VOLUME 49

2021

National Ataxia Foundation

GENERATIONS

THE OFFICIAL PUBLICATION OF THE NATIONAL ATAXIA FOUNDATION

What is Needed for Treatments or a Cure for Ataxia?

Sue Hagen, NAF Research Services Director Pg. 8

NAF Funded Research

2021 Grants Awarded Pg. 12

Researcher Spotlight

Meet Felicia Williams Pg. 7

Meet a Member

Amanda Simmons and Paul Vandergriff
Pg. 21

Annual Ataxia Conference

What to Expect at 2022 AAC
Pg. 4

Table of Contents

NAF Updates & News

Living with Ataxia

Research

Research Participation Opportunities

Please direct correspondence to:

National Ataxia Foundation
Ensuring no one experiences Ataxia alone, until no one experiences Ataxia, period.
www.ataxia.org

National Ataxia Foundation
PO Box 27986
Golden Valley MN 55427
Phone: (763) 553-0020
Fax: (763) 553-0167
Website: *www.ataxia.org*
E-mail: *naf@ataxia.org*
CFC #10752

The National Ataxia Foundation does not endorse products, therapies, services, or manufacturers. Those that are mentioned in ***Generations*** are included only for your information. The NAF assumes no liability whatsoever for the use or contents of any product or service mentioned in the newsletter.

NAF Update:

Letter from the Executive Director

Andrew Rosen,
Executive Director

Throughout 2021, NAF has added staff to build our programs and services that we offer to the Ataxia community. This was capped off by our recent announcement of Dr. Lauren Moore as our very first Chief Scientific Officer. I believe that the depth and breadth of candidates we've attracted for all of our new hires says a few important things about NAF and this moment in time: first, we have built a strong reputation since our founding in 1957 for advancing the field of Ataxia research and providing much needed support for everyone impacted; and second, job applicants recognize that this is an exciting time to be joining NAF. The increased pace of activity from our pharmaceutical partners means that treatments have never been closer to reality. People want to be part of what is going to be a truly impactful next decade in Ataxia research and clinical development.

NAF staff has been laser-focused in 2021 on delivering on our mission — to accelerate the development of treatments and a cure while working to improve the lives of those living with Ataxia. You will see that throughout this edition of Generations, from summaries of our funded research, to education on what's involved in a clinical trial, to our 2022 virtual AAC. Here's to a new year filled with hope and promise for all of us!

Andrew

Andrew

2021 NAF Staff

Become a Member

ataxia.org/JoinNAF

Join a Research Study

ataxia.org/help-develop-new-treatments

Find a Support Group

ataxia.org/support-groups/

From Care to Cure

NAF

2022 Annual Ataxia Conference

Time to get excited!

AAC is more than just a conference. It's an online gathering place where Ataxia clinicians share strategies to help you manage care, people affected by Ataxia network with peers and build relationships that last far beyond the conference, and everyone works together to accelerate treatment development. Be a part of it!

Living with Ataxia is a journey that should not be taken alone. **Join us at the virtual 2022 AAC to connect, learn, and take action toward a cure.** From Care to Cure, NAF will be with you on the journey.

A Virtual Experience

Registration Opens January 2022

ataxia.org/2022AAC

Only $50 per attendee

Industry rate $500

Registration Scholarships

We understand that the registration cost can be too great of a financial burden for some. We want everyone to have an opportunity to experience AAC. NAF will be awarding a limited number of registration scholarships for the virtual event to low-income individuals with Ataxia.

Apply by 3/1/2022 at **https://www.surveymonkey.com/r/2DHZH2Q**

FOR MORE INFORMATION VISIT:
WWW.ATAXIA.ORG/2022AAC/

Thank you to our sponsors:

biohaven pharmaceuticals

Biogen

AAVANTIBIO

MassMutual

REATA PHARMACEUTICALS

Everything You Need to Know About Clinical Trial Phases

Let's chat about Clinical Trial Readiness with a focus on Ataxia. Clinical trials ensure that treatments are safe and effective before they gain approval for widespread use in humans. Clinical trials test new treatments and therapies including: new drugs, different use for an already approved drug, medical devices, new treatment/therapy combinations, and so much more. Clinical trials can also evaluate which treatment is the most effective for disease and different disease variations. Clinical trials can focus on new ways to relieve, remove, or treat various symptoms. They can also help investigators and providers find new ways to detect and diagnose disease. Clinical trials can vary in length, anywhere from a few months to several years to complete.

Pre-Clinical Trial Steps

- Before a clinical trial can be initiated in human volunteers, scientists spend months to years studying and testing treatments in a laboratory using cell and animal models.
- Then, this research is submitted to the FDA for approval to begin a clinical trial.
  - o Investigators submit an Investigational New Drug (IND) application to the FDA.
  - o What does the IND include?
    - – How the drug is made, who makes it, ingredients, and more
    - – Results from the investigator's research
    - – Plans for the clinical study including protocols, informed consent forms, risk assessments, agreement for IRB (Institutional Review Board) approval, and more
    - – Details on the investigators to ensure they are equipped to run a clinical trial

Phase I: Safety

Phase I is the first phase in most clinical trials. In this phase, a small number of participants are enrolled, and safety is a top priority. This phase has the most associated risk but has the potential to help.

- The goals in Phase I are to determine the best dose amount for a new treatment for the best result, discover any side effects of a new treatment, and the optimal way to deliver the treatment
- Safety is a top priority
  - o Extra monitoring, tests, and smaller doses are used.
- There are a small number of participants in Phase I (typically 20-80 volunteers)
- Placebos are not typically used.

Phase II: Efficacy

Once treatment has successfully gone through Phase I and is determined to be safe, Phase II begins. Phase II addresses how well a particular drug or treatment works. For example, is it effective in relieving dizziness, or does it improve the Ataxia patient's quality of life?

- A larger group of patients enrolled in Phase II studies (typically 100-300 volunteers).
- Dosage varies.
  - o Placebos are still not utilized
  - o Side effects are uncovered

Phase III: Comparison to Current Treatments

If the treatment in Phase II benefits enough patients, then the trial moves on to Phase III. Phase III has two main goals: first, to ensure that the findings in Phase II remain valid, and second to compare against current treatments available.

- Study participants are often randomly assigned to one treatment.
  - Sometimes, neither the investigator nor the patient is aware of which treatment is used (blinding).
  - Phase III usually involves a large number of participants (anywhere from 300 to thousands of volunteers).
    - Offered in a larger geographical area
  - Typically, the most prolonged phase in a clinical trial; lasts up to several years.
  - Side effects are monitored closely, and the treatment could be terminated if deemed necessary.

