

Letter from the Director



Dear Ataxia Community,

It has been more than two years since the COVID-19 pandemic began, leading to the loss of many of our loved ones and forcing us to adapt our daily activities. Within the Johns Hopkins Ataxia Center, we also adapted to this changing world. When the emergency order was declared in mid-March 2020, we immediately transitioned to telemedicine for all patient care. While this transition was not without its challenges, including connection problems and slow internet speeds, telemedicine allowed us to continue to care for our patients throughout the United States. We all also discovered the convenience of telemedicine and how it improves access to care for many. Moving forward, the best healthcare model is one that maximizes flexibility and

accessibility, which for most ataxia patients would include some in-person visits and some televisits over their disease course.

The pandemic also led to the adaptation of the Ataxia Center's health education program and support groups. We created online support groups via zoom, that met with greater frequency than our previous in-person events and we also had complimentary educational lectures and demonstrations. We found that these online-based support groups increased access and convenience to the groups for our patients and their care partners and allowed us to recruit a broader network of specialists, who may have otherwise not been able to attend. To keep our patients safe, and in keeping with JHU-based guidelines, we have kept our support groups and education activities virtual. We recognize that the virtual environment is not the same as in-person, though, and we are very excited to be returning to some in-person activities beginning with the return of adaptive sailing on June 11, 2022. Like in clinical care, the best model for our efforts to create an ataxia community is likely a hybrid model, some events will be in person while others remain virtual, thus maximizing participation and in-person connections.

This pandemic has consistently taught us the need to be flexible and we will continue to adapt the Ataxia Center to the changing needs of our patient population and the pandemic. We look forward to seeing you, virtually or in-person.

Sincerely,

Liana S. Rosenthal, M.D., Ph.D.

Three Ways to Use Music as a Coping Tool

Kerry Devlin, MMTL LPMT, MT-BC, Senior Music Therapist, Johns Hopkins Center for Music & Medicine

Music is a powerful medium for self-expression, regulation, and connection. Here are three different ways to use music as a meaningful coping tool at home.

1. Create Playlists that Match Your Moods

Listening to songs that speak to how we're feeling in the moment can be affirming and soothing. Spend time putting together customized music featuring your favorite songs and artists that reflect different mood states—such as a “calm down” playlist, a “get motivated” playlist or a “feeling down” playlist. It can be helpful to identify songs and artists in advance so that it's as easy as clicking play on your favorite streaming platform when you need them.



2. Focus on Your Breath While Listening to Preferred Music

Breath work can be a meaningful way to tune in to your body's needs, especially on days when you're feeling particularly anxious or having high pain levels. Turning on a song you love even just for a few minutes can be a way to center your body and mind before returning to your day. As you listen, try closing your eyes and noticing your breath. Where do you feel your breath? Is it fast or slow? Try breathing in for 4 beats and exhaling for 4 beats along with the rhythm of the song. Repeat as many times as needed.

3. Play Instruments to Move Strong Emotions Out of Your Body

It can be a cathartic experience to physically play an instrument as a means of expressing yourself – no musical experience required! Feeling angry? Beat on a drum. Need to find calm or grounding? Take deep breaths while playing an ocean drum, rain-stick, or singing bowl. If you don't have instruments at home, try closing your eyes and humming soft or singing as loud as you can along to your favorite song.

Learn More About The Center for Music and Medicine:

<https://www.hopkinsmedicine.org/center-for-music-and-medicine/>

Learn More About Music Therapy:

<https://www.musictherapy.org>

Traveling with Ataxia

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

Now that spring is finally upon us and flowers are beginning to bloom, this is the time that many people start solidifying summer travel plans. Traveling when you have ataxia can be challenging but there are some helpful resources when deciding which locations and hotels provide accessible options. Handiscover is a site to find accessible accommodations in 50 countries. You can filter your results by mobility level. Accessiblego is a one-stop shop for travelers with disabilities who are looking to book hotels, cruises, transportation and more.

Another helpful resource site when traveling with a disability is the U.S. Department of Transportation. This site contains helpful information about the Air Carrier Access Act (ACAA) which is a law that makes it illegal for airlines to discriminate against passengers due to having a disability. The law applies to all flights to, from, or within the United States. The site also provides information about training materials that have been developed by the Department of Transportation to assist passengers with disabilities to better understand their rights. While there may be many hassles, the benefits of traveling usually make it worth the extra effort!

