

Letter from the Director



Dear Ataxia Community,

Our ongoing efforts to increase awareness of ataxia got a boost this Fall when the National Football League (NFL) and the NFL Players Association added ataxia to the list of symptoms that preclude a player from returning to play following a head injury. This concussion checklist sets up a series of history questions and physical examinations that must be performed to determine whether it is ok for a player to get back on the field. The addition of ataxia to the concussion checklist came after Miami Dolphins quarterback Tua Tagovailoa had an ataxic gait after a head injury but was still allowed to play. When he suffered a second head injury the next week, the concussion was even more severe and many said he should not have even been allowed to play, given that he had symptoms of ataxia

the week before. As a result of these changes, any player who demonstrates symptoms of ataxia in the future will not be allowed to play.

This addition of ataxia to the concussion protocol checklist has led to intense media coverage surrounding the symptoms of ataxia that many in this community know all too well. The in-coordination, slurred speech, vision changes, and balance and walking difficulties described by media outlets are part of the daily life for all our patients with ataxia. The change in the concussion protocol will hopefully increase protection to NFL players. It also brings up an interesting question though. Is ataxia a diagnosis and disease or a set of symptoms?

I believe that ataxia can be both. “Diagnosis” is the identification of the nature of an illness. When patients come to clinic and see their doctor, they describe the changes that are happening to them and, with the proper examination and testing, we can tell people that their symptoms are due to cerebellar ataxia. It is an answer to what is happening. However, it is not the full answer. The full answer includes an explanation as to why the ataxia is happening. So, while ataxia can indeed be a diagnosis, it is only part of the story. In this way, ataxia is a set of symptoms, all caused by an underlying illness. Sometimes the best name we have for that illness is ataxia, and sometimes we can go further and explain that the ataxia is a result of a genetic, autoimmune syndromes, exposure to a toxic substance, alcoholism, or some other cause. Our hope is that we can both determine whether someone has ataxia and then also determine its cause. While we work toward that goal, we will continue to try to improve the quality of life of those with ataxia and ultimately develop therapies that stop the disease.

Sincerely,

Liana S. Rosenthal, MD, PhD

Music Therapy Virtual Program at Johns Hopkins Ataxia Center

This fall, the Johns Hopkins Ataxia Center hired a music therapist. Our virtual music therapy program is open to patients, caregivers and family members living with ataxia. The music program will allow individuals to engage in song discussion, music listening, movement and singing to encourage stress management, emotional expression, community support and enjoyment. The virtual music group is held via zoom on Wednesdays at 1 pm (EST). The program will run in 12-week cycles. The fall program ran until November 16, and the winter cycle hopes to begin in mid-January. If you would like to participate, please email Melissa Egerton at megerto2@jhmi.edu.

Music and Mood Regulation by *Amanda Rosado, MMT, LPMT, MT-BC*

Music is often touted as an accessible, creative and innately human experience. If you take a moment to think about your own relationship with music, you may find that you naturally use it as a means to cope and connect with your emotions, as a distraction from something, or simply for the sake of enjoyment.

Researchers who focus on the neuroscience of music have found that the presence of music, especially preferred music, helps to naturally increase the body's "feel good" chemicals, such as dopamine, which in turn can naturally help manage stress and improve quality of life.

In copious music therapy research, clinicians note a person's response to music as "entertainment" — essentially, how the body and brain naturally mirrors musical experiences. Think about times when you automatically nod your head and tap your foot to an upbeat song that you enjoy, or how you maybe even feel a sense of peace while listening or singing along to a slower song. These physical responses are in part coming from the vagus nerve and autonomic nervous system, the systems most associated with breathing, heart rate, and emotion regulation. So, when you have a free moment in a time of stress, release it by listening along to a song you enjoy, while noticing the physical responses in your body (including your breathing). I personally love recommending having a small, curated playlist on hand for you to go, maybe through You Tube or a streaming device, when you feel like you most need it.



