

Movement Disorders Digest

Director's Corner



Research: Back in Full Swing

In March of 2020, the Johns Hopkins Institute for Clinical and Translational Research, along with the Institutional Review Board halted most clinical research that involved humans at our Center in light of the worsening COVID19 pandemic. By September-October of 2020, many research protocols were allowed to proceed with modified study procedures to minimize the amount of time participants spent in the hospital or clinics. This made it very difficult for our center—and others across the nation—to pursue our mission of conducting important research to better understand the cause of Parkinson's disease and movement disorders as well as to test new therapies aimed at improving

Kelly Mills, MD, MHS symptoms or slowing disease progression. After vaccines became widely available in the spring of 2021, we started to see more participation in clinical trials and research studies, but I want to write you today to let the movement disorders community know that our research programs are back in full swing and we need your help as research study participants!

We currently have open clinical trials attempting to slow progression in Parkinson's disease, biomarker studies to identify new brain imaging and blood markers of disease progression in Parkinson's disease and atypical parkinsonism, and clinical trials aimed at alleviating the symptoms of Parkinson's disease. Many research studies require comparing people with Parkinson's disease, ataxia, or atypical parkinsonism to people who do not have any of these neurologic disorders, so-called "controls". If you are a spouse, adult family member, friend, or advocate of someone with Parkinson's and want to participate in research that could better the lives of people with this condition, we could use your help too!

We greatly value patient and research participant safety, and have implemented safety protocols to make it safe. All of our staff are required to be vaccinated across the entire hospital system, and we still have a masking mandate to keep patients and study participants as safe as possible. With these measures, we are back in full-swing with our research programs!

For more information about research studies and to see if you or someone you know could participate, please call 410-955-6672 or email PDMDcenter@jhmi.edu.

What is Your Why?



Nigel Harrison, MD
Clinical & Research Fellow

To begin, the pursuit of medicine has not always been my calling. When I was four I wanted to be a kangaroo. By six I realized a kangaroo was an inappropriate career choice for the current economic climate and moved on to much less lofty achievements such as the first man on Mars, the creator of a real life Jurassic Park, or maybe the Prime Minister of Canada (if I under-achieved). In the end

some people may say I settled but my mother is still quite proud that I became a doctor.

My fascination in Neurology began slowly. Like that itch you can't scratch, it crept up on me, needling, cajoling, my brain telling me 'Hey learn more about me!' I of course succumbed as I found I could not resist the compelling complexity and mystery of the

brain. However, as I learned more and more I kept finding myself drawn to the control of movement. It was therefore a natural fit to pursue a job in treating the very disorders where movement is impaired. What continues to drive my interest however is the patient interactions I get to have everyday. Working together with my patients to develop a plan to improve their day to day always brings a smile to my face.

Thus far my time in the hallowed halls of Johns Hopkins has been an extraordinary learning experience. I just hope you as patients and family learn half as much from me as I do from you. I look forward to working with you all soon.



JOHNS HOPKINS
MEDICINE

Music & Medicine *by Sarah Phelan*

This fall, the Johns Hopkins Center for Music & Medicine welcomed a new Senior Music Therapist to the team. Kerry Devlin, MMT, MT-BC. The Center for Music and Medicine is a network of initiatives taking place across The Johns Hopkins University and Johns Hopkins Medicine which bring together clinicians, researchers and musicians to explore the complex relationship between music and health and the possibilities for healing through music. Kerry is a board certified music therapist, and brings more than seven years of experience and extensive education to her new position.

As a disabled clinician, Kerry understands the unique experience of moving through the health care system as both a patient and a provider. She is passionate about disability justice and affirming the lived experience of therapy participants through co-constructed music experiences. Her research has been published in Music Therapy Perspectives and Current Neurology and Neuroscience Reports, and she has created sought-after professional development courses centered on

anti-oppressive early childhood music approaches and telehealth tools for music therapists. Kerry also holds a certification in neurologic music therapy.