Travel links:

Handiscover: *Handiscover: Home | Accessible accommodations, apartments and hotels for disabled worldwide*

Accessiblego: *accessibleGO.com – Accessible Travel Made Smart*

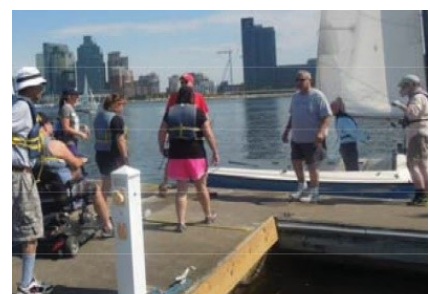
US DOT: *Traveling with a Disability | US Department of Transportation*

Ataxia Sailing Day is Back!

After 2 years of cancellation due to COVID-19, the Johns Hopkins Ataxia Center is excited to resume the Ataxia Sailing Day event, which is scheduled for **Saturday, June 11, 2022 from 10 a.m.-12 p.m.** Individuals with ataxia and their family and friends are all welcome to attend. The Downtown Sailing

Association is a non-profit organization that provides the community with affordable and accessible quality sailing programs and events. They provide education in sailing for all levels for all ages and abilities. Registration is required to attend. We hope you can join in the fun! We will be following the up-to-date CDC and JHU guidelines regarding COVID-19 precautions, which may include mandatory mask wearing. Details will be provided closer to the event.

For registration information contact
Melissa Egerton at megerto2@jhmi.edu.

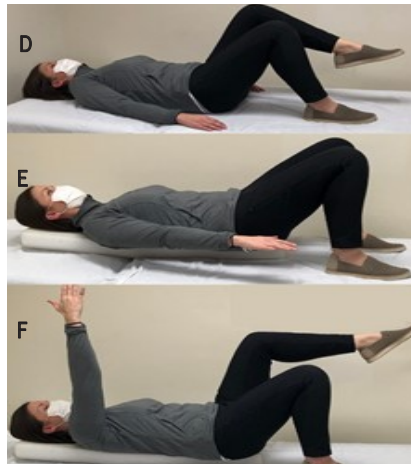
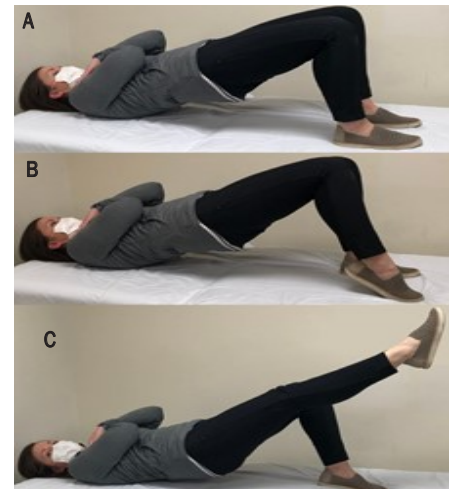


Exercises for People Living with Ataxia

By Johns Hopkins Ataxia Clinic Physical Therapists, Meredith Drake, PT, DPT, NCS and Jennifer Millar, MS, PT

Supine Exercises:

- A.** Bridges are an effective exercise for strengthening the hips and core, and may be progressed by performing with arms across chest, or with a narrow base of support.
- B.** Progression: Bridges with reduced support (alternating heel raises)
- C.** Progression: Bridges with removed support (alternating leg raises).



- D.** Marching is both a core stability and coordination exercise, with emphasis on slow, controlled, movements.
- E.** Stabilizing on half round roller without arm support, with knees apart.
- F.** Half foam roller progression: adding alternating arm and/or leg raises.

Foam roller size: 36" x 6" x 3"

Quadruped Exercises:

- G.** Maintaining a quadruped position can be a challenging core stability task in itself.
- H.** Progression: lifting one arm or leg at a time, or simultaneously lifting one arm and the opposite leg.



General Balance Training Recommendations:

Frequency/Duration: 4 times/week, 20 minutes minimum.

Intensity: Challenge matters! Yet, individuals are encouraged to modify tasks to ensure safety and success. Progressions should be gradual, with small incremental changes.

