

Director's Corner



Kelly Mills, MD, MHS

It has been a trying winter for many of our patients, their families, and others in the movement disorders community. The pandemic has restricted access to exercise classes and gyms while the cold weather made even socially distanced outdoor activities difficult. COVID-19 distanced us, physically, from our loved ones during holidays usually devoted to togetherness. It took some people away for good, much sooner than we had ever imagined. And yet, many found a way to persevere in their journey with Parkinson's disease, ataxia, dystonia, and other movement disorders.

Inspired by your perseverance and adaptability, members of the Johns Hopkins Parkinson's Disease and Movement Disorders Center have worked tirelessly to support your efforts to make it through this tough time. We have directed funds raised through Pacing-4-Parkinson's and other resources to continue exercise classes, support groups, and educational series remotely. With support from the Parkinson's Foundation, we even began a new virtual art therapy group to improve socialization, reduce stress, and work on hand motor function. Our physicians and therapists quickly pivoted to telemedicine and became emergency licensed in nearby states to be able to provide continuity of care to our patients. (Please forgive the children screaming and dogs barking in the background at our "office"). We welcomed a new Health Educator, Sarah Phelan, who has hit the ground running and is already growing our virtual outreach efforts. Finally, we are seeing many of our patients getting access to vaccines and with the encouraging data from large clinical trials, are excited about their potential to *dramatically* reduce serious risk from COVID-19. We are so happy to welcome the spring with newfound optimism and while the "new normal" will undoubtedly be different, we are steadfast in our commitment to provide the community with comprehensive clinical care, educational programs, and cutting-edge research opportunities. We would like to thank all of you for pushing through this dark, cold winter; this continues to motivate us to keep going along with you.

What is Your Why?



Ashley Paul, MD
Clinical & Research Fellow

When I was still in medical school, I had the opportunity to spend a week working with the movement disorder specialists and I recall feeling this sense of “this is where I belong.” I discovered a burgeoning curiosity for why patients can have excessive movements or lack of movements. I loved observing the long-term relationships that were built between patients and

their physicians. Although Parkinson’s disease was first described over 200 years ago, we are still working to understand the nuances of the disruption of complex brain circuits that result in Parkinson’s disease and other movement disorders. Unlike many other fields of medicine, coming to a diagnosis relies heavily on clinical acumen – it is all about asking the

right questions, doing an appropriate but detailed neurological exam, and just simple observation. While the science itself is fascinating, most of all I love listening to the patient’s story. To me this is a field where weird symptoms, elegant observation, and characterization collide with a human being at the center of it all. I found that treating patients suffering from these diseases required compassion, tact, patience, and even a sense of humor. It felt like my calling was to help patients navigate these life altering diseases and guide them on maintaining their quality of life. Every day I feel so fortunate to be training as a current movement disorder fellow at one of the top institutions in the world here at Johns Hopkins. I hope to serve my patients with both the knowledge and humility that this field requires.



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.

How Much Do You Know About Palliative Care?

What kinds of services do palliative care professionals provide? What’s the difference between palliative care and hospice care? How can palliative care help with the symptoms of Parkinson’s Disease? The Johns Hopkins multidisciplinary team of palliative care specialists is comprised of physicians, advanced practice providers, nurses, pharmacists, chaplains, child life experts and social workers. Palliative Care teams can help with the symptoms and the stress of living with a serious illness, including controlling pain, providing support for the mental and emotional effects of an illness, and managing other bothersome symptoms. Join us for a free educational Zoom seminar at 6:00 pm on Thursday May 27th to learn the answers to these questions and more ways to help improve quality of life. Contact JHPDMD Health Educator Sarah Phelan at sphelan2@jhmi.edu for registration information.

