

Director's Corner



Find your community!

In being involved in the lives of many people living with Parkinson's disease or other movement disorders like cerebellar ataxia or dystonia, I have found that one of the things that really helps people feel that they are thriving and not just surviving is that they are part of a community. Regular engagements with neighbors, a group of old friends, new friends met through a support group, participants in an exercise group, religious community members, or extended family keeps people motivated and also reminds them of how much they are appreciated by others. Ours is a social species and we thrive on interactions with others. Some people with movement disorders feel discouraged or even ashamed that they cannot participate in activities to their previous, fullest potential. Having a sense of community with a group of people outside the home can remind people of their worth and contributions they can make to a group and the lives of others, even if they are personally struggling with the nagging symptoms of a movement disorder like Parkinson's disease. We always encourage our patients to get engaged in some type of community, whether it is specific to their disease or not, and we often see their quality of life improve when they do so. To try and help with this, our center helps to facilitate communities through financial and logistic support to multiple support groups for various diseases (and even specific stages of Parkinson's disease), exercise classes, and even just social events like Ataxia Sailing Day or the social events associated with Pacing for Parkinson's. During the initial year and a half of the COVID19 pandemic, we saw many of these communities erode and this severely affected quality of life in our patients. As we work to build back and grow these communities, we encourage everyone living with a movement disorder to make a proactive attempt to reengage in some type of group outside the home (even if virtual). Our Parkinson's Foundation Center of Excellence health educator or Ataxia Center health educator can help with ideas if you or a loved one are struggling to reengage.

We're on Instagram!

The Johns Hopkins Parkinson's Disease and Movement Disorders Center has come to Instagram!

There's now a new way to learn more about these diagnoses, hear about upcoming events in our area, and stay up to date on new research opportunities.

Follow us [@johnshopkinspdmd](https://www.instagram.com/johnshopkinspdmd) to see posts like the ones shared here!

The Johns Hopkins Parkinson's Disease and Movement Disorders Center's Instagram account is intended for informational purposes only. Questions or comments on treatments or individual cases should be directed to your treatment team.

Care Partner Stats

- 43.5 MILLION Care Partners in the U.S.
- 470 BILLION Dollars worth of labor annually
- 89 % OF PARTNERS Educate healthcare providers about the disease

Find support from groups listed in the comments

HOW IS PARKINSON'S DIAGNOSED?

a person **MUST** have bradykinesia (slowness of movement) **AND** one or more of the following...

DID YOU KNOW?

Loss of smell can be an early indicator of Parkinson's

WELCOME

Follow The Johns Hopkins Parkinson's Disease and Movement Disorders Center

FACIAL MASKING (HYPOMIMIA)

A SERIOUS OR MAD APPEARANCE, AND DECREASED BLINK RATE

Pacing for Parkinson's Join Us Today!

p4parkinsons.org



What is Your Why?



Joseph Seemiller, MD
Research and Clinical Fellow

In our last issue, you saw the addition of two new Fellows to our team!

Dr. Joseph Seemiller joined the Johns Hopkins Parkinson's Disease and Movement Disorders Center this summer as a Research and Clinical Fellow. Read on to learn more about what drew him to work with movement disorders patients.

“Watching a deep brain stimulator get activated for

the first time was a magical experience as a medical student. I learned that the right interventions, for the right patients, can make a world of difference.

In movement disorders, the right diagnosis hinges on the right questions and exam maneuvers, more than in other branches of medicine. Also, there are also lots of symptoms that we are still trying to understand,

especially about how disorders like Parkinson's disease impact our cognition and thinking, which has been a longstanding area of interest for me.

I've aspired to learn to treat these conditions, but also to study and contribute to research, especially about the cognitive aspects of movement disorders. I'm fortunate to be training with a great team at the Johns Hopkins movement disorders division, and I'm so thankful for our patients who have trusted me with their care from my very first day here.”



JOHNS HOPKINS
MEDICINE

Community

Thank You!

Thank you to all Pacing for Parkinson's participants, both virtual and in-person, for being part of the team this year! Because of your support, our **132 participants** raised over **\$55,000 dollars** from over **500 donations** this year!

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.



Get in Touch!

Web: pacing4parkinsons.org

Email: pacing4parkinsons@gmail.com

Instagram: [@pacing4pd](https://www.instagram.com/pacing4pd)

Facebook: [Pacing4Parkinsons](https://www.facebook.com/Pacing4Parkinsons)

The Mind and Parkinson's

by Sarah Phelan

It is an important part of our center's mission to share knowledge with the movement disorders community to benefit patients and their support networks.