Researcher Spotlight

Meet Felicia Williams

NAF is proud to feature Felicia Williams as a recipient of NAF's 2020 Diverse Scientists in Ataxia Pre-Doctoral Research Fellowship. Felicia developed a new method to identify genes that suppress protein clumping.

Bio:

Felicia Williams graduated from the University of Georgia in 2019 where she studied genetics and biotechnology. Here she began her research career at the USDA Agricultural Research Service in the lab of Dr. Scott Gold working on fungal plant diseases of corn. She currently attends Duke University in the lab of Dr. Matt Scaglione where she researches protein maintenance in microorganisms with support from the NAF Diverse Scientists in Ataxia Research Pre-Doctoral Fellowship.

Lay Summary:

A number of spinocerebellar ataxias (SCAs) including SCA1, SCA2, SCA3, SCA6, SCA7, and SCA17 are caused by presence of an expanded tract of the amino acid glutamine in specific proteins. In these diseases, these long polyglutamine tracts cause proteins to clump up and disrupt brain cell function, ultimately resulting in neurodegeneration. Therefore, one potential way to treat these diseases is to prevent this protein clumping phenomenon. In my PhD laboratory, we realized that an amoeba naturally had thousands of polyglutamine tracts, and we found that this organism is naturally resistant to this polyglutamine protein clumping. We next wanted to identify how this amoeba resists protein clumping. To streamline this process, I developed a new method to identify genes that suppress protein clumping in this amoeba. Using this method, I hope to identify how nature has prevented protein clumping. This information will then be used to aid in developing therapies to treat diseases including SCAs.

What is Needed for Treatments or a Cure for Ataxia?

By Sue Hagen, NAF Research Services Director

In the 14 years that I have been on staff at the National Ataxia Foundation, I have heard many times that clinical trials for therapy development for Ataxia will start within the next 5 years. And I have seen the Ataxia community patiently and at times, impatiently, waiting for those trials to begin. The good news is that within the last five years, there have been two significant trials sponsored by industry: one for Friedreich's Ataxia and one for some types of SCA.

However, I think I can speak for those living with Ataxia that more clinical trials are needed. And the sooner the better. So, I want to share with you, the Ataxia community, how urgently your help is needed to pursue NAF's vision of: A World Without Ataxia.

Why Your Participation is Essential

In my role at NAF, I participate in meetings with pharmaceutical companies, Ataxia researchers, the NAF Drug Development Collaborative and other groups who are working diligently in research for the development of treatments for Ataxia. They have the brain power, the scientific knowledge, the financial resources to move forward, but more than anything, they need the Ataxia patient population to participate. **Drug development cannot take place without patient involvement.**

The participation of the patient population cannot be overstated.

Ways to Bring Approved Treatments to the Ataxia Community

- Become a member of NAF. It is free and easy to sign-up at www.ataxia.org/JoinNAF. We currently have 7,779 members. Let's bring that number up to 10,000! There is strength in numbers.

- Join the CoRDS Ataxia Patient Registry at https://research.sanfordhealth.org/rare-disease-registry. Encourage your family members and friends who have Ataxia to do the same.

- Join a support group. Information on support groups is located at www.ataxia.org/support-groups.

- Learn about the natural history study run by the Clinical Research Consortium for the Study of Cerebellar Ataxia. If you qualify, contact a Research Coordinator at a site near you. www.ataxia.org/crc-sca/

- If you are able and qualify, consider donating biosamples for research. Sometimes this will be a blood draw, but also needed is cerebrospinal fluid (CSF), which is done by a lumbar puncture. This may cause some temporary discomfort, but the value of CSF from patients with certain SCAs is necessary to bring us closer to drug development. (Speak with your physician about whether it is safe for you to undergo a lumbar puncture.)

- If you have participated in a clinical trial or research study, share your story with NAF. Stories can be sent to **naf@ataxia.org**. Your story may encourage others to participate in research.

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 Services Associate, at *mary@ataxia.org* or 763-231-2750.

2021 United Against Ataxia Hill Day

NAF, FARA and over 150 volunteer advocates came together on September 29, 2021, for the third United Against Ataxia Hill Day. The Ataxia Advocates had a full day of raising awareness about Ataxia and speaking with Congressional Members to support legislation that will directly impact the Ataxia Community. There were four specific asks:

1. A Senate Resolution to declare September 25th as National Ataxia Awareness Day (S.Res. 339)
2. The addition of "Hereditary Ataxia" into the Congressionally Directed Medical Research Program (CDMRP)
3. Accelerating Access to Critical Therapies (ACT) for ALS (H.R. 3537/S. 1813)
4. The BENEFIT Act (S. 373/H.R 34472)

We would like to say a HUGE Thank You to Senators Cindy Hyde-Smith and Christopher Murphy for co-sponsoring the Resolution to declare September 25th as National Ataxia Awareness Day which was read into the record. At the end of the day, we held the 1st Hill Day Celebration to recognize Senators Hyde-Smith and Murphy as the inaugural Ataxia Research Champions!

You can watch a recording of the celebration on our website here, www.ataxia.org/HillDayCelebration.

International Ataxia Awareness Day

INTERNATIONAL ATAXIA AWARENESS DAY SEPTEMBER 25

International Ataxia Awareness Day (IAAD) — September 25

International Ataxia Awareness Day falls on September 25th each year and is a perfect time to post your Ataxia stories and photos on all forms of social media.

For #IAAD21 you shared our social media post 415 times. It reached 25,000 people! Thank you!

BECOME AN ATAXIA ADVOCATE

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

On the advocacy webpage you can:

- Join the Advocacy mailing list
- Learn how to contact your local representatives
- Check out advocacy events happening around the country.
- Get the latest news on legislative issues impacting the Ataxia community.
- Download the Advocacy Toolkit

We want to hear from you if you have a relationship with a US Congressman or Senator. You could help further support of legislative issues that impact the Ataxia community.

2021 NAF Funded Research

At NAF, we support researchers in many ways, including our grant process. Research grants allow Ataxia investigators to request funding for their studies. In 2021, we were able to fund 13 research studies for a total of $655,000.00 in funded research. Lay summary title and researcher information are available below for the research funded in 2021.