Focus on quality of movement, not speed!

Static Standing Balance Exercises: *Standing tasks should be performed in a corner of a room for safety, with a chair or walker in front for an extra point of balance; or with a second person.*



- I.** *Standing with Narrow Base of Support or Feet Together:* Arms across chest, or at side, eyes open.
Progression: closing eyes or turning head slowly.
- J.** *Semi-Tandem Stance:* (standing with feet overlapped)
Progression: gradually decreasing the amount of overlap, 1 inch at a time.
- K.** *Step Stance:* (standing with one foot on a step or stool)
Progression: standing with feet positioned slightly closer; adding intermittent eye closure, or adding slow head turns.
- L.** *Standing On a Compliant Surface:* (pillow), feet apart, arms across chest.
Progression: standing with feet closer together or feet overlapped; adding intermittent eye closure, or head turns.

Dynamic Sitting Balance Exercises: (*edge of chair*)

- M.** *Marching in Place:* Stabilize your gaze on your hand as you reach across your body to tap your opposite knee. Switch.
- N.** *Side to Side Weight Shift:* Lean your body to the side while maintaining your gaze on your hand. Hold 5 seconds. Return to center. Switch.
- O.** *Forward and Backward Weight Shift:* Lean your body back with your hands in front. Avoid touching the back of the chair. Then lean your body forward, with your hands back, head up. Repeat.
- P.** *Squats In Standing:* This should be performed under the advice of a physical therapist and/or with a second person; as well as a chair behind and/or walker in front.
- Squat with your hips back, feet apart, eyes open.
 - Hold 5-10 seconds. Repeat.



Tips for People with Ataxia and Care Partners

When Should I Definitely Call My Healthcare Provider?

Symptoms and time of onset may vary according to the type of Ataxia. Each person may experience symptoms differently. Contact your provider if you have any new onset of these symptoms:

- Balance and coordination problems
- Lack of coordination in hands, arms, or legs
- Slurring of speech
- Wide-based gait (manner of walking)
- Difficulty with writing and eating
- Slow eye movements
- The symptoms of ataxia may look like other conditions or medical problems. Always see your healthcare provider for a diagnosis.

Tips to Help You Get the Most from a Visit to Your Healthcare Provider

- Know the reason for your visit and what you want to happen.
- Before your visit, write down questions you want answered.
- Bring someone with you to help you ask questions and remember what your provider tells you.
- At the visit, write down the name of a new diagnosis, and any new medicines, treatments, or tests.

Also write down any new instructions your provider gives you.

- Know why a new medicine or treatment is prescribed, and how it will help you. Also know what the side effects are.
- Ask if your condition can be treated in other ways.
- Know why a test or procedure is recommended and what the results could mean.
- Know what to expect if you do not take the medicine or have the test or procedure.
- If you have a follow-up appointment, write down the date, time, and purpose for that visit.
- Know how you can contact your provider if you have questions.

The RAIN Mindfulness Technique

Ed Geraty, LCSW, INSITEintegrative.com

Mindfulness is a meditation technique in which a person focuses on being keenly aware of what they are sensing and feeling in the present moment and accepting their thoughts and emotions without judgment. Meditation can be helpful by relieving the body and mind of stress, leading to decreased anxiety, pain, insomnia and depression.

A meditation exercise called **RAIN** (an acronym for the four steps of the process), is a four-step mindfulness process that helps you recognize your emotions so you can respond instead of react to challenging situations. It can be accessed in almost any place or situation. It directs our attention

in a clear, systematic way that cuts through confusion and stress. The steps give us somewhere to turn in a painful moment by allowing us to realize we can't control our experiences, but we can transform our relationship to them.



R Recognize The first step is to get in the habit of putting words to your thoughts and feelings as they are occurring. For example: “I am feeling overwhelmed”. Recognition is seeing what is true in your inner life. It starts the minute you focus your attention on whatever thoughts, emotions, feelings or sensations are arising right here and now.

A Allow life to be just as it is. Allowing means “letting be” the thoughts, emotions, feelings or sensations you discover. You may feel a natural sense of aversion, of wishing that unpleasant feelings would go away. As you become more willing to be present with “what is,” a different quality of attention will emerge. Allowing is intrinsic to healing, and realizing this can give rise to a conscious intention to “let be.”

