Movement Disorders Digest



News from the Johns Hopkins Parkinson's Disease and Movement Disorders Center

Spring/Summer 2022

Director's Corner



Kelly Mills, MD, MHS

"What can I do to help?"

Opportunities for Those Without Parkinson's Disease

Many people with Parkinson's disease will encounter family members, friends, and even neighbors asking "What can I do to help?" It turns out that there is a lot they can actually do to help the Parkinson's disease community through their involvement in research. While it can sometimes be challenging to recruit people with Parkinson's disease to participate in research, it can be even more difficult to find people without Parkinson's disease to serve as "controls". Many research studies compare some measure such as a blood test, brain scan, or other test in persons with and without Parkinson's disease. So in order to perform the research and to

share the findings with the rest of the world, we rely on people <u>without</u> Parkinson's to volunteer to serve as controls. It can actually be very gratifying for friends, family, or other allies of people with Parkinson's to participate in research, giving them a sense of having contributed to something that may one day help their friend or family member. This sentiment was well-described in a letter recently written by the wife of a person with Parkinson's disease who volunteered to participate in one of our research studies:

Why did I decide to participate in a research project? It goes back to when Steve was diagnosed by a neurologist at a community hospital. After attending Rock Steady Boxing classes at the gym, and talking with fellow boxers, he elected to transfer to the Movement and Disorder Clinic. He had expressed an interest in participating in research, which he is part of the Access Project. At his yearly visit for Access, we discussed the need for control volunteers. It was shortly after that I contacted Emily to be a participant...The donation of time on those 3 days is PRICELESS knowing that it may help people with Parkinson's in the future.

-Sally

So, the next time someone asks you how they can help, feel free to remind them that there are many research studies in need of people without Parkinson's disease and their contribution would be helpful to everyone dealing with this disease now and in the future!

Research Recruiting Now!

The Michael J. Fox Foundation launched PPMI in 2010 to better understand Parkinson's and advance new treatments. Since then, the study has changed how research is done and what scientists know about the brain. It is a cornerstone of our understanding of disease and has heavily influenced clinical trials.

PPMI follows people — with and without Parkinson's — over time to learn more about how disease starts and changes. That information may lead to insights and tools that can help better diagnose, treat and even prevent brain disease. The study shares its data set — the most robust in Parkinson's research — with scientists to speed breakthroughs.

This landmark initiative is only possible through partnerships. Leaders across the field and nearly 40 funding partners have helped shape PPMI. Most importantly, more than 1,400 participants enrolled in PPMI over its first decade. Many of those people continue in the study.

Now we're enrolling new study participants, including controls without Parkinson's, who can contribute to a more detailed look into the way the disease develops and changes over time.

Additional details can be provided by your local study coordinator. To learn more, contact:

Kori Ribb

Email: klough2@jhmi.edu

Phone: 410-614-2216

Information and language included in this article is sourced from The Michael J. Fox Foundation for Parkinson's Research



What is Your Why?



Seneca Motley, BS
Senior Research Program
Coordinator

Seneca Motley is a Senior Research Program
Coordinator at the Parkinson's Disease and Movement Disorders
Center. She was introduced to neuroscience research early when she had the opportunity to shadow on projects with providers at the University of Richmond in Virginia while still in high school.

In 2015, Seneca came to Baltimore to study

neuroscience at Johns Hopkins University. While completing her undergraduate degree, she was able to spend some time in a lab at JHMI that was conducting Alzheimer's research, but was largely occupied by coursework.

Upon graduating in 2019, Seneca knew she wanted the opportunity to do more direct, hands-on work with

patients. Her knowledge of neurosciences and a background that included research experience made her an outstanding candidate for joining the research team at Hopkins' PDMD Center.

She came on board shortly before the beginning of the COVID-19 pandemic. Those circumstances required extensive adaptation to how research projects could safely be conducted. During this time, Seneca has been a valuable part of a number of different studies on Parkinson's disease. Some of her current work includes projects evaluating the safety and patient outcomes involved in clinical tools like movement data recording systems and radiotracers in PET scans.