You can view the full summery at
www.ataxia.org/2021-naf-funded-research

RESEARCH SEED MONEY GRANTS

Role of iron-dependent dysfunctions in microglia toxicity
Nadia D'Ambrosi, PhD - University of Rome Tor Vergata, Department of Biology - Rome, Italy

Role of KIF1C motor protein in myelination – Involvement in ataxia
Khalid El Hachimi, PhD -Institut du Cerveau et de la Moelle epiniere -Paris, France

Intermittent fasting as a novel therapeutic strategy for SCAs
Andreia Teixeira-Castro, PhD - Life and Health Sciences Research Institute (ICVS) and ICVS/3B's – PT Government Associate Laboratory, University of Minho - Braga, Portugal

Long-read sequencing to decipher a repeat expansion causative of SCA36
Marka Van Blitterswijk, MD, PhD – Mayo Clinic Jacksonville – Jacksonville FL

PIONEER SCA TRANSLATIONAL AWARD

Targeting Hsc70-4 to mitigate SCA3/MJD
Sokol Todi, PhD – Wayne State University – Detroit, MI

YOUNG INVESTIGATOR AWARD

Ataxia-Telangiectasia and cytoskeleton stress: pathological implications for neurodegeneration
Giulia Bastianello, PhD - IFOM, Fondazione Istituto FIRC di Oncologia Molecolare - Milano, MI, Italy

Molecular Mechanisms of Human Purkinje Cell Degeneration in Ataxia-Telangiectasia
David Buchholz, PhD - The Rockefeller University - New York, NY

MicroRNA-specific small molecule modifiers as a new and promising therapeutic approach for Machado-Joseph disease/spinocerebellar ataxia type 3 (MJD/SCA3)
Sónia Duarte, PhD - Center for Neuroscience and Cell Biology (CNCB) - Coimbra, Portugal

Naturally occurring metabotropic glutamate receptor 1 mutations in rare spinocerebellar ataxias; characterization and pharmacological manipulation
Shane Hellyer, PhD - Monash Institute of Pharmaceutical Sciences - Parkville, Australia

The common mechanism of SCA35 and gluten ataxia
Chih-Chun Lin, MD, PhD - Columbia University Medical Center - New York, NY

POST DOC FELLOWSHIPS

Mechanisms of and therapy for progressive ataxia due to KCNC1 PA potassium channel mutation
Huijie Feng, PhD - The Children's Hospital of Philadelphia - Philadelphia, PA

Using a C. elegans model of Spinocerebellar Ataxia 3 to investigate new therapeutic approaches: optogenetic activation of redox signaling in GABAergic neurons activates stress response pathways and extends healthspan
Franziska Pohl, PhD - Washington University in St. Louis - St. Louis, MO

RAN proteins in sporadic ataxias and SCA8: diagnostic tools and therapeutic potential of metformin
Setsuki Tsukagoshi, PhD - University of Florida - Gainesville, FL

DIVERSE SCIENTISTS IN ATAXIA PREDOCTORAL FELLOWSHIP

Development of a Positive Selection High Throughput Genetic Screen in Dictyostelium discoideum
Felicia Williams, PhD - Scaglione Lab - Durham, NC

Uncovering Mechanisms of SNX14-SNX13 Interaction in Cerebellar Function and Disease
Vanessa B. Sanchez, PhD - University of Pennsylvania - Philadelphia, PA

ASK THE ATAXIA EXPERT

A bimonthly series that empowers you with the knowledge you need to live better with Ataxia. An experienced Ataxia clinician will join us to answer your questions related to Ataxia.

Don't have a question? Join us to listen in!

Visit **www.ataxia.org/asktheexpert/** to see past Ask the Ataxia Expert Sessions.

Past Experts include:
- Susan Perlman, MD
- Theresa A. Zesiewicz, MD, FAAN
- Pedro Gonzalez-Alegre, MD, PhD
- Liana S. Rosenthal, MD, PhD
- Christopher Gomez, MD, PhD
- Jeremy Schmahmann, MD, FAAN, FANA, FANPA

2021 RESEARCH DRIVE

THROUGH DECEMBER 31, 2021

There is power in partnership — with community members like you.

It is in this partnership that our vision of a world without Ataxia will become a reality.

Visit the website to make your donation before time runs out!

WWW.ATAXIA.ORG/RESEARCHDRIVE

Contributions to the Research Drive help NAF fund the very best Ataxia research. Last year, we funded more than $1 million in research initiatives. Our goal for this campaign is to raise $400,000. Help us fund as much research as we can!

Your gifts have impacted the Ataxia research field in big ways! NAF grants have often been the start-up funding needed for research that went on to make huge changes in what we know about Ataxia. Most of the biggest discoveries can be traced back to NAF and support from donors like you. Your gifts have funded projects that led to identification of gene mutations in Ataxia and given a start to projects that went on to receive funding from NIH (one study received more than $1 million!).

WE COULDN'T DO IT WITHOUT YOU!

We asked our recent research grant recipients how the grant from NAF impacted their work. Here is what they had to say…

“The grant has been supporting our efforts to develop novel Biomarkers for spinocerebellar ataxias. **The studies are still ongoing, but we may have a clue for a new biomarker**” —**GAL BITAN, PHD**

(PICTURED: DR. BITAN’S CHILDREN, AGES 1 & 3)

“Funding from NAF has had an immense impact on my lab’s research. First, it has allowed us to generate pilot data to obtain future funding from the NIH. Importantly, it has provided some surprising results on the emergence of ataxia in GHS.”

—**ANGELA MABB, PHD**

WALK N'ROLL TO CURE ATAXIA

National Ataxia Foundation

Watch the event here

https://www.youtube.com/watch?v=74pLeNaJn2A

In 2020 when COVID kept us all home bound and unable to gather, we held our first Virtual Walk N' Roll with much success.

This year, Joel and Dana were back again to host the 2021 Virtual Walk N' Roll to Cure Ataxia! During the hour-long event we met Ataxia advocates, researchers, and those living with Ataxia every day. In addition to our virtual event there were 8 in-person Walk N' Rolls across the country: Chicago, Minnesota, Sioux Empire, Central Indiana, Massachusetts, Pittsburgh, Tri-State, and Utah. These Walk N' Rolls along with the Virtual Walk N' Roll raised $269,810 for the National Ataxia Foundation.

The Walk N' Roll to Cure Ataxia campaign is NAF's largest grassroots fundraising event. It makes a large impact on our ability to support those living with Ataxia and their families. Thank you to our organizers that volunteer to host a Walk N' Roll in their communities. Thanks to these events NAF is proud to fund more than $1 million in Ataxia research initiatives each year.