RESEARCH STUDIES

1. XTRA PET for Cognitive Function in Parkinson's (NA_00076249)

Objective: To understand the brain chemistry involved in cognitive function in PD patients, and how this affects the outcome of DBS surgery

Eligibility: PD patients scheduled to undergo DBS; PD patients not considering DBS

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

Contact: Research Assistant: 410-955-6672

2. 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

3. Investigations of Neurovascular Abnormalities in the Olfactory Cortex Using Advanced MRI Technologies (IRB00141396)

Objective: To investigate neurovascular abnormalities in the olfactory cortex using advanced MRI techniques

Eligibility: PD patients diagnosed for more than 3 years who are able to tolerate an MRI brain scan and undergo smell and memory identification tasks

P.I.: Jun Hua, Ph.D.

Contact: Adrian Paez: 443-923-9551

4. 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

5. 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

6. 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

7. 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

8. 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

9. 4RTNI-2 (NA_00130505)

Objective and Eligibility: Select individuals with CBD, PSP or vPSP; healthy controls, caregiver component

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

Contact: Diane Lanham: 443-287-4156

RESEARCH STUDIES (continued)

10. General Characterization: Movement Disorders (NA_00055442)

Objective: To study the genetic risk factors involved in movement disorders

Eligibility: Individuals with PD, atypical parkinsonism, dystonia, ataxia and Lewy body dementia

P.I.: Jeffrey Rothstein, M.D., Ph.D.

Contact: Sonja Scholz: 301-435-7606

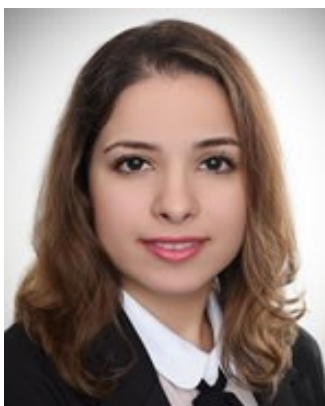
11. PET Study for individuals with REM Sleep Behavioral Disorder, PD and Healthy Controls

Objective and Eligibility: A PET scan study to determine if there is inflammation in the brain of people with early Parkinson's. Age 50-80 and healthy controls.

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

Contact: Emily Carman: 410-955-8909

EDUCATION



Jumana Alshaikh, MD

Clinical & Research Fellow

11 Reasons To Exercise If You Have Parkinson's Disease

1- Exercise may delay the onset of Parkinson's and help slow down the progression of PD even after symptoms start.

2- Exercise enhances balance and gait performance, and reduces the fall rate in PD patients.

3- Exercise improves the slowness of movement that occurs in Parkinson's.

4- Exercise can improve the efficacy and reduce the side effects of anti-parkinson medications such as wearing-off and dyskinesias.

5- Exercise could help preserve and improve cognition in PD patients.

6- Exercise enhances mood and helps treat depression and anxiety which commonly occur in Parkinson's.

7- Regular exercise of moderate intensity improves quality of sleep.

8- Physical activity and exercise are important in promoting healthy bowel movements, thereby preventing and treating constipation which Parkinson's patients are at risk for.

9- Exercise could decrease pain and assist with pain control in PD patients

10- Exercise improves bone mineral density and prevents osteoporosis, thereby reducing the risk of bone fractures if falls occur.

11- Exercise has many other health benefits, and reduces the risk of other diseases that can worsen quality of life for PD patients such as diabetes, hypertension, heart disease, and strokes.

If you're interested in participating in exercise groups for Parkinson's patients of all abilities and interests, see a sampling on page 7 of this newsletter of what's offered in our area.

Pacing For Parkinson's (page 6) is another great way to get involved, give back, and get moving!

For help finding other exercise group options, please contact our Health Educator, Sarah Phelan at sphelan2@jhmi.edu.

Your COVID-19 Concerns Addressed *by Sarah Phelan, MS, Health Educator*

Over a year into the COVID-19 pandemic, we've all learned a lot about how to safely navigate many of the tasks of daily life from the widespread information on preventing the spread of the virus. What hasn't been as readily available is guidance on how to manage your care with a Parkinson's diagnosis. In this article, we share information from The Parkinson's Foundation to address some of the most common questions and concerns from patients about maintaining the best possible health during these unusual times.