Music therapy can take several different forms to be of benefit to both physical and mental health. Practice moving to music has been shown to

improve both pace and smoothness of gait. Many find the experience of crafting their experiences with illness into lyrics to be set to music. Playing an instrument, some show dexterity they often struggle with in daily life.

To learn more about becoming involved in music therapy, contact musicandmedicine@jhmi.edu.



Kerry Devlin, MMT, MT-BC
Senior Music Therapist

Community



Pacing for Parkinson's (P4P) is a large charity team that in typical years participates in the annual Baltimore Running Festival. It is a volunteer-led campaign that raises awareness of and funds for Parkinson's disease (PD) research, community outreach, education, and patient care at the Johns Hopkins Parkinson's Disease and Movement Disorders Center and Johns Hopkins Medicine.

In 2021, P4P held our second-ever virtual Pacing for Parkinson's Week, which emphasized the benefits of different types of movement through [demonstration videos](#) and shared the stories of the Parkinson's community through our [Parkinson's Warriors Vignettes](#). We had 122 members of the 2021 P4P team, raised more than \$56k for the Center and Johns Hopkins Medicine, moved for more than 449 hours, and traversed 2,000 miles in one week. Wow!

Want to join the fun? Pacing for Parkinson's welcomes involvement at all levels from anyone interested - P4P volunteers are folks with Parkinson's, care partners, or friends; they are local to Maryland or live elsewhere in the country; they are able-bodied or disabled; they have a lot of time to give, or just a little. Join P4P 2022 with our kickoff event coming in the spring and registration opening in April, or if you're interested in getting more involved, consider joining the committee. Want to know more? Visit www.pacing4parkinsons.org or email pacing4parkinsons@gmail.com to get in touch.

What Does P4P fund?

Each year the funds raised by dedicated volunteers and sponsors of Pacing for Parkinson's help to support many of the programs provided for the region's Parkinson's community.

The proceeds from the 2020 race have been awarded to groups in the area for classes to come in 2022. The Johns Hopkins Parkinson's Disease and Movement Disorders Center is proud to offer support in the coming year to Dance for Parkinson's Disease, Adapted Tai Chi for People with Ataxia, Forest Hill Health and Fitness Rock Steady Boxing, and Maryland Association for Parkinson's Support Aquatics for Parkinson's. These varied options offer great ways to get the exercise that is so vital to patients with movement disorders with no cost for participation!

For more details on the programs mentioned here and many others, see the listing of events and classes on pages 8 and 9 or contact the center's Health Educator, Sarah Phelan at sphelan2@jhmi.edu



PARKINSON'S PROGRAM CALENDAR

Harford County PD Support Group

1st Thursday @ 2:00 pm

Contact: Sarah Phelan; sphelan2@jhmi.edu

Mid-Shore PD Support Group

2nd Tuesday @ 11:00 am

Contact: Jack Harrald; jharrald@gmail.com

Baltimore County PD Support Group

2nd Thursday @ 1:30 pm

Contact: Sarah Phelan; sphelan2@jhmi.edu

Newly Diagnosed PD Support Group

2nd Thursday @ 5:00 pm

Contact: Sarah Phelan; sphelan2@jhmi.edu

Atypical Parkinsonism Group

4th Thursday @ 2:00 pm

Contact: Sarah Phelan; sphelan2@jhmi.edu

Lewy Body Dementia Support Group

1st Monday @ 1:00 pm

Contact: Melissa Daily; melissadaily610@gmail.com

Harford County Caregivers Group

4th Thursday @ 11:00 am

Contact: Emily Carman; ecarman1@jhmi.edu

Hagerstown PD Support Group

1st Thursday @ 11:00 am

Contact: Judy Fiery; jpfieri@verizon.net

Allegany, Garrett, and Mineral Counties and Surrounding Area PD Support Group

Contact: Sarah Phelan; sphelan2@jhmi.edu

MAPS Care Partner Support Group

Via Zoom

Contact: Jdobbs02@comcast.net

Parkinson Foundation of the National Capital Area

PFNCA provides about 30 wellness classes live online each week focusing on exercise and voice strengthening (Associated with nominal fee that can be waived if necessary)