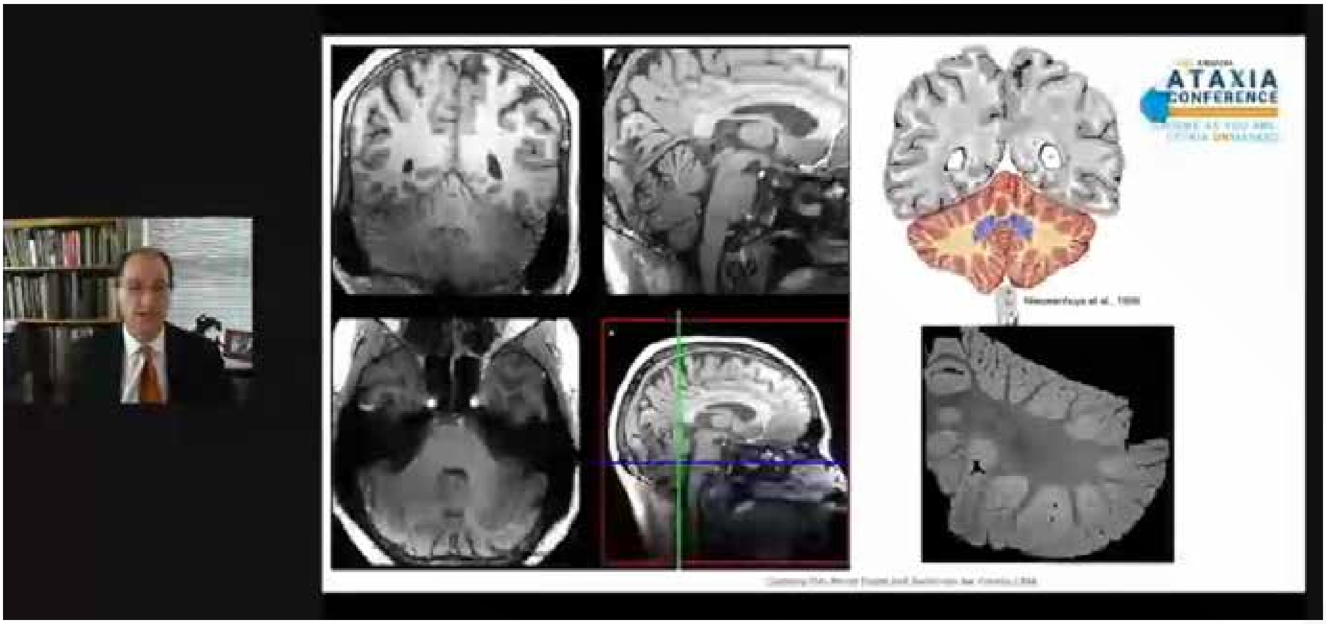
2021 AAC

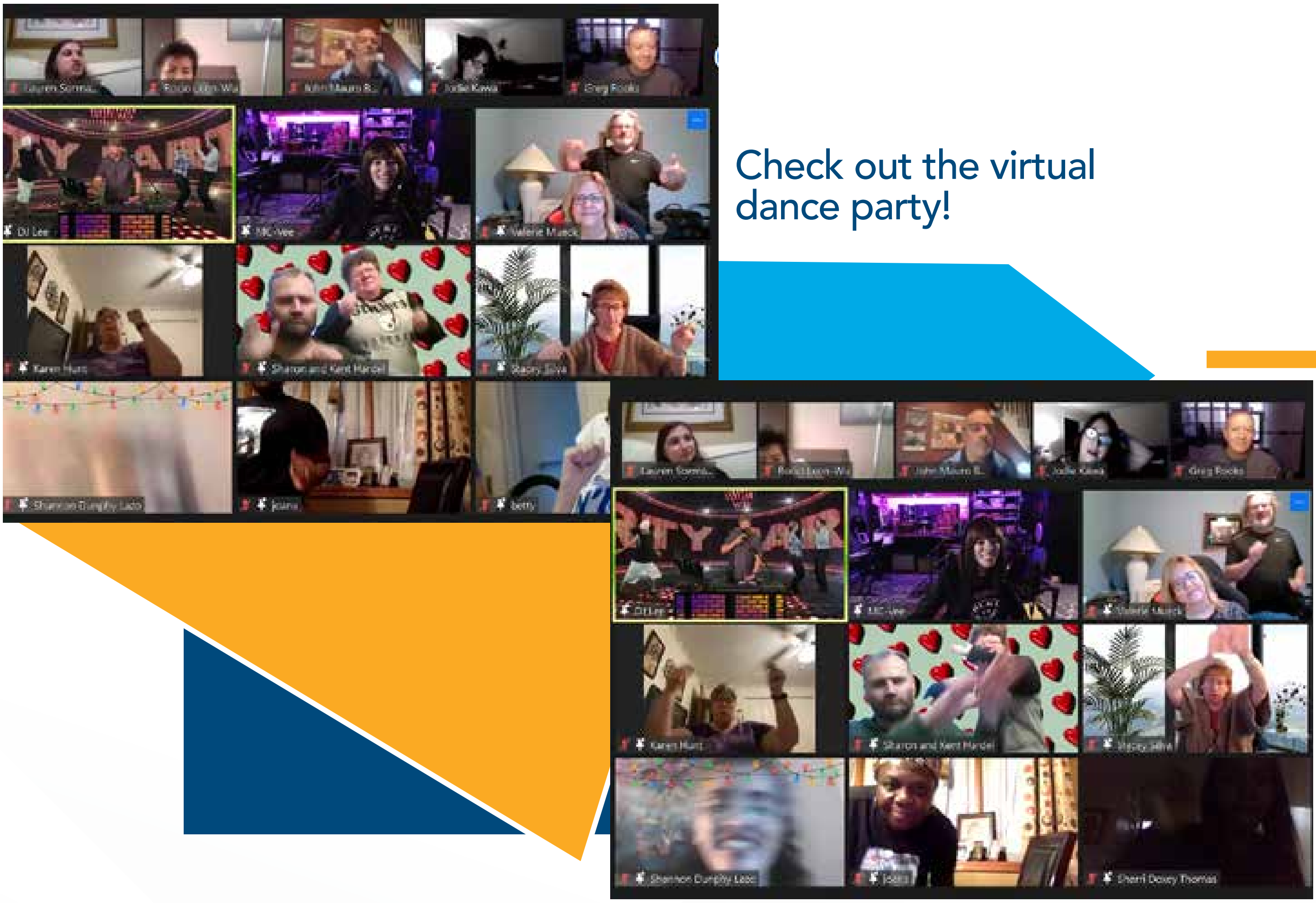
One thing became clear at the 2021 virtual Annual Ataxia Conference (AAC) — a pandemic can't stop our community from coming together!