Learn more about other ongoing research at Hopkins on pages 6 and 7 of this newsletter.



Community

P4P is coming back to Baltimore!

We are returning to the Baltimore Running Festival! We will continue to have a virtual option for individuals wishing to participate from home. If you can participate in person, we are excited to see you under the tent on October 15. To participate, all you need to do is fundraise, move, and commit to raising \$100 for P4P! And, because of our multiple formats, anyone can participate. Regardless of your age, ability, identity, or where you live, everyone can join in on the P4P Week 2022 fun!

What is P4P?

Pacing for Parkinson's (P4P) is a volunteer-led campaign that raises awareness of and funds for Parkinson's disease research, community outreach, education, and patient care at Johns Hopkins by participating at the Baltimore Running Festival each year. The Johns Hopkins Parkinson's Disease and Movement Disorders Center provides comprehensive, compassionate, and timely treatment to people living with Parkinson's and other movement disorders.

How Do I Join P4P in 2022?

First, register for your event and create a fundraising page to join the team. Whether you're moving at home as a virtual participant or participating in the Baltimore Running Festival, we're excited to have you on the team. Then, let your friends and family know what you're doing and why the cause is important to you. You can use our fundraiser's toolkit, complete with downloadable templates and social media images, if you need help.

Get in Touch!

Learn more about Pacing for Parkinson's by visiting our website pacing4parkinsons.org. Questions? Email pacing4parkinsons@gmail.com.

Please "like" us on Facebook (Pacing4Parkinsons)

And follow us on Instagram (@pacing4pd).

Thank You!

P4P is entirely volunteer-run so we rely on all of you to spread the word, fundraise, and donate. Together, we'll work to raise awareness and funds for Parkinson's Disease research, education, and patient care.



PARKINSON'S PROGRAM CALENDAR

Harford County PD Support Group

1st Thursday @ 2:00 pm Contact: sphelan2@jhmi.edu

Mid-Shore PD Support Group

2nd Tuesday @ 11:00 am Contact: jrharrald@gmail.com

Baltimore County PD Support Group

2nd Thursday @ 1:30 pm Contact: sphelan2@jhmi.edu

Newly Diagnosed PD Support Group

2nd Thursday @ 5:00 pm Contact: sphelan2@jhmi.edu

Atypical Parkinsonism Group

4th Monday @ 12:30 pm Contact: sphelan2@jhmi.edu

Care Partner Support Group

4th Thursday @ 4:00 pm Contact sphelan2@jhmi.edu

Lewy Body Dementia Support Group

1st Monday @ 1:00 pm Contact: melissadaily610@gmail.com

Harford County Caregivers Group

4th Thursday @ 1:30 PM sphelan2@jhmi.edu

Hagerstown PD Support Group

1st Thursday @ 11:00 am Contact: jpfiery@verizon.net

MAPS Care Partner Support Group

Via Zoom

Contact: Jdobbs02@comcast.net

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

Contact: bearsden65@atlanticbb.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

Parkinson's Foundation Virtual Classes

Mindfulness Mondays Wellness Wednesdays

Fitness Fridays

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)

Tuesday June 21st @ 7:00 pm

Sleep & Parkinson's

Register at www.marylandparkinsonsupport.org

Newly Diagnosed PD Educational Series

Twice a year, learn about PD basics, treatments, care teams, community resources, and more.

Contact: sphelan2@jhmi.edu

Advanced Therapies Seminar

Quarterly seminar for patients considering surgical options for PD.

Contact sphelan2@jhmi.edu

Dance for PD

Contact: 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 wo are part of both the LGBTQ+ and Parkinson's communities, learn about valuable resources, and share your experiences.