This year, after a two year hiatus due to the COVID-19 pandemic, we were excited to celebrate a return to in person events with a symposium held at The University of Delaware's STAR campus. Experts from the Johns Hopkins Parkinson's Disease and Movement Disorders Center delivered talks as part of "The Mind and Parkinson's" focusing on cognitive and psychiatric symptoms and treatments related to movement disorders.

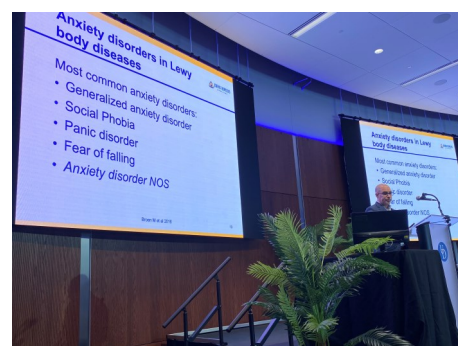
Patients, partners, and providers gathered to learn and discuss these symptoms and their management. Attendees also had the opportunity to gather extensive print resources on these topics and meet with researchers from Johns Hopkins to find out more about current studies related to the day's topics.

For those who weren't able to attend, recordings of each presentation will be made available online in the near future.

Keep an eye on upcoming newsletters and emails for information on events like these to come in 2023!



Drs. Alexander Pantelyat, Kelly Mills, Liana Rosenthal, and Gregory Pontone take questions from the audience



Dr. Pontone delivers remarks on

PARKINSON'S PROGRAM CALENDAR

Harford County PD Support Group

1st Thursday @ 2:00 pm
McFaul Activity Center, Bel Air and via Zoom
Contact: sphelan2@jhmi.edu

Mid-Shore PD Support Group

3rd Tuesday @ 11:00 am via Zoom
Contact: jrharrald@gmail.com

Baltimore County PD Support Group

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

Newly Diagnosed PD Support Group

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

Atypical Parkinsonism Group

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

Lewy Body Dementia Support Group

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

Hagerstown PD Support Group

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

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

Contact: bearsden65@atlanticbb.net

Young Onset PD Support Group

1st Wednesday @ 7:00 pm via Zoom
Contact: sphelan2@jhmi.edu

Care Partner Support Group

4th Thursday @ 4:30 pm via Zoom
Contact: sphelan2@jhmi.edu

Harford County Caregivers Group

4th Thursday @ 1:30 PM
McFaul Activity Center, Bel Air and via Zoom
Contact: sphelan2@jhmi.edu

MAPS Programs and Support Groups

<https://www.marylandparkinsonsupport.org/programs>

Conversations With A Doc

Quarterly, no-cost speaker series sponsored by MAPS
Register at www.marylandparkinsonsupport.org

Tuesday January 24th @ 7:00 pm

Your Vision and Parkinson's with Dr. Brett Levinson

Tuesday March 21st @ 7:00 pm

What Causes Parkinson's Disease? with Dr. Kelly Mills

Tuesday June 20th @ 7:00 pm

What Frustrates You About Healthcare? with Dr. Lisa Shulman

Dance for PD

Contact: ellentalles@comcast.net OR
powalker11@gmail.com

Parkinsonics

Choir for patients with Parkinson's and theater project
Contact: ellentalles@comcast.net

PD Drumming

Contact: rx4rhythm@gmail.com

Aquatics for Parkinson's

Aquatic therapy sponsored by MAPS
Contact: info@marylandparkinsonsupport.org

CLOSE CONTACT for Couples

Partnered communication and movement
Contact: judithsacs@mac.com

Newly Diagnosed PD Educational Seminar

January 25th

Contact: sphelan2@jhmi.edu

Or register at <https://tinyurl.com/NewlyDxSeminar>

Advanced Therapies Seminar

For patients considering surgical options for PD
March 8th @ 12:00 pm

Parkinson Foundation of the National Capital Area

parkinsonfoundation.org/programs

Parkinson's Foundation

Resources and Support
<https://www.parkinson.org/resources-support>

Rock Steady Boxing

Find classes scheduled near you at
rocksteadyboxing.org

New Clinical Trial at Johns Hopkins Aims to Slow Disease Progression

by Kori Ribb, RN, BSN, CNRN

Dr. Kelly Mills and Kori Ribb are recruiting people with early Parkinson's disease to participate in a clinical trial. The Orchestra Study will examine an investigational medication called UCB0599 in individuals with early-stage Parkinson's disease.