You joined us in record numbers to learn about the latest in treatment development, find new research opportunities, and network with other attendees and Ataxia clinicians.

AAC BY THE NUMBERS

873	Attendees	23	Countries Represented
508	First Timers	18	Exhibitors
31	Speakers	7	Sponsors





Check out the virtual dance party!

2021 ANNUAL
ATAXIA CONFERENCE
COME AS YOU ARE:
ATAXIA UNMASKED

To those who were not able to attend AAC, we have the General Sessions on our website for you to watch.

www.ataxia.org/2021-annual-ataxia-conference

Thank you to our sponsors:

ASPER
biohaven pharmaceuticals
exicure
VICO Therapeutics
uniQure
variantyx

Meet Amanda Simmons

My name is Amanda Simmons and I was diagnosed with SCA6 in 2018 just after my 45th birthday. I inherited from my father. I am the youngest of five children and as far as we know I am the only one with SCA6, which I very much hope is true because I am also the only one who doesn't have children. If the SCA6 buck stops with me in our family I'm happy to carry the burden, stumbles and all.

My SCA 6 Story

To simply say I have always been a very active person would be an understatement. I've ridden my bike from SF to LA, participated in a 24 hour spin class, ran a marathon in Hawaii, raced with a cycling team, ran countless half marathons, rock climbed, CrossFitted…you get the point. In 2007 I decided to turn my love of fitness and nutrition into a full time career and left a well paying executive sales position with benefits, vacation time, and free snacks to open my own business. I had one client at the time. Ten years later I had built a strong client base and had the studio of my dreams. Unfortunately, my life was about to change drastically. Actually, it had been changing and deep down I knew what was happening.

I started to notice things that weren't really on my radar for SCA6. My parents had somewhat downplayed what my father was going through since he was about 70 when his symptoms started. They said we kids had nothing to worry about and all the research I had done basically said SCA6 was a balance and speech issue. For years I had been doing things that demanded high levels of strength and coordination, in fact, as a child I was known (teased actually) for riding a unicycle to school. So when trying to write at night my eyes started shifting rapidly side to side I just thought I was tired. Tired or exhausted was a word that seemed to creep into everything I did. Workouts that normally wouldn't even break a sweat started to cause major fatigue and my recovery times were getting longer.

One day on a run it was as if I was in a video game, my vision was bobbing and I couldn't look to the horizon, I tried to focus on the stop signs ahead and could not. At the same time my limbs felt like they were going in a million directions without me having any control over them and my heart rate was off the charts. The other thing of note was my mood and increasing inability to communicate my feelings and control my frustrations, small things that I would normally shrug off were getting under my skin. For transparency I will say I have always run a little hot in the temper department but this felt different, it was confusing and concerning.

Getting a Diagnosis

I decided it was time to get tested for SCA6 so I contacted my GP and got set up with a genetic counselor to start the process. Like many things in life, nothing can prepare you for something like this. I will never forget the day the genetic counselor called with my results. When she said the test came back positive, time literally felt like it stopped. I sobbed instantly. Thankfully my wife was and has been by my side with loving, kindness and support. I would not be able to handle any of this without her.

It has been two years, a couple bad falls, a frozen shoulder, my mothers death, the closing of my business, and a pandemic since my diagnosis. Rough doesn't begin to describe the last two years. Devastating might be more accurate. Nonetheless, I am grateful. I have lost the ability to do so many things I love. My whole existence revolved around movement and pushing myself beyond expectations. In many ways I took those abilities for granted and assumed they were a given. Today I appreciate being able to walk, get on my spin bike, take easy hikes with my family, and swallow (mostly).

Do you have an Ataxia story you would like to share with our community? Submit it today to: naf@ataxia.org

Meet Paul Vandergriff

I was in high school when I saw *Pride of the Yankees* the story of Lou Gehrig. In this 1942 movie Gary Cooper played Lou Gehrig who played in 2130 consecutive games. Gherig, who had ALS, died a year before the films release. In the movie as Lou Gehrig (Gary Cooper) says words something like this on the day of his retirement: "Today I consider myself the luckiest man in the world."

I feel much the same way.

I have a late onset form of Ataxia. I got to complete college, USAF pilot training, including instructor pilot training. I had a very interesting career in petroleum land work following my Air Force Service. I have a beautiful, helpful wife, a fine son and daughter who married a handsome son-in-law, and three very brilliant, beautiful and talented granddaughters. Great replacements already in place!

My wife has been a long serving and willing helper for almost thirty years after my retirement. In addition to household chores, she has driven, carried out trash, overseen yard work, budgeted, decorated, and achieved many things not regularly thought of as being a wife's responsibility. Plus, she has a hearing problem while I—like many Ataxians—have a speech problem. Not fun for us at all!

My Ataxia was first diagnosed in 1983 after a fall on ice in our yard. The diagnosis by x-ray was first noticed as a black spot on my cerebellum. An older brother had an unknown form of Ataxia. A genetic test confirmed my Ataxia. A kind, helpful supervisor always alerted me before scheduled fire drills so that I could ride down the elevator rather than walk six floors of stairs during the drill. I worked and walked unaided until 1990, and retired then at my neurologist's insistence.

Neither parent had Ataxia; however, my maternal grandmother had what doctors said was a stroke. From my observation of my maternal grandmother's wavering hand movements and also hearing her speech, I'm convinced she had Ataxia. She was not lucky— we lived in the country where neither a walker nor a wheelchair were of benefit. Our frame farm house was NOT handicap accessible. It had no electricity. It had no running water. Bedrooms were hot in the summer and cold in the winter. The nearest paved road was over six miles away.

A brother with Ataxia died at age 89. I'm uncertain of the cause. He'd had falls from oil derricks, survived pipeline explosions, WW II, colitis, liver cancer, Ataxia, and other disorders.

I exercise almost daily. However, I am under no illusion that exercise may add length to my life. My brother lived to age 89 without <u>any</u> exercise. Perhaps exercise may postpone some disorders as may some medications and foods. Hopefully, a cure for Ataxia will be found soon.

I'm not the celebrity or hero Lou Gehrig was. I've never played for the Yankees. I still think I'm lucky.