Contact: mhyman@bidmc.harvard.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

Theater project

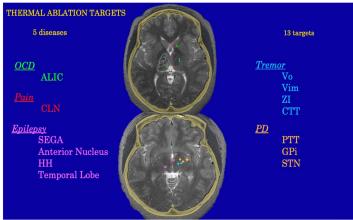
Contact: ellentalles@comcast.net

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

Treatments and Therapies by Sarah Phelan

Following a press release on the procedure this spring, patients and families living with Parkinson's Disease were eager for more information on focused ultrasound. Many asked how the procedure worked and if it could be of use in controlling their Parkinson's symptoms.

For movement disorders, the mechanism is ablation (thermal disruption of the tissue) that can be aimed at several different treatment targets. This novel technology focuses beams of ultrasonic energy precisely and accurately on targets deep in the brain without damaging surrounding normal tissue. Focused ultrasound has the potential to achieve symptomatic relief by making thermal lesions deep in the brain to interrupt circuits involved with tremor and dyskinesia. Symptoms and targets being assessed for treatment using focused ultrasound include:



Ablation targets for various symptoms of neurological diseases

- Parkinsonian tremor target in the thalamus (thalamotomy)
- Parkinsonian dyskinesia target in the globus pallidus (pallidotomy) or subthalamic nucleus
- Parkinsonian tremor, akinesia or dyskinesia target in the pallidothalamic tract

There are a number of pros and cons to consider when deciding between surgical options. Much like deep brain stimulation, focused ultrasound primarily impacts motor symptoms such as tremor and rigidity, but will not have an effect on most nonmotor symptoms like balance and memory. Compared to deep brain stimulation, focused ultrasound is a single procedure, and does not require subsequent procedures/visits to replace batteries, repair broken wires, or adjust

simulator settings. It also does not involve the collateral damage to healthy tissue or the risk of infections associated with implanting a foreign body. Like a magnifying glass focuses light, focused ultrasound concentrates ultrasound energy on a target in the body without harming nearby tissue.

There are, however, some precautions to consider before pursuing treatment of this kind. Perhaps the most important is that the effects of this procedure are permanent, as there is no way to restore the tissue that has undergone ablation. If the correct site was not targeted, if your symptoms are unresponsive, or if you suffer any side effects, you are unable to have the procedure reversed in the way that you could have DBS leads removed.

The procedure may also be cost prohibitive for many patients. While focused ultrasound is FDA approved, it is not yet fully covered by some insurance companies so it's wise to look into individual coverage before pursuing the costly procedure. There are, however, some treatment sites now being reimbursed by Medicare.

Travel may also prove challenging for some, with only a handful of providers in the United States performing focused ultrasound. Fortunately, two of those locations are nearby for Mid-Atlantic patients. Both University of Maryland in Baltimore, MD and University of Virginia in Charlottesville, VA have the teams and equipment needed.

For more information on focused ultrasound, consult the Focused Ultrasound Society on their website, www.fusfoundation.org

Always discuss new treatment options with your doctor to determine if they are a good option for you. Your particular symptoms and medical history will determine whether pursuing a different treatment is likely to succeed.

Language and graphics in this article were sourced from the Focused Ultrasound Society.

Treatment and Therapy (Part II)

One of the often unaddressed challenges for both patients and their care partners is the physical and mental effort of the moving, communication, and lifting involved in going about their daily lives with Parkinson's disease. These are the tasks that Judith Sachs assists the Parkinson's community with through her CLOSE CONTACT program.

Judith is a certified **Dance for PD®** teacher in Philadelphia and a 2020 and 2021 Parkinson's Foundation COE Grantee for her innovative therapy program, **CLOSE CONTACT for COUPLES®** with **PD**. This year, the program runs in collaboration with Penn Medicine and the Lou Ruvo Center for Brain Health, Cleveland Clinic, Las Vegas.

As partnered couples change with age and with the considerations of their various medical conditions, they need to collaborate on movement. This workshop teaches better partnered communication and new ways to trust and touch. Participants explore the activities of daily living and experiment with different ways of assisting one another from bed to chair, chair to floor and down the street, making movement and collaboration easier and safer for both patient and partner.