Am I more at risk because of my Parkinson's diagnosis?

Most doctors report that Parkinson's patients are not more at risk of *catching* the coronavirus than others, aside from other factors such as age, comorbid health issues, etc. The main concern is *complications* that may arise once a patient has COVID-19. Early data shows that those with Parkinson's have a higher mortality rate as well as less-complete recovery. Illness and hospitalization may also disrupt the normal treatment regimens, leading to a worsening of Parkinson's symptoms and the need for adjustments in medication.

Once I'm fully vaccinated, can I return to my normal routine?

Being fully vaccinated drastically reduces the risk of severe illness from COVID. However, until more long-term information is available, the CDC and epidemiology experts recommend continuing to wear a mask, practicing social distancing, and avoiding large gatherings of people.

How long does immunity last after vaccination?

There's no exact number yet on how long protection from the different vaccines will last. Early data indicate that immunity likely lasts for at least six months, with the possible need for a booster shot for continued protection.

Will the vaccine protect me from the new strains of the virus?

The vaccine was not formulated specifically for these mutations of the virus that causes COVID-19. However, preliminary research indicates that while the degree of immunity may not be as high, the vaccines do appear to offer some protection from the variants.

What kind of side effects does the vaccine have?

The goal of the vaccine is to spur an immune response, which results in cold or flulike symptoms. Patients may experience irritation at the injection site, soreness and body aches, headache, nausea, mild fever, and other similar effects. These symptoms may be more severe after the second shot of the vaccine, as the body is primed to have a stronger immune response. This is a normal reaction and should only last one or two days. If symptoms are severe or last for an extended period, you should contact your healthcare provider.

Which vaccine should I get?

Each of the vaccines offers a drastic reduction in risk from the virus. With supplies being limited, most experts agree that patients should take the first vaccine available to them.

How do I maintain my Parkinson's care if I'm hospitalized during the COVID-19 pandemic?

Consistency is of vital importance for an effective Parkinson's treatment regimen. Taking medications on schedule, getting proper nutrition and exercise, and contact with your support network are all key parts of better quality of life and prognosis in Parkinson's. Hospital staff are spread thin more than ever with the large number of COVID cases, and loved ones are often not able to accompany patients due to safety regulations. It's best to be prepared for these circumstances by planning ahead. Make sure you have a complete list of medications as well as the schedule for their administration. Contact information for your medical team, a cell phone and charger to remain in contact, and documentation from your neurologist explaining to hospital staff the importance of your routine are also helpful. The Parkinson's Foundation provides a free "Aware in Care" kit, as well as booklets on hospitalization action plans, and letter formats for your neurologist to provide instruction.

Should I try telemedicine or wait until my doctor is seeing patients in person?

Some appointments, like bloodwork or imaging, just have to be in person. However, with a few adjustments, telemedicine can be an excellent way to stay on top of your health while also staying safe. Here are some tips for making the most of your telemedicine appointment.

Get ready. Prepare as you would for an in-person visit. Make sure you have your medication list and questions ready.

Review medication. Check to see if you have enough pills at home or if you need refills.

Download communication software. You will most likely use a video platform like Zoom, FaceTime, Skype, Epic or others.

Check technology. Make sure you set up in a location with a good Internet connection. Charge your device before the appointment.

Be ready to move. Try to position yourself near a space where you can perform typical tasks your doctor or specialist may ask you to complete. For instance, a Movement Disorder Specialist or physical therapist may ask you to walk. It may be helpful to have a family member ready to help during the appointment.

Gather your tools. Have a paper and pen nearby, along with any items your healthcare specialist may have asked you to bring to your appointment (for instance, a thermometer, scale, medication bottles).

Prepare your space: Speak in your normal voice. Do not place papers or objects near the microphone. Put your phone on silent if you are not using it for the appointment. Limit any clutter between you and the camera. Avoid backlighting (like windows behind you) Limit background noise that may come from a TV, radio or pets which affect your device's microphone (a fan overhead, loud AC unit, open window)

Ask questions. Take notes and add them to your medical file.