Author Bio: Paul is a Certified Professional Landman and a former helicopter pilot. He is not a writer. He is still able to bathe, feed, and dress himself. He cannot walk or drive.

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.

Columbia University
Nadia Amokrane
Na2855@cumc.columbia.edu

Emory University
Jonna Seppa
jonna.k.seppa@emory.edu

Houston Methodist
Titilayo Olubajo
tolubajo@houstonmethodist.org

Johns Hopkins University
Ann Fishman
ann.fishman@jhu.edu

Massachusetts General
Jason MacMore
jmacmore@partners.org

Northwestern University
Kyle Tingling
kyle.tingling@northwestern.edu

University of California, Los Angeles
Aaron Fisher
ADFisher@mednet.ucla.edu

University of California, San Francisco
Daven Crossland
daven.crossland@ucsf.edu

University of Chicago
Cindy Jimenez
cindyj@uchicago.edu

University of Florida
Grace Lien
grace.lien@neurology.ufl.edu

University of Michigan
Frank Ferrari
frankfer@med.umich.edu

University of Minnesota
Diane Hutter
hutte019@umn.edu

University of South Florida
Chase Kingsbury
ckingsbury1@usf.edu

University of Texas, Southwestern Medical Center
Pheba Sunny
PhebaElizabeth.Sunny@
UTSouthwestern.edu

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

Thank you to Drs. Sheng Han Kuo, Liana Rosenthal and Vikram Shakkottai who provide leadership and enthusiasm to make this consortium successful in its goals. And, thank you to each of the sites' clinical researchers and research coordinators who perform the research necessary to move the field closer to treatments and a cure.

For more information on the study, you may contact Kelsey Trace at kelsey@ataxia.org or 763-553-0027

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.

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 January - November 2021.

IN HONOR

Aly Bourbeau
Amy and Corby Legault
Amy B. Messigian
Amy DeLeon
Amy Messigian-Legault
Anabela Azevedo
Anne Sanchez
Antoinette Arddizone Varron
Ashleigh Thiele
Austin Lefeld
Aya Kito
Benny Frei
Brett Masserant
Brian Bredberg
Brian Jones
Cameryn Cobb
Carmen Pieragastini
Carol Biby
Carol Larson
Carol Segura
Carol Stabenow
Caroline Heilweil
Celia Baculi
Charlton Heights Elementary School
Cheryl Serge
Cheryl Wright
Chicago Ataxia Support Group
Chie Franklin
Chris Cozmanoff
Christian Gregory
Christina Cozmanoff
Christopher Gomez, MD
Christy Plotnock
Clementz Family
Clyde Fano
David W. Henry Jr.
Debra Charlesworth
Debra Covington
Dennis Hill
Diane Ballard
Dirk Desserault
Donald Santa Croce
Doug Brunnert
Ed Schwartz
Elle Anthone Barnhart
Ellen Moetsch
Ellie Martin
Ellin Palmer
Erica Baldwin
Erin Peterson
Evan Taylor
Francine Zdrale
Frank Orlowski
Glenn Gardiner
Grace Dunne
Jack Moore
Jack Perme
Jacob Van Buren
James Hughes II
Janet Cunningham
Jason Hubbard
Jason Michael Aiello
Jason Myers
Jean Hardy
Jeannette Viveiros
Jeff Razmus
Jene Ebron Wilkerson
Jennifer Leader
Jens-Ingo Farley
Jeremy Hume
Jerry McCollum
Jim Richards
Jodie Kawa
Joe Decrescenzo
Joe Sweeney
Joel Sutherland
John and Dana Mauro
John and Kara
John Koiter, Jr
Jonathan Zilles
Judy Allal
Judy Johnson
Karen Russell
Karen Suchomel
Kathleen Schnobrich
Kathy Hoffman Bucholz
Kelly and Kim Tambourino
Kelly Fisher Tambourino
Kelly Rutledge
Kelly Tambourino and Kim Michael
Keri Naccarato
Kevin Cook
Kim Poor
Kimberly Fisher Michael
Klitz Family
Kory Macy
Kyin K. Fong
Kylie Till
Leah Minkin
Lenore Healey Schultz
Leroy Bader
Leroy Wernsing
Lillian Heller
Linda Meier
Lindsay Denning
Lindsey Graham Guinn
Lisa Jaffe
Loera Family
Lori Hoffman Goetzman
Louise Estabrook
Marc Heilwell
Margie Myers Grace
Marie Riordan
Mark McGowan
Mary Beth Farley
Mary Jo Brechtl
Mary Schlickbernd
Matt Stabenow
Melissa Schmittler
Melody Price
Michael Gehr
Michael Leader
Michele Storm
Michelle Reid
Michelle Williams
Mike Anderson
Mike Cammer
Mike Derosa
Nan Vail
Nancy Kochevar
Nate Stabenow
Pam D'Ermilio
Pam Perault
Patty Perez
Paul Ford
Penni Sutherland
Peter Lanzo
Raymond Robinson
Refiye Miller
Regina Hildreth
Renuka Kalaria
Rick Roemke
Rita Nystrom
Robb Lubin
Robert Alderman, Sr.
Robert Baker
Robert Michaels
Robert Peterman
Robert St. George
Roberta Santa Croce
Robin Manley
Rocio Wu
Roger Cooley
Roop Maraj
Rose Michaels
Sally Riley
Sandy Read
Santa Croce Family
Sarah McNaughton
Scott Moore
Sebastian Castro
Shawn Andrus
Sheng-Han Kuo, MD
Sophia Scozzesi
Soula Lane
Stephanie F. Wilkins
Stephanie Hales
Stephen Comora
Sterling Yarborough
Steve Ofenstein
Stuart Booth
Susan Berry
Susan Harris
Sweeney Family
Taylor Crooks
Temaine Nagappen
Teresa Coccaro
The Stoutenburgh Family
The Strojny Family
The Yingling Family
Tom Sweeney
Treasure Coast Support Group
Wayne Walters
Witcher Family
Zach and Morgan Brownlee