I Investigate inner experience with compassion. Investigation means calling on your natural interest—the desire to know truth—and directing a more focused attention to your present experience. Simply pausing to ask, “What is happening inside me?” might initiate recognition, but with investigation you engage in a more active and pointed kind of inquiry. Ask: “Why do I feel this way?” and “What may be influencing how I feel?”

N Non-Identification The lucid, open and kind presence evoked in the R, A and I of RAIN leads to the N: the freedom of Non-identification, and the realization of Natural awareness or natural presence. Non-identification means that you don't define your thoughts and feelings to your self-worth and identity.

RAIN helps people process their difficult emotions and can be practiced anytime you are feeling stressed or overwhelmed and fosters self-compassion.

Assistive Technology Resources

Denise Schuler, MS, Director of Reuse at MATR Maryland Assistive Technology Reuse Program

The definition of assistive technology is any item, device, or piece of equipment used to maintain or improve the functionality of people with disabilities, allowing them to be more independent in education, employment, and community living activities.

There are many items which can fall into the category of assistive technology and can assist someone living with ataxia. Walkers, rollators and well-placed grab bars can help with mobility. A video magnifier, with or without OCR, can help with vision issues. (OCR is optical character recognition, which can turn text into speech – basically read out a page of text.) Voice amplifiers that can be worn around the waist can amplify one's voice loudly enough to be more easily heard. AAC (Augmentative alternative communication) are devices that can speak for the individual who cannot speak clearly. Weighted utensils, or utensils with built-in gyroscopes can aid in feeding oneself. Many spill-proof cups are also on the market. Dressing aids such as a sock donner and zipper pull can help an individual dress more independently. There is a variety of alternative mice and keyboards available to access the computer. Environmental controls to make your house into a "smart home" are becoming mainstream.



www.autismadventures.com



www.accessibletelecoms.org.au

In order for an individual to make an informed decision on which device is appropriate for them, they should contact someone with training and knowledge about the items. For mobility, a Physical Therapist or mobility specialist would be best. An Assistive Technology Specialist can help with the other devices. If speech is an issue, a Speech Language Pathologist can also help.

The cost of assistive technology can run from a few dollars into over \$10,000. Some states have an Assistive Technology Financial Loan Program. These programs can loan money to individuals and their family members at a low interest rate to purchase any type of Assistive Technology. Centers for

Independent Living (CIL) may also have small grants. Durable medical devices such as walkers and wheelchairs can be purchased through insurance. Medicare, Medicaid and private insurance may also fund a communication device. Insurance calls them SGD's (speech generating devices) and requires an assessment from a certified Speech Language Pathologist. Your local Department of Seniors and Disability may have grants and waivers to help with the cost of assistive technology.

Each state has an Assistive Technology (AT) Program where the AT can be seen and demonstrated. You can find your program by searching on <https://www.at3center.net/stateprogram>. Individuals can see demonstrations of various devices, then borrow them to see if the items fit their needs. The loans are typically around 30 days. The professionals there can also point you in the direction of funding sources. Your state AT Program is a great place to start on your assistive technology journey.

Johns Hopkins Ataxia Research Studies (Current as of 1/13/2022)