parkinsonfoundation.org/programs

JHPDMDC Quarterly Educational Series

Dec 9th @ 6:00 pm

Physical Therapy for PD Motor Symptoms with Mirasol Jacobs, PT, DPT

Contact: Sarah Phelan; sphelan2@jhmi.edu

JHPDMDC Quarterly Educational Series

Dec 9th @ 6:00 pm

Physical Therapy for PD Motor Symptoms with Mirasol Jacobs, PT, DPT

Zoom ID: 941 5559 5164

Contact: Sarah Phelan; sphelan2@jhmi.edu

Parkinson's Foundation Virtual Classes

Mindfulness Mondays

Wellness Wednesdays

Fitness Fridays

[www.parkinson.org/Living-with-](http://www.parkinson.org/Living-with-Parkinsons/Resources-and-Support/PD-Health-at-Home)

[Parkinsons/Resources-and-Support/PD-Health-at-Home](http://www.parkinson.org/Living-with-Parkinsons/Resources-and-Support/PD-Health-at-Home)

Parkinson's Foundation Care Partner Program

<https://www.parkinson.org/Summit>

Series of free Online Courses for Family Care Partners

-Welcome Course

-Staying Healthy as a Care Partner

-Ambiguous Loss

-What is Caregiver Burnout?

-Mood for the Person with PD

-Cognitive Changes on a Continuum

-The Role of Sleep

-Recognizing Early Cognitive Changes

-Nutrition for Care Partners

PARKINSON'S PROGRAM CALENDAR (continued)

Conversations With A Doc

Quarterly, no-cost speaker series sponsored by MAPS (the Maryland Association for Parkinson's Support)

December: Sleep & Parkinson's

Register at www.marylandparkinsonsupport.org

Newly Diagnosed PD Educational Series

Each week in March 2022. Learn about PD basics, treatments, care teams, community resources, and more.

Contact: Sarah Phelan; sphelan2@jhmi.edu

Advanced Therapies Seminar

For patients considering surgical options for PD

Dec 7th @ 6:00 pm

Contact: Sarah Phelan; sphelan2@jhmi.edu

Dance for PD

Contact: Ellen Talles; ellentalles@comcast.net

Adapted Tai Chi for People with Ataxia

Zoom classes

Contact: Jennifer Keller at Kennedy Krieger

443-923-2716

Parkinson's Pride: Engaging the LGBTQ+ Community

Parkinson's Pride offers an innovative series of free virtual monthly meetings where you can connect with others who are part of both the LGBTQ+ and Parkinson's communities, learn about valuable resources, and share your experiences.

Care Partner Education

In April 2022 learn about caring for patients with Parkinson's disease, gather resources and contacts, and more

Contact: Sarah Phelan; sphelan2@jhmi.edu

Rock Steady Boxing

Find classes scheduled near you at rocksteadyboxing.org

Easton Family YMCA 410-822-1515

eastonfamily@rsbaffiliate.com

Hagerstown YMCA 301-739-3990 ext 4237

ymcahagerstown@rsbaffiliate.com

Forest Hill 410-893-4153

foresthill@rsbaffiliate.com

MAPS at Charm City 443-873-0040

charmcity@rsbaffiliate.com

MAPS at Myerburg 443-963-1450

myerburgcenter@rsbaffiliate.com

Orokawa Y in Towson 410-823-8870

orokawa@rsbaffiliate.com

Residences at Vantage Point 410-964-5454 ext 2015

vantagepoint@rsbaffiliate.com

YMCA of Frederick County 301-663-5131 ext 1244

frederick@rsbaffiliate.com

Aquatics for Parkinson's

Aquatic therapy sponsored by MAPS

Contact: info@marylandparkinsonsupport.org

Shake, Rattle, and Roll with Charlotte

Dance class for all abilities

Thursdays at 1:00 pm

Trinity Life Church Lutherville

Contact: cbsstpierre@yahoo.com

Parkinsonics

Choir for patients with Parkinson's

Wednesdays 1:30-3:30 on Zoom

Theater project

Tuesdays 1:00-2:30

Contact: ellentalles@comcast.net

Many classes/events have schedules and locations TBD as programs return to in person meetings. For more information on these or any other classes or resources, please contact JHPDMD Health Educator Sarah Phelan at sphelan2@jhmi.edu