IN MEMORY

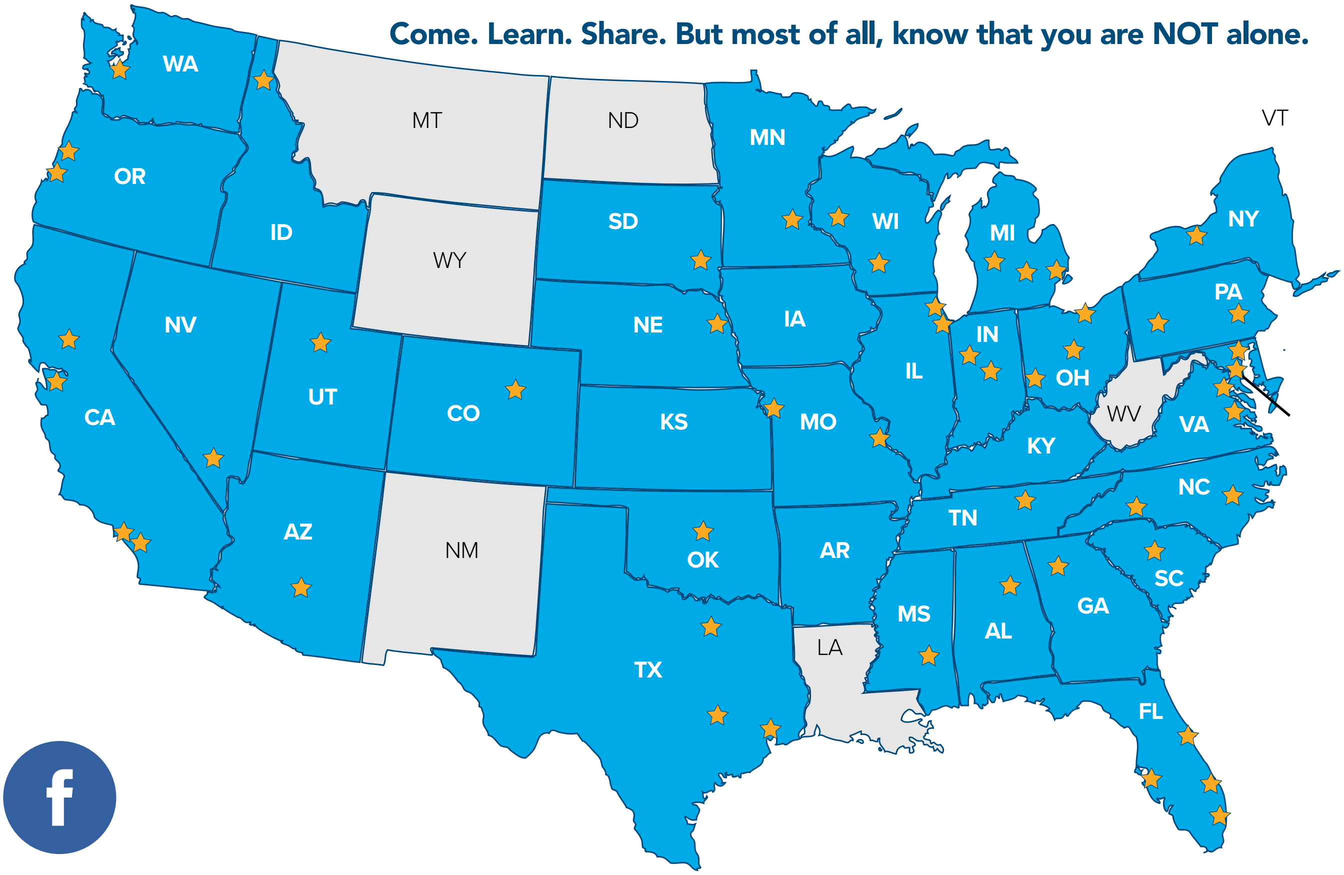
Adam Main
Adrienne Cole
Alan Tindal
Alex Atzeff
Alice Holms
Alice Surico
Alyn Platt, PhD
Amy Lynn Bac
Ann Duke Smith
Anna Face
Anna Lau
Anne Teicher
Antonio Pimentel
Arlene Hindmen
Barry Clark, Sr.
Barry Washburn
Beloved cat Jax
Beloved dog Sugar
Bert Galas
Betty and Clair Beck
Bettylou McIntosh
Bill McCorkle
Bob Schlickbernd
Bob Stackle
Bobby Crudup, Sr.
Bonnie Dunkelberg
Brad Machado
Brandon Crudup
Brenda Fortune
Brent Masserant
Brian McCall
Brian Rice
Brian Rice
Brittany Mumford
Carol Gudino
Carol Haukos
Carol Heon
Carole Brown
Catherine O'Brien Edge
Cecil Bergman
Charles C. Williams
Charles Stebbins
Cheri Morse
Cheryl Belsly
Cheryl Meyer
Christian Mitchell
Christina Lawlor
Christine Ball-Llovera
Chuck Mitchell
Cindy Rapasadi
Claire Cooper
Clarice Kaup
Clark Lawrence
Cletus Brunnert
Clinton James Stewart
Cole Rezendes
Conrad 'Boo' Ferguson
Consuela Klein
Dale Kunkle
Dale Wendorff
Dan Antonellis
Daniel Di Silvio
Daniela DiSilvio
Danuta Engel
David Alessi
David Allen Shumaker
David Marker
Debbie and Brad Blaes
Debi Adair
Denise Mitchell
Denise Nielsen
Denise Van Voorhis
Diane Even
Diane Sifert
Dick Fudali
Donald Golminas
Doug Andersen
Dwight Klotz
Earl Moore
Edward Falardeau
Edward Goodspeed
Edward Roehrick
Ellie Smith
Esther Spitz
Eva Kobayashi
Evelyn Silverman
Everett Johnson
Fola Odegbami
Fred Staat
Gary Peterson
George Arruda
Glenn Davis
Gordy Hoffmann
Grace Mutschler
Greg Smith
Gregory J. Pettit
Hank Laundy
Harold Crawford
Harold Pfeifer
Helen Anderson
Helen Mahnken
Henry Joe
Henry Ramirez
Henry, Richard, Alan and Kevin VanVeldhuizen
Hinman Family
Holly Wagner
Howard Everts
Howard Lyle
Ilana Sarfati
Irene Williams
Jacqueline A. Devito
Jafar Bloom
James Bouras
James Jeffers
James Keating, III
James Ledford
James Wheeler
Jane Moomaw
Janet Bair
Janet Snyder
Jeff Biard
Jeff Kist
Jeff Kvam
Jeffrey Baird
Jeffrey Klas
Jenette Kuhlmann
Jeremy Masserant
Jesse Hayes
Jessica Grabowski
Jessica Pedersen
Jim Horne Hankins,
Evelyn S. Hankins,
Jimmy Hankins
Jim Mellor
Joan Beard
Joann Moore
Jodi Lund
Jodi Willard Lund
Joe Thell
John Cutrell
John Harkulich
John Mauro, Sr.
John Paul Pellegrino
John Schimke
Jordan and Sydney Hubbard
Joseph Christie, Sr.
Joseph Martinho
Joseph Papa
Joseph Smith
Joseph Souza Farias
Josephine Seguin
Joyce Elaine Able
Judith Allene
Johnston Hanson
Judith Hanson
Judy Crawford Weidick
Julie Griffin Bradley
Kai Ming Chau
Kamryn Jones
Karen Brueske
Katherine Baker
Kathleen King Lowry
Kathryn D. Smithers
Katie Campbell
Katie Moliter
Kevin Fahey
Kevin Michael Fleming
Kim Marie Franzese
Kirk Asp
Krista Humes
Larsen Gregory
Laura Del Grosso
Lee Wittbrodt
Lenda Barth
Leonard Brune
Leonita Wittbrodt
Linda Ruby
Linda Ruby
Lois L. McCamy
Lorraine Fraser
Lorri Giddings
Lucille Comingani
Lynda Gillam
Mandy Morse
Margaret Tseng
Marie Matykowski
Marilou Singco Omictin
Mark Bledsoe
Mark Golomski
Mark Happell
Martha Stout
Martha Stout
Martin "Marty" Keniley
Mary Colgan
Mary Gretz
Mary Halley
Mary Jane Matykowski
Mary Romero
Maurine Nell Jones
Michael Anderson
Michael Bedell, Sr.
Michael J. Athey
Michael MacCarthy
Michael Workley
Michael Zarzecki
Mike Mitchell
Mike Williams
Morty Smilow
Murray Cooper
Nathan J. Stackle
Nathan Robinson
Nello Victor Poli
Pat Klotz
Patricia Rymut
Paul Askea
Paul Aust
Paula Jean Pulley
Pauline Castronuevo
Peggy Ann Frasier
Peggy Taylor
Penny Tressler
Peter D. Castaneda
Phyllis Rapson
Pierre Begorre
Precious Bloom
Rainey Garton
Ralph William Aiello
Raymond Beard
Raymond Roderick
Rebecca Booth
Regis Gottschalk
Richard Bruse
Richard Davis
Richard Hartmann, Jr.
Richard Worster
Rita Beggs
Rita Dean
Robert Alderman
Robert Allen
Robert Brooks
Robert Dugal
Robert Green
Robert J. Schriefer, Jr.
Robert Klassen
Rodney Rydeen
Roger Basick
Ron Stewart
Ronald Randol
Roseann Rash
Rosemary Burgess
Ruth Boyles
Sarah Myers
Sean Riley
Shantel Prasad
Sharon Baggett
Shelia Palubicki
Shirley Pat Berry
Silvana Martinho
Stephen Scott Griswold
Stevany Myrick
Steve Golomski
Suaro "Sunny" Prom
Susan Harmer
Susan Sevage
Suzanne Mondy
T. Blaine Kuss
Thelma Hale
Therese Bower
Thora Mae Lankton
Thornton Family
Timothy Lane
Tom Machi
Toni Rosen
V Ramachandran
Vandna Gupta
Verna Gilliland
Virgie Corbin Wince
Virginia Holiday
Walter Herbert Jones
Wayne Rose
William Ellis
William Lee
William Lepek
William Nixon
William Shainline, Jr.