Learn More About Music Therapy:

<https://www.musictherapy.org>

How to Become More Optimistic

By Melissa Egerton, M.S., Johns Hopkins Ataxia Center Health Educator
Source: *Glass Half Full: The Power of Optimism* (www.thevoiceofwoman.com)

Optimism is a form of positive thinking. Cultivating a positive mindset may lead to a happier and longer life span and lower rates of depression. According to a recent research study, optimists were found to live 11 to 15 percent longer than less optimistic people. Although no one knows why optimism has protective benefits, one possible theory suggests that optimists have lower levels of inflammation or higher levels of good cholesterol or healthier bacteria in the gut.

Some helpful way to boost optimism include:

- Deep breathing exercises – helps to calm down anxious thoughts and focus on being calm
- Start a gratitude journal. At the end of each day, take a few minutes to write down three good things that happened that you were thankful for.
- Create a positive music playlist – music is a great way to boost mood. Songs can evoke positive memorable life events. Create your own music playlist using Spotify

- Listen to inspiring podcasts and TED Talks—they help listeners gain a fresh perspective and learn ways to improve
- * “Ten Percent Happier” Podcast with Dan Harris
[Podcast with Dan Harris — Ten Percent Happier](#)
- * “The Power of Vulnerability” by Brene Brown
[Brene Brown: The power of vulnerability | TED Talk](#)
- Use Self-Affirmation statements to help keep you motivated—affirmations are short encouraging statements to create a positive frame of mind. Each morning, select some self-affirmations to say out loud or write



In-Person Events Have Returned!

We are excited to begin to offer in-person events again for patients, care partners and family members. Moving forward, events will be a combination of in-person and virtual educational and social events. In June of this year, we offered our first in-person adaptive sailing day event at the Baltimore Inner Harbor. In September we offered an educational event and in October we had our fall picnic.

In person events are a great opportunity to come together as a community and connect with one another on a meaningful level.

Here are a few quotes from our participants about why in-person events are worth attending:

- * There are less distractions and you get to interact directly with participants and presenters—John Chung
- * We enjoy being able to talk with all our ataxia friends which is so much more personal in person—Joan and Doug Campbell
- * In person events give a nice opportunity to catch up with friends—Libby Sullivan



How Job Accommodation Network (JAN) Can Help

By Matther McCord, M.S., Senior Consultant

The Job Accommodation Network (JAN) has been providing free, expert, and confidential advice on job accommodations and disability employment issues since 1983. JAN provides individualized guidance to assist with:

- Employers and their representatives seeking advice on practical ways to engage in the interactive process, provide job accommodation solutions, and comply with Title I of the Americans with Disability Act (ADA).
- Individuals with medical conditions and disabilities seeking information and job accommodation solutions, employment rights under the ADA.
- Family members and rehabilitation, medical, educational, and other professionals in their effort to support successful employment outcomes for individuals with medical conditions and disabilities.

Some common ataxia accommodations that have been provided for people with balance difficulties to minimize falling include:

- Creating an emergency plan of action for use during an evacuation
- Installing grab bars or hand railings along walls
- Use of mobility aids like canes, walkers, or wheelchairs

Some common ataxia accommodations that have been provided for people with fine motor coordination difficulties include:

- Anti-vibration gloves and tool wraps
- Book holders and page turners
- Extra grip gloves and gripping aids
- Speech recognition software
- Touchscreens or camera-controlled computer mice

For more information about the services JAN provides contact: **ASKJAN.org**

800-526-7234

Email: JAN@ASKJAN.org

Tips for meeting with an attorney to discuss applying for disability

By Richard Newworth, Esq

When considering whether or not to apply for disability benefits, a number of factors have be considered including one's financial condition, health insurance, possible long term coverage and the psychology of not coming to work either on a part-time or full-time basis for a considerable period of time.

There are several disability benefit programs that are available to individuals suffering from various physical and mental medical conditions including Social Security disability benefits, short and long term disability benefits and disability pensions from either private or public employers.