WELLNESS




Daily Exercises to Get You Through the Winter Months

by La'Tai Jenkins, PT, MBA, DPT and Brittany Colebank, OT

It is never too early after receiving the diagnosis of Parkinson’s Disease to use principles of movement, flexibility, posture and balance in your daily routine! It is actually important to incorporate exercises into the activities that you already love, and to maintain the connections and shared interests with your friends and family. Making your breakfast or baking with your grandchildren can be an opportunity to sneak in a few key functional movements. The Parkinson’s brain is working to slow everything down, so it is important to make big movements with bursts of energy to combat those efforts. Here are some great exercises that progress from beginner to advanced and will help you beat the cold winter blues! Mix and match! Your body and brain love to be surprised and you will work a variety of vital muscle groups. The key is consistency, aim to do some sort of movement every single day.



Morning Mobility Prep

It sometimes may be difficult to “Rise and Shine” if you have stiffness. A lot of people living with Parkinson’s Disease report increased rigidity of their muscles in the morning which makes rolling, standing and walking more challenging. Here are 3 easy exercises to get your muscles and moving and trigger the brain to prepare for the day:

Bridges	Cross Crawl	Sit to stands
		
<p>Squeeze buttocks and draw belly button in. Lift hips off of the bed. Hold for 5 seconds while keeping the muscles squeezed. Repeat 5 times</p>	<p>Draw belly button in and make sure your lower back is flat. Tap opposite hand to opposite knee. Rotate your neck to follow the hand that is tapping with your eyes. Repeat 10 times</p>	<p>Sit on edge of bed with your feet flat. Keeping the back straight hinge forward. Squeeze buttocks and push through your heels to stand fully with stable balance. Push hips back to sit back down. Repeat 10 times</p>

Posture Program









It can sometimes be characteristic of Parkinson’s progression to experience increased forward head, rounding of the shoulders, and slumping over at the back. Many people living with Parkinson’s Disease develop low back pain which is caused by poor posture and their walking pattern. Here are 3 exercises you can do while sitting or standing to strengthen your trunk muscles:

Chin Tucks	Scapular Retraction
	
<p>With tall sitting posture use your neck and trunk muscles to pull your ears back towards your shoulders, just until you are in alignment. Hold for 5 seconds, relax. Repeat 10 times</p>	<p>With tall sitting posture keep your elbows tucked into your sides, palms up. Move your palms away from your body by pinching your shoulder blades together. Hold for 5 seconds, relax. Repeat 10 times</p>

It's all Fun and Games! Keep yourself Warm with this Indoor Winter-Themed Routine


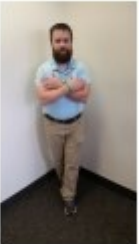

Studies have shown that performing movement patterns to a timed beat can help improve motor function. Try pairing this routine with some enjoyable music to help with your arm and hand function.

Perform each movement 8 times each direction until you have completed the routine

<p>Make a Snow Angel jumping jacks</p>	<p>Pull Icicles from the Roof rotate body and neck</p>	<p>Pack a Snowball alternate hand clasp</p>	<p>Chop the Wood diagonals across torso</p>
			
<p>Get snow off of boots both arms out wide then clap to the side</p>	<p>Pull cookies from the oven Lean forward, pull back</p>	<p>Pour some cocoa turn thumb down</p>	<p>Warm your fingers every finger to thumb</p>
			

Go Stand in the Corner.....to work on Balance!

Standing in the corner is an excellent place to work on balance. If needed, you will have a wall on either side of you to make sure you do not fall. Daily practice with focus on activating your core muscles will help strengthen your standing balance.