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 Sarah Pilato of the NAF staff at sarah@ataxia.org or (763) 553-0093.



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

Join one of our Facebook Support Groups!

NAF Support Group	*facebook.com/groups/NAFmail*
Under 30 with Ataxia	*facebook.com/groups/under30withataxia*
Parents of Kids with Ataxia	*facebook.com/groups/ParentsOfKidsWithAtaxia*
African Americans with Ataxia	*facebook.com/groups/501238100417901*
Spouses and Partners of Loved Ones with Ataxia	*facebook.com/groups/AtaxiaSpousesAndPartners*
U-MATTER, Unbroken - Military Members with Ataxia	*facebook.com/groups/922015755298690*

NAF Staff Directory and Social Networks

NAF Staff Directory:

Andrew Rosen, Executive Director	(763) 231-2745 • *andrew@ataxia.org*
Kyle Billadeau, Finance Director	(763) 231-2746 • *finance@ataxia.org*
Joel Sutherland, Development Director	(763) 231-2748 • *joel@ataxia.org*
Jon Wegman, Development Associate	(763) 231-2750 • *jon@ataxia.org*
Sue Hagen, Research Services Director	(763) 231-2742 • *susan@ataxia.org*
Kelsey Trace, Research Services Manager	(763) 553-0027 • *kelsey@ataxia.org*
Beth Bowerman, Research Services Coordinator	(763)553-0085 • *beth@ataxia.org*
Mary Ann Peterson, Research Services Associate	(763) 231-2747 • *mary@ataxia.org*
Lori Shogren, Community Program and Services Director	(763) 231-2743 • *lori@ataxia.org*
Sarah Pilato, Program Coordinator	(763) 553-0093 • *sarah@ataxia.org*
Stephanie Lucas, Communications Manager	(763) 231-2744 • *stephanie@ataxia.org*
Mollie Utting, Communications Coordinator	(763) 231-2741 • *mollie@ataxia.org*

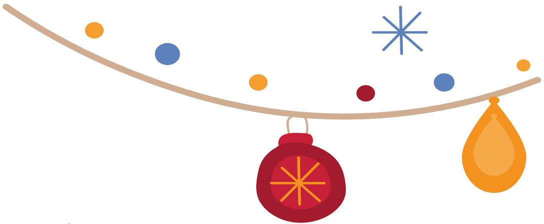
Social Networks:

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*

Join the Conversation!

More than 10,000 people have joined our Facebook group as a place to connect and learn from one another.

Join at www.facebook.com/groups/NAFmail



HAPPY HOLIDAYS!

From all of us at NAF, We wish you and your families all the best in the New Year!

National Ataxia
Foundation

PO BOX 27986
Golden Valley MN 55427
(763) 553-0020

Non-Profit
Organization
U.S. Postage
PAID
Madison, SD
Permit No. 32

A Note from NAF's Medical and Research Advisory Board Members –

Ataxia patients are at a high risk for respiratory complications, and it is therefore recommended that they receive the COVID-19 vaccination after discussion with their physician.

Generations is published by the National Ataxia Foundation, Inc., Minneapolis, MN.
Please contact us for permission to reprint or post on the Internet any article from *Generations*.

Copyright 2021 by the National Ataxia Foundation, Inc. All rights reserved.