You can learn more about this program and others, as well as options for enrolling in classes at **anyonecanmove.com**. This website is where Judith shares videos with examples of class activities, registration for classes, and additional information on the benefits of improved movement and communication.



Judith Sachs, Director, Anyone Can Dance describes classes in the CLOSE CONTACT for Couples program

Welcome to the Team



Dr. Ashley Paul will be starting in September as an Assistant Professor of Neurology. In addition to seeing Movement Disorders patients like our other providers, she will be piloting a sleepmovement clinic in Howard County, and will be taking a major role in the Neurology Clerkship

to pursue her love of medical education. Dr. Paul is originally from New York. She went to undergraduate and medical school there, but then trained at Wright State University in Dayton, OH before coming to Johns Hopkins where she is completing a two year fellowship in the Movement Disorders Center before starting her new position in the fall.



Dr. Joseph Seemiller, MD comes to us from Pennsylvania, where he completed medical school at the Geisinger Commonwealth School of Medicine and a neurology residency at Geisinger Medical Center. Dr. Seemiller has done research in Alzheimer's disease and enjoys

helping patients with both movement and cognitive problems. He enjoys running, swimming, and spending time with his cats and turtles. Dr. Seemiller will be joining Johns Hopkins as a Clinical and Research Fellow.



Dr. Stephen Berger, MD, PhD completed his medical training and a PhD program at NYU Grossman School of Medicine in New York., followed by a neurology residency at NYU Langone. His hobbies include cooking, theater, and caring for his many plants and tropical fish. Dr. Berger will be joining Johns Hopkins as

a Clinical and Research Fellow.

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. 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

2. 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

3. 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: Colin McGregor: 410-616-2816

4. A Clinical Study of TPN-101 in Patients with Progressive Supranuclear Palsy (PSP) (NCT04993768)

Objective: This is a Phase 2a study to assess the safety and tolerability of TPN-101 in patients with PSP

Eligibility: Individuals 41-86 years old with a confirmed diagnosis of probable progressive supranuclear palsy.

P.I.: Jee Bang, MD

Contact: Kori Ribb; 410-614-2216

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

Objective and Eligibility: The goal of this project is to identify biomarkers in blood, urine and CSF that can help us develop a clinical test for PSP. Individuals over the age of 40 years old with a diagnosis of Parkinson's Disease (PD), Progressive Supranuclear Palsy (PSP), or healthy controls may take part. The study also requires a study partner or caregiver to participate.

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

Contact: AJ Hall: ahall52@jhmi.edu

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: AJ Hall: ahall52@jhmi.edu

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: cmotley1@jhmi.edu

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: Kori Ribb; 410-614-2216

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) (NCT04891107)

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. 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

12. 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

13. Quantitative At-Home Assessment of Motor and Cognitive Function in PSP (The PSP Wearables Study) (IRB266462)

Objective and Eligibility: The purpose of this project is to assess the feasibility of developing and using remote assessment tools like wearable digital sensors and a tablet, to monitor the symptom progression and motor function of individuals with Progressive Supranuclear Palsy (PSP) and Parkinson's Disease (PD) while at home over time. Individuals between 18 and 89 years old with a diagnosis of PSP or PD who are able to walk 10 feet unassisted may take part. The study also requires a study partner or caregiver to assist with study related procedures.

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

Contact: AJ Hall; ahall52@jhmi.edu



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 Baltimore, MD 21287 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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Disclaimer: The Movement Disorders Digest is published by the Johns Hopkins Parkinson's Disease and Movement Disorders Center to provide timely and useful information. Every effort has been made to verify the accuracy of the content. However, this newsletter is not intended to provide specific medical advice, and individuals are urged to follow the advice of their physicians. The PDMD Center is not responsible for the information or opinions expressed in its articles. 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.

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