<p>Feet Touching</p>	<p>Tandem Stance</p>	<p>Rock and Reach</p>
		
<p>Keeping your eyes open, bring your feet together so they are touching and fold your arms across your chest. Focus on keeping your abdominals pulled in and your buttock muscles squeezed. Work up to holding this position for up to 1min!</p>	<p>Keeping your eyes open, bring one foot in front of the other like you are standing on a tight rope. Fold your arms across your chest. Focus on keeping your abdominals pulled in and your buttock muscles squeezed. Work up to holding this position for up to 1min!</p>	<p>Take a big step forward with one foot, shift weight forward and back while swing your arms all the way up to your ears, and all the way behind your hips. When you shift your weight back the front toes should come up off the ground. Repeat 10 times on each side</p>

RESEARCH STUDIES

Your participation will allow you to have firsthand experience with developing new medical treatments that may be beneficial to others. Current treatment methods for neurologic disorders are only available because of volunteer participants in clinical trials. Clinical trial information is excerpted from www.clinicaltrials.gov.

1. A Clinical Study of NLY01 in Patients With Early Parkinson's Disease (NCT04154072)

Objective: Phase 2 study designed to assess the safety, tolerability and efficacy of **NLY01** in subjects with early untreated Parkinson's disease

Eligibility: Individuals 30 to 80 years old, with early-stage Parkinson's Disease, not on any current treatments

P.I.: Emile Moukheiber, M.D.

Contact: Kori Ribb; 410-614-2216

2. Longitudinal Biomarkers of Individuals with Atypical Parkinsonism (IRB00062534)

Eligibility: Individuals w/ dx of MSA, PSP, CBS or DLB; able to complete annual follow-up visits for 5+ years

P.I.: Alex Pantelyat, M.D.

Contact: Vanessa Johnson; 410-616-2815

3. Udall Center Brain Donation Program (NA_00032761)

Objective: Examine the pathological changes in the brain tissue of individuals diagnosed with PD or related disorders as compared to controls

Eligibility: Individuals diagnosed with PD or atypical PD and those without a neurological diagnosis

P.I.: Liana Rosenthal, M.D.

Contact: Catherine Bakker; 410-616-2814

11. 4RTNI-2 (NA_00130505)

Objective and Eligibility: The goal of this study is to identify the most reliable methods of analysis for tracking CBD, PSP, and o/vPSP over time. Select individuals with CBD, PSP or variant PSP; healthy controls, caregiver component

P.I.: Alex Pantelyat, M.D.

Contact: Diane Lanham; 443-287-4156

4. Biomarker Discovery and Validation in Progressive Supranuclear Palsy (DIVA-PSP) (IRB00173663)

Eligibility: Individuals with a diagnosis of PD or PSP, healthy controls; (caregiver/study partner also required for participation)

P.I.: Alex Pantelyat, M.D.

Contact: AJ Hall; 410-616-2813

5. Multimodal MRI in PSP (IRB00062534)

Eligibility: Individuals diagnosed w/ PSP (PSP-RS, PSP-SL, PSPCBS) or PPA; willingness/ability to complete MRI and lumbar puncture

P.I.: Alex Pantelyat, M.D.

Contact: Diane Lanham; 443-287-4156

6. Dystonia Coalition (NA_00074297)

Objective: Create an international repository to learn more about dystonia, treatment methods and patient response

Eligibility: Individuals over the age of 18 who have primary dystonia

P.I.: Alex Pantelyat, M.D.

Contact: Sydney Baybayan; 410-955-6692

7. PET Study for individuals with REM Sleep Behavioral Disorder, PD and Healthy Controls (IRB00237032)

Objective: A PET scan study to determine if there is inflammation in the brain of people with early Parkinson's.

Eligibility: Age 50-80 and healthy controls.

P.I.: Kelly Mills, M.D.