To discuss their various choice with an attorney, many questions will be asked, some important questions will include:

- Is an application for disability benefits already been filed and if so, how long ago
- Is the disabled person already receiving disability benefits, what disability program and for how long
- Is the medical condition expected to remain the same, get worse or improve
- How long has the potentially disabled person worked and paid into the Social Security systems
- Is the person applying for disability married and if so, how long
- How long has the disabled person been out of work for; what medical conditions prevent or could prevent the disabled person from continued employment whether on a full or part-time basis
- What is the name and address of the treating health care providers; what prescription medications is the disabled person taking and for how long, side effects experienced

It is helpful to obtain and have copies of any and all work histories from the Social Security Administration, the federal government, the United States military or W-2s or 1099 from private work that have been filed with taxing authorities. Absences from work if dates have been noted as well as possible changes in employment and if and when part-time work began. Other information includes the dates of treatment with health care providers, their addresses, telephone numbers, fax and email information. Prescription medications should also be spelled out and how long such medications have been taken along with side effects. Marriage and death certificates may also be needed as well.

Telehealth Visits and Tips to Make the Most of Your Appointment

By Melissa Egerton, M.S., Johns Hopkins Ataxia Center Health Educator

For various reasons, telehealth visits have proven to be very convenient and more accessible, especially for vulnerable populations. Johns Hopkins continues to offer secure and HIPAA compliant virtual appointments via your smartphone, computer or tablet for both current and new patients. However, it is important to note that each state has different regulation policies. Patients who live in a state other than the state where your provider is located may not be able to conduct a tele-health visit. Make sure you ask your health care provider if you can be seen via telehealth before you schedule your visit [states-waiving-licensure-requirements-for-telehealth-in-response-to-covid-19.pdf \(fsmb.org\)](#) To schedule a telehealth appointment you can use MyChart (for existing patients) or schedule directly through the Department of Neurology [Neurology and Neurosurgery | Johns Hopkins Medicine](#)

To optimize your telehealth session with your healthcare provider be sure to:

- 1. Prepare ahead for your session:** Find a quiet place to talk in private, be sure to be sitting in a well-lit area that is near a window and have your camera at eye level.
- 2. Check your technology is working:** Make sure your Wi-Fi is connected, your microphone is working and you have the most recent updates installed for zoom. Make sure your devices are charged.
- 3. Make sure you have access to a phone:** Just in case you lose internet connection it's helpful to have your phone nearby to talk by telephone.
- 4. Wear comfortable clothing:** Your physician may want to observe you to make an assessment. Wear clothing that can be rolled up if need be.



Compensatory Speech Strategies

By Lindsey Kelly, M.A., CCC-SLP

Compensatory strategies are helpful to improve your intelligibility, or the ability to be understood by your communication partners. Strategy use may also increase your confidence in various speaking situations across settings. Here is an acronym that reviews four strategies targeting clear speech in people with dysarthria.



S Slow down the rate of your speech



L Increase your speech volume or **loudness**



O **Over-emphasize** your sounds with greater effort



P Take more breaks or **pauses** between words and sentences

What to do in the event of a communication breakdown?

- Eliminate any background noise that may be present
- Ensure good eye contact and repeat slowly
- Re-word phrase/sentenced as needed
- Use multimodal communication (body language, gestures, writing, drawing, etc)

Johns Hopkins Ataxia Research Studies (Current as of 10/25/2022)

IRB approved					
Condition	Study Name	Eligibility/Information	Enrollment (Current or Closed)	Principle Investigator	Contact
Ataxia	Transcranial Direct Current Stimulation (tDCS) to augment dysarthria treatment in neurodegenerative ataxias IRB00239380	10 sessions of free speech therapy; 5 sessions combined with sham. Age 18-80 years Right handed Fluent speakers of English No reimbursement, free parking, and free speech therapy	Open enrollment	Rajani Sebastian, PhD	Sarah Cust, SLP scust1@jhmi.edu 410-502-2445
Ataxia	Natural History Study of Genetic Modifiers in SCA NA_00034854	Positive genetic testing either in participant or family for SCA 1,2,3,6,7,8,10 Blood sample, neurological exam, and other tests; study visit every 12 months Ages: over 6 years old Reimbursement: \$50/session	Open enrollment	Chiadi Oniyike, MD Liana Rosenthal, MD, PhD	Vanessa Nesspor vjohns23@jhmi.edu 410-616-2815
Ataxia and MSA	Biomarkers for ataxia and Multiple System Atrophy IRB00205116	Cerebellar ataxia (of unknown etiology) with symptoms for at least 8 years or MSA diagnosis Blood draw, lumbar puncture, cognitive testing 1 visit with possible yearly follow ups \$100 for 1 st visit, \$25 for subsequent visits	Open enrollment	Liana Rosenthal, MD, PhD	Vanessa Nesspor vjohns23@jhmi.edu 410-616-2815
Ataxia	Multimodal Bio-Signal Repository for Parkinson Disease and Movement Disorder IRB00234370	Eligibility: Established diagnosis of ataxia or other movement/neurodegenerative disorder English native speaker 1 required visit, lasting ~60-75 minutes total Reimbursement: parking compensation	Open enrollment	Ankur Butala, M.D.	Seneca Motley cmotley1@jh.edu 667-776-1908