In the Orchestra Study, we are trying to find out if the study drug UCB0599 might be able to slow down the progression of the disease and, as a result, its symptoms as well. In order to do this, participants in the study must have early stage Parkinson's disease with mild symptoms and not yet require treatment to control symptoms or have been on medications for less than 30 days. Due to the way the study drug works in the brain, it may take some time for improvement in current symptoms or prevention of new symptoms to occur. It is also possible that your symptoms will not improve.

Previous research on UCB0599 has indicated that the drug could delay the worsening of Parkinson's disease symptoms by preventing the clumping of Lewy bodies in the brain and stopping their spread from cell to cell.

For more information, please email Research Nurse Kori Ribb at klough2@jhmi.edu.

Read more at <https://tinyurl.com/OrchestraStudyInfo>



Getting By With a Little Help From Those Who Understand

by Elizabeth Flury and Lori Deporter

The pathway to a diagnosis of Parkinson's Disease (PD) is often a journey that can take years. And, when you finally hear those words, "you have PD," any number of emotions can consume you - from relief that you finally have a diagnosis - you aren't "crazy," to fear for the unknown and what this disease will mean for you, your family, your life. Diagnosis is a time of many questions and few answers. Many don't know, or have ever known, anyone with PD and, if they knew someone - that individual was likely old - but, you are not.

Meet Lori and Elizabeth. Two women diagnosed with Young On-set Parkinson's Disease (YOPD) and patients of Dr. Alexander Pantelyat, Director of the Atypical Parkinsonism Center at Johns Hopkins and the Co-Founder and Co-Director of the Johns Hopkins Center for Music & Medicine. Both women gave Dr. Pantelyat permission to share their contact information with patients he thought would benefit from getting to know each other.

Two years ago, they were introduced as strangers. Now, they are best friends who share a passion for exercise, an attitude of "never give up," and a desire to help others with Parkinson's to live their best life which led to the creation and launch of the Johns Hopkins YOPD support group/network.

Yes. You are too young to have PD, but you are not alone. The realities and struggles of PD can leave many feeling isolated and lonely. Being part of a Support Group whose members understand your struggles, your fears and concerns can make all the difference in the world in how you take on each new day.

Announcing the Johns Hopkins Early Onset Parkinson's Support Group

- The Support group meets via ZOOM the first Wednesday of each month from 7-8 p.m.
- Each Meeting provides both an education session on a topic of interest to the group, and open sharing
- Open to all who were diagnosed with PD by age 60
- There is no charge/cost for participation in the group
- Direct any questions to Sarah Phelan at sphelan2@jhmi.edu or 410-205-9601

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: Kori Ribb klough2@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: Seneca Motley 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. Oral UCB0599 in Study Participants With Early-stage Parkinson's Disease (NCT04658186)

assess the safety and tolerability of UCB0599 and to demonstrate the superiority of UCB0599 over placebo with regard to clinical symptoms of disease progression over 12 and 18 months in participants diagnosed with early-stage Parkinson's Disease.

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

Contact: Kori Ribb klough2@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



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
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.

Physician Faculty

Jee Bang, MD
Ankur Butala, MD
Jason Chua, MD, PhD
Ted Dawson, MD, PhD
Kelly Mills, MD, MPH
Emile Moukheiber, MD
Alex Pantelyat, MD
Ashley Paul, MD
George Ricaurte, MD, PhD
Liana Rosenthal, MD, PhD

Fellows

Stephen Berger, MD, PhD
Nigel Harrison, MD
Joseph Seemiller, MD

Additional Faculty

Jason Brandt, PhD
Valina Dawson, PhD
Daniel Gold, DO
Stephen Grill, MD, PhD
Gregory Pontone, MD
Sonja Scholz, MD, PhD
Shawn Smyth, MD
Howard Weiss, MD

Neurosurgical Team

William Anderson, MD, PhD
Pam Lowe

Allied & Research Team

Catherine Bakker, MS
Melissa Egerton
Kecia Garrett
Anna J. Hall, BA
Tonya Jackson
Michelle Joyce, BS
Kyurim Kang, PhD
Nichole Marcantoni, BSN
Arita McCoy, CRNP
Colin McGregor, BA
Seneca Motley, BS
Jennifer Millar, PT
Vanessa Nesspor, BS
Ebubechukwu "Obi" Onyinanya, BS
Kate Perepezko, BA
Sarah Phelan, MS
Renee Campbell
Kori Ribb, BSN, RN, CNRN
Maria Schmidt, AGPCNP-BC
Teshome Wubishet

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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