Contact: Emily Carman; 410-955-8909

8. The Parkinson's Progression Markers Initiative (PPMI) 2.0 (NCT04477785)

The overall goal of PPMI 2.0 is to identify markers of disease progression for use in clinical trials of therapies to reduce progression of PD disability. Including healthy controls

P.I.: Emile Moukheiber, M.D.

Contact: Sydney Babayan; 410-955-6692

RESEARCH STUDIES (continued)

9. Feasibility and Preliminary Effects of Using a Music-based, Rhythm-modulating Wearable Sensor System in the Community in Persons with Parkinson's Disease (MedRhythms Study)

The purpose of this clinical study is to evaluate the effects of music, tailored to the participant's cadence, on adherence, quality of life, gait speed, functional mobility, and walking activity in individuals with Parkinson disease when used in the home and community environment.

P.I.: Alex Pantelyat, M.D.

Contact: Colin McGregor; 410-616-2816

10. Molecular Imaging of Depression in Aging and Parkinson's Disease (Controls and Patients with Parkinson's Disease and Depression) (IRB00068329)

Are you over 60 and feeling depressed? Symptoms of depression in older adults are common yet often go undetected. Symptoms could include feelings of sadness or hopelessness, loss of energy, inability to enjoy pleasurable activities, changes in appetite or sleeping patterns, or poor concentration/memory. If you are feeling depressed, not taking antidepressant medication and in good physical health you may be eligible to participate in a research study involving treatment. Qualified people will participate at no cost to them and will be compensated for their time and transportation

P.I.: Gwenn Smith, PhD Contact: 410-550-4192

11. A Clinical Trial Investigating the Efficacy, Safety and Tolerability of Continuous Subcutaneous ND0612 Infusion in Comparison to Oral IR-LD/CD in Subjects With Parkinson's Disease Experiencing Motor Fluctuations (BouNDless)(NCT04006210)

A double-blind study of subcutaneous levodopa infusion to evaluate efficacy as compared to oral levodopa management in moderate to advanced PD.

P.I.: Ankur Butala, M.D.

Contact: Emily Carman; 410-955-8909

12. Biomarkers for Ataxia and Multiple System Atrophy (IRB00205116)

A major impediment to developing new treatments for neurological diseases is the absence of biological markers for early diagnosis and treatment response. Currently the diagnosis of ataxia and MSA is based on the presence of clinical signs and, in some cases, genetic testing. The research seeks to identify biomarkers for ataxia and MSA in an effort to improve diagnosis and therapeutics for these diseases.

P.I.: Liana Rosenthal, M.D.

Contact: Michelle Joyce; mjoyce14@jhmi.edu

13. Visual Hallucinations and Memory Impairment in Parkinson's Disease: the Role of Hippocampal Networks (IRB00242772)

The goal of this project is to assess the role of hippocampal networks in memory impairment and hallucinations in PD and determine whether hippocampal network dysfunction predicts greater cognitive and functional decline longitudinally.

P.I.: Arnold Bakker, PhD, MA and Gregory Pontone, M.D.

Contact: 410-502-4797 or memory@jhmi.edu



CENTER OF EXCELLENCE

Since 2006, The Johns Hopkins' Parkinson's Disease and Movement Disorders Center has been named a Center of Excellence by the Parkinson's Foundation. The Parkinson's Foundation peer-review committee chooses Centers of Excellence based on an individual center's demonstrated excellence, resources and dedication to Parkinson research, clinical care and outreach.

The Johns Hopkins Parkinson's Disease and Movement Disorders Center

The Johns Hopkins Parkinson's Disease and Movement Disorders Center is dedicated to the tripartite mission of education, research, and excellent care of those living with movement disorders.

Johns Hopkins Outpatient Center
601 North Caroline Street, Suite 5064
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410-955-8795
www.hopkinsmedicine.org/neuro/movement

Please consider supporting our center! The work of the Johns Hopkins Parkinson's Disease and Movement Disorders Center would not be possible without the generous support from our patients and the community. For more information about supporting the center, please contact the Development Office at **443-287-7877**.

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