Kahn
Jeff Suhr
Jennifer Leader
Jens Farley
Jessica Moore
Jhoanne Mecija
Jim Horne Hankins, Evelyn S. Hankins, Jimmy Hankins
Jim Richards
Jimmy Campbell
Jimmy Cecchini
Jo A. Robinson
Jodie Kawa
Joe Decrescenzo
Joe Ortiz
Joe Sweeney
Joe Thell
John and Dana Mauro
John Brennan, Jr.
John Dretto
John Dwyer
John E. "Buck" Turnbull
John Graham
John H. Surabian

John Lehto
John Marten
John Murphy
John Paul Pellegrino
John Sweeney
Jonathan Zilles
Joshua Kirschbaum
joyce kennedy
Juanita Way
Judy Lund
Julianna Hanner
Justin Garcia
Kai M. Chau
Karen Ann Young-Simmons
Karen Suchomel
Karen Young Simmons
Katherine Gorman
Kathryn D Smithers
Kathryn Mecija
Kathy Gardner
Kelly Rutledge
Kelsey Poor
Ken Porter
Kenneth Clark
Kennon & Page Davis
Kevin Adkins
Kevin Michael Fleming
Krista Humes
Kyle Simone
Lauren Moore
Leah Minkin
Leonard Schloff
Leonella Lake
Leslie Anderson
Linda Jensen
Linda Mae Skarica
Linda Swinkola
Lindsey Graham Guinn
Lisa Dix
Lisa Kornberg
Liz Booth
Lori Albright
Lorraine Delli Muti
Lorraine Kasprzak
Louise Estabrook
Lowry Family
Lt. Col. Robert 'Dave' Scales
Lynda Gillam
Mackenzie Harwood
Mae Smart
Marc Alessi
Margaret M. Emanuele
Margaret Tseng
Margie Grace
Maria Viveiros
Marie Riordan
Mark Miller
Marlene and Maria Sequeira
Martin "Marty" Keniley
Martin Gorovsky
Mary Griswold
Mary Jean Smith
Mary Romero
Mary Rotolo
Mary Schlickbernd
Matt Stabenow
Matthew Pickens
Maura Keniley-Pedersen
Maurice Mitchell
Meg McLane
Megan Harwell
Megan Musilli McNally
Michael J. Athey
Michael Lana
Michael Leader
Michael Lundquist
Michael Rooth
Michael Tenison
Michele Storm
Michelle Grunwald
Mike Cammer
Mike Derosa
Mike Lana
Mike Sweeney
Moira Greenway
Mr. and Mr. William Deane
Murray Cooper
Nancy Bethay
Nate Stabenow
Nelson Larot
Nicholas Ramos Gonzalez
Nina Piatetsky
NOCO/WYO Support Group
Norman Karas
Pam Perault
Pam Wollangur
Patricia Rymut
Peggy Burttram
Peggy Taylor
Penni Sutherland
Penny Tressler
Phil Turnbull
Phyllis Hoekstra Meima
Raymond Roderick
Rebecca Jarrell
Renuka Kalaria
Rich Korosa
Richard Bethay
Richard Lewis
Rick Roemke
Robb Lubin
Robert and Michael Williams
Robert Clausen
Robert Morrison Williams
Robert Shawn Jefferson
Robert Tucci
Robin Lu
Robin Ortega
Rodney Rydeen
Roy Yamamoto
Sahil Gidda
Sam Blustein
Sandra Lou Deane
Sandy Gierlaszynski
Sarah Hale
Sarah Michaels
Sevenski Family
Sharon Bond
Sheng-Han Kuo, MD
Stacy Coyne Leger
Stephen Scott Griswold
Steve Brune
Steven and Lynn Neuendorf
Stryker Quellhorst
Suaro "Sunny" Prom
Suchi Trivedi
Sue Majesky
Summer Seguin Little
Susan Macauley
Susan Penn
Taylor Crooks
Team Evan
Teddi Vaile
The Leader Family
Theresa Hurtado
Thomas Baker
Thora Mae Lankton
Tiffany Seguin Miller
Tom Likai
Tom Sathre
Tom Swenney
Tony Alessi
Tony Schlickbernd
Walter Herbert Jones
Wanda Nederveld
Warren Way
Willard Family
William Chwee
William Gessner Johnson, MD
William Johnson
Zachary Zmithrovitch

Natural History Study needs SCA Research Participants

The Clinical Research Consortium for the Study of Cerebellar Ataxia (CRC-SCA) continues to recruit research participants who have a confirmed diagnosis of SCA 1, 2, 3, 6, 7, 8 or 10. This is an opportunity for anyone in the United States with those forms of SCA at any stage of the disease to participate. Contact the research coordinator at a site near you to learn more about how you might be able to help in Ataxia research efforts to discover a treatment.

The National Ataxia Foundation encourages anyone with SCAs 1, 2, 3, 6, 7, 8 and 10 to participate.

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This research is generously supported by the Gordon and Marilyn Macklin Foundation and the National Ataxia Foundation.

We are pleased to announce that leadership of the CRC-SCA has rotated to the following clinical researchers: Dr. Sheng Han Kuo, Columbia University, Dr. Liana Rosenthal, Johns Hopkins University and Dr. Vikram Shakkottai, University of Michigan. We are grateful to Dr. Henry Paulson, University of Michigan, who provided hours of counsel and leadership to the CRC-SCA and we say "Thank you" to our new leaders for taking on these important roles.

For more information on the study, you may contact Sue Hagen at susan@ataxia.org or 763-231-2742

Disappointed that you don't qualify for this research study?

Take an important step to make sure that you are notified of future studies for which you might qualify. Enroll in the CoRDS Ataxia Patient Registry.

If you are affected with any type of Ataxia, enroll in the registry by going to the website: https://cordsconnect.sanfordresearch.org/BayaPES/sf/screeningForm?id=SFSFL. If you have questions about enrollment in the registry, contact the CoRDS staff at 877-658-9192.

NAF Staff Directory and Social Networks

NAF Staff Directory:

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Social Networks:

NAF Facebook Page	*www.facebook.com/ataxiafoundation/*
NAF YouTube Channel	*www.youtube.com/user/NatlAtaxiaFound*
NAF Twitter	*www.twitter.com/NAF_Ataxia*
NAF LinkedIn	*www.linkedin.com/company/nationalataxiafoundation*

THE ATAXIA COMMUNITY IS INTERESTED IN YOUR GREAT IDEAS.

If you have Ataxia Tips or a personal story you would like to share in a future issue of *Generations*, please submit it to ***naf@ataxia.org***. Those submitting a personal story are asked to please include a photo or two and a brief author bio (1-2 sentences).

THE DEADLINE FOR SUBMITTING MATERIALS

for the Summer issue of *Generations* is June 1, 2020. Please send articles, your personal story, recaps of Ataxia-related events, photos and reports to ***naf@ataxia.org***. Thank you.

Support Groups are going

VIRTUAL!

Support Groups are finding ways to stay connected while in-person meetings are cancelled due to precautions from the Coronavirus. Many groups have set up virtual meetings and Facebook groups to reach out to their members. For more support group information go to www.ataxia.org/support-groups

Find a Meeting Near You and Join!

WWW.ATAXIA.ORG/EVENTS

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