Ataxia and vestibular	Identification of relationships of abnormal eye movements and activity in individuals with balance disorders including ataxia and vestibular dysfunction IRB00246479	This study aims to understand the relationships of oscillopsia symptoms (bouncy vision and/or dizziness), eye/head coordination, balance and gait in people living with ataxia. Eligibility: Diagnosis of ataxia Ambulatory, without a device Age 18-80 English native speaker 1 session, 2-3 hours No reimbursement, parking pass and test results provided.	Open enrollment	Jennifer Millar, PT	Jennifer Millar jmillar1@jhmi.edu
Ataxia	Ataxia Clinical Research Registry IRB00191999	Anyone who is seen at the Ataxia Clinic Will serve as a recruitment database and a clinical data database No reimbursement No additional visits are required	Open enrollment	Liana Rosenthal, MD, PhD	Melissa Egerton Megeto2@jhmi.edu
Ataxia	Using Motor Imagery and Machine Learning-Based Real-Time fMRI Neurofeedback to Improve Motor Function in Cerebellar Ataxia IRB00281329 and IRB00300264 and NCT05436249	To use MRI and motor imagery to improve motor function in cerebellar ataxia Ataxia and health controls: 18-100 years old Diagnosis of SCA or cerebellar ataxia \$100 for 1 in-person visit and parking compensation	Enrollment winter 2023	Cherie Marvel, PhD	Cherie Marvel, PhD Cmarvel1@jhmi.edu

Other Research Resources

Clinicaltrials.gov *ClinicalTrials.gov* is a registry and results database of publicly and privately supported clinical studies of human participants around the world.

Connecting Organizations for Regional Disease Surveillance (CORDS) <http://www.cordsnetwork.org>
Non-Governmental Organization comprised of six international networks, working to reduce and prevent the spread of infectious disease by exchanging information between surveillance systems globally.

National Ataxia Foundation <http://www.ataxia.org/>

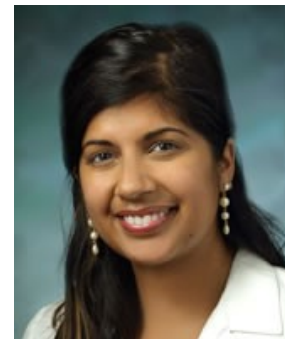
The National Ataxia Foundation is a national, public non-profit organization dedicated to improving the lives of person affected by ataxia through support, education and research.

Fredreich's Ataxia Research Alliance (FARA) <http://www.curefa.org/index.php>

The Friedreich's Ataxia Research Alliance (FARA) is a national, public, non-profit, organization dedicated to the pursuit of scientific research leading to treatments and a cure for Friedreich's Ataxia.

Physician Spotlight

Ashley Paul, M.D. is the Johns Hopkins Ataxia Center's newest neurologist. She is an Assistant Professor of Neurology and current Movement Disorder specialist at Johns Hopkins Hospital. She also serves as the co-Clerkship Director for the Neurology Clerkship through the Johns Hopkins School of Medicine. She earned her M.D. from Albany Medical College, New York. She completed her neurology residency at Wright State University in Dayton, Ohio. Dr. Paul has expertise in Parkinson's Disease, atypical parkinsonism, tremors, chorea, dystonia, ataxia, restless leg syndrome, rapid eye movement sleep behavioral disorders, periodic limb movement of sleep and deep brain stimulation.