Condition	Title	Enrollment	Eligibility and Other Study Details	Principal Investigator	Contact
Ataxia	Transcranial Direct Current Stimulation (tDCS) to augment dysarthria treatment in neurodegenerative ataxias IRB00239380	Open enrollment	<ul style="list-style-type: none"> 10 sessions of free speech therapy; 5 sessions combined with sham. Age 18-80 years Right handed Fluent speakers of English Free parking, and free speech therapy 	Rajani Sebastian, PhD	Sarah Cust, SLP scust1@jhmi.edu 410-502-2445
Ataxia	Natural History Study of Genetic Modifiers in SCA NA_00034854	Open enrollment	<ul style="list-style-type: none"> 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 Over 6 years old \$50/session 	Chiadi Oniyike, MD Liana Rosenthal, MD, PhD	Ann Fishman: Ann.fishman@jhu.edu 410-502-5816
Ataxia and MSA	Biomarkers for ataxia and Multiple System Atrophy IRB00205116	Open enrollment	<ul style="list-style-type: none"> 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 1st visit, \$25 for subsequent visits 	Liana Rosenthal, MD, PhD	Michelle Joyce Mjoyce14@jhmi.edu
Ataxia	Ataxia Clinical Research Registry IRB00191999	Open enrollment	<ul style="list-style-type: none"> Anyone who is seen at the Ataxia Clinic Will serve as a recruitment database and a clinical data database No additional visits are required 	Liana Rosenthal, MD, PhD	Michelle Joyce Mjoyce14@jhmi.edu
Ataxia	Using Motor Imagery and Machine Learning-Based Real-Time fMRI Neurofeedback to Improve Motor Function in Cerebellar Ataxia IRB00281329	Estimated to begin enrollment Fall 2022	<ul style="list-style-type: none"> To use MRI and motor imagery to improve motor function in cerebellar ataxia 18-100 years old Diagnosis of SCA or cerebellar ataxia \$100 for 1 visit and parking compensation 	Cherie Marvel, PhD	Michelle Joyce Mjoyce14@jhmi.edu

Condition	Title	Enrollment	Eligibility	Principal Investigator	Contact
Ataxia	Multimodal Bio-Signal Repository for Parkinson Disease and Movement Disorder IRB00234370	Open enrollment	<ul style="list-style-type: none"> Established diagnosis of ataxia or other movement/ neurodegenerative disorder English native speaker 1 required visit, lasting ~60-75 minutes total Parking compensation 	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	Open enrollment	<ul style="list-style-type: none"> Diagnosis of ataxia Ambulatory, without a device Age 18-80 years old English native speaker 1 session, 2-3 hours Parking pass and test results provided. 	Jennifer Millar	Jennifer Millar jmillar1@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.

Meet the Ataxia Center New Staff Members



Melissa Egerton, M.S., is the new full-time health educator for the Johns Hopkins Ataxia Center. She joined the center late fall 2021. She previously worked at Goucher College as the Assistant Director for Transfer Admissions. Prior to working in higher education, she spent several years working for non-profit organizations providing advocacy and case management services to people with various neurological and developmental disabilities. Melissa is excited to support ataxia patients, their families and care partners by providing education, information, and resources that promote and improve overall health and well-being. Melissa obtained her Masters of Science degree in health science with a focus in community health from Towson University. Outside of work, she enjoys hiking, traveling, spending time with her son, (who will be attending college in the fall), family, friends and her rescue dog Chihuahua Miniature Pinscher mix, Bruiser.



Michelle Joyce, B.S., is the Ataxia Center's research coordinator. She joined the team in fall 2020. She assists with several ataxia-related projects under the direction of Dr. Rosenthal and Dr. Marvel. Previously, she served in the United States Marine Corps as a Pashto Cryptologic Linguist. She was deployed to Afghanistan to work as a translator. Michelle obtained her Bachelor of Science degree in neuroscience from American University and also is a certified nursing assistant. She will be applying to medical school soon and is looking forward to learning more about movement disorders and incorporating what she learned into her future practice. Outside of work she enjoys hiking and spending time with her family and friends.



Teshome Wubishet, A.A.S., is the Ataxia Center's Clinic Coordinator. He joined the team May 2021. He coordinates and schedules patient appointments. He also assists with patient's needs in between clinic visits including facilitating prescription refill requests and relaying messages from patients for the physicians and allied health professionals. Teshome received his A.A.S. in biotechnology from Baltimore City Community College. He previously worked as a research program assistant for clinical trials. He enjoys assisting patients with their scheduling needs. In his free time he enjoys spending time with his family and trying new food.

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 and sign up for Mychart. Please use the following link: <https://mychart.hopkinsmedicine.org/MyChart/signup>. Please include demographic information (so we know who to contact when we get the records), neurology clinic notes, reports of your most recent MRI, lab results, and any genetic testing results. These notes can be faxed to (410) 367-3318; Attn: Ataxia Center for review by one of our neurologists. 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, occupation therapist, speech therapist, genetic counselor and for vestibular testing, neurocognitive testing, and/or neuro-ophthalmology. Our center believes in a multi-disciplinary 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! If you have any questions please call (410) 616-2816 Option 2.

- Teshome Wubishet, Ataxia Clinic Coordinator



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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.