“As a neurologist and movement disorder specialist at Johns Hopkins, I am often humbled by the patients I see and the complex neurological diseases that I have the privilege to treat. Ataxia is no exception. When I was training as a Movement Disorder Clinical and Research Fellow, I initially found ataxia to be a daunting subject. The myriad of etiologies behind a person's presentation with ataxia can be considered mind-boggling. Every day the field continues to grow, and we slowly inch forward in our understanding of the nuances, diagnosis, and treatment of ataxia syndromes”.

The Johns Hopkins Ataxia Center: How to Become a Patient in Our Clinic

Welcome to our Ataxia Center at Johns Hopkins! The first step in the process to becoming one of our patients is to have neurology records sent to us. Please include demographic information (so we know who to contact when we get the records), neurology clinic notes within the past year, reports of your most recent MRI, lab results, and genetic testing results. These notes can be faxed to 410-630-7900; Attn: Ataxia Center for review by one of our physicians. The decisions to accept a patient into our clinic is based on our neurologist's assessment of whether the patient would benefit from being seen by physicians and therapists with an expertise in neurodegenerative cerebellar ataxia. Based on review of the clinic records, patients may also be scheduled with a physical therapist, occupational therapist, speech therapist, genetic counselor and for vestibular testing, neurocognitive testing, and/or neuro-ophthalmology. Our center believes in a multidisciplinary approach to recognize and treat cerebellar ataxia. All of these appointments are geared towards diagnosing and providing treatment recommendations. Each appointment provides a thorough work up and concentrated care to our patients.

When coming to your appointment day, please make sure to have a copy of the most recent MRI on a CD, and questions to ask your physician. Before you leave the appointment please make sure you have all referrals, orders, prescriptions or refills placed for you. Right after the visit please make sure you call to get a follow up appointment right away, since we tend to book up quickly. We always look forward to assisting in your care!

- Teshome Wubishet, Ataxia Clinic Coordinator

The Many Ways That Tears Can Be Beneficial to Your Health

By Melissa Egerton, M.S., Johns Hopkins Ataxia Center Health Educator

Source: [Ashley Marcin 9 Benefits of Crying and Why It's Good and When to Get Help \(healthline.com\)](#)

Tears are a normal and healthy way to express emotion. Crying can help alleviate stress and decrease the level of cortisol in our body. It's important to allow yourself time to cry if you feel like it. According to several researchers, crying is both beneficial to your body and mind. There are 3 kinds of tears: reflex tears, continuous tears and emotional tears. Reflex tears clear debris such as smoke and dust from your eyes. Continuous tears lubricate your eyes and help prevent infection. Emotional tears flush stress hormones and other toxins out of our system.



Crying helps by allowing us to self-soothe. When we cry for long periods of time, we release feel good chemicals called endorphins and you feel a sense of calm. Crying can also help improve your mood. When we cry we take in many quick breaths of cool air and the cooler air that we breathe helps regulate and lower the temperature in your brain. A cool brain is more pleasurable to your body than a warm brain. Crying also lets others around you know you are in need of support, care and comfort. Crying can also help with processing grief.

It is important to note that excessive crying is something that should be discussed with a medical professional. If crying starts to interfere with your everyday activities it may be a sign of depression.



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M E D I C I N E

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Please consider supporting our center!

The work of the Johns Hopkins Ataxia Center would not be possible without the generous support of the *Gordon and Marilyn Macklin Foundation*, the *National Ataxia Foundation*, our patients and the community.

For more information about supporting the center, please contact Kaylin Kopcho, Senior Associate Director of Development at **443-287-7877** or **kaylin.kopcho@jhmi.edu**.

If you prefer not to receive fundraising communications from Johns Hopkins Medicine, please contact us at 1-877-600-7783 or FJHMOptOut@jhmi.edu. Please include your name and address so that we may honor and acknowledge your request.