Provide updates. Your pharmacy, insurance, or contact information may have changed. Let the doctor's office know before your appointment ends.

Talk about follow up care. Schedule your next appointment if possible.

Community

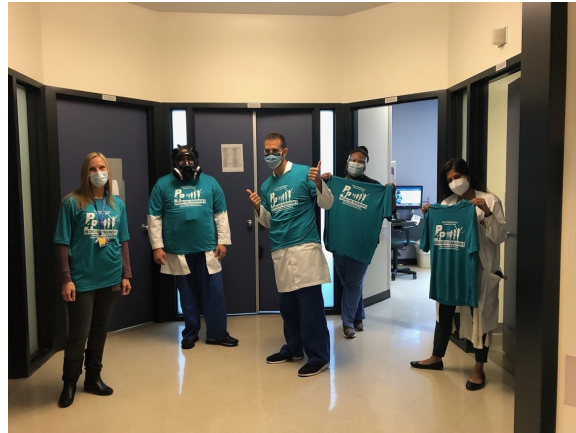


Your support of Pacing for Parkinson's in 2020 helped the 100+ virtual team members from 14 states and D.C. raise almost \$50,000 and cover more than 2,300 miles for Parkinson's disease research, education, and patient care at Johns Hopkins Parkinson's Disease and Movement Disorders Center.

Mark your calendars! We will be celebrating Pacing for Parkinson's virtually over the course of one week, Saturday, October 2 through Saturday, October 9, 2021.

To participate in P4P Week, all you need to do is create a fundraiser and move! Create a fundraising page on pacing4parkinsons.org and let your friends and family know what you're doing and why the cause is important to you. Then, come October, get moving! You can run, walk, or bike; you can do yoga or cut the grass. You can even walk up and down the hallway!

Anyone can participate! Regardless of your age, ability, identity, or where you live, anyone is welcome to participate in P4P Week 2021.



THANK YOU to our 2020 sponsors for your support of Parkinson's disease research, care, outreach and education. Sponsors included Giant, Amneal, Kyowa Kirin, NuStar, and AbbVie.

We are looking for sponsors for Pacing for Parkinson's Week 2021! You can find more about becoming a sponsor on our website, pacingforparkinsons.org. To become a 2021 P4P sponsor, please contact: Rachel Ermer, Neurology Development Officer, at (410) 916-1605 or email

PARKINSON'S PROGRAM CALENDAR

Virtual Fitness Classes - Parkinson's Foundation Fitness Fridays

<https://www.parkinson.org/Living-with-Parkinsons/Resources-and-Support/PD-Health-at-Home/Fitness-Fridays>

Rock Steady Boxing

Classes from Patty Wessels

Class times will vary. Contact Patty at charmcity@rsbaffiliate.com for information

Patricia Wessels, PT

Head Coach--Rock Steady Boxing MAPS @ Charm City (443) 873-0040

Mid Shore classes from RSB Coach, Lyn Sutton, from Grasonville, MD.

Please email midshore@rsbaffiliate.com for an invitation to join our classes

MAPS

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

Ability Boxing - supported by Johns Hopkins Parkinson's Disease and Movement Disorders Centers

Stephanie Mendez MOTR/L

Slynnmendez@gmail.com

Greater St. Louis APDA Chapter (YouTube Channel – Tai Chi, Yoga, Seated Exercise, Interval Training)

<https://www.youtube.com/channel/UC71A1FouZukPAYBrb3yEJig/feed>

Parkinson Foundation of the National Capital Area (Associated with nominal fee that can be waived if necessary)

<https://parkinsonfoundation.org/programs>

JHPDMDC Quarterly Educational Series

May 27th: Palliative Care in Parkinson's

Contact Sarah Phelan

Harford County PD Support Group

1st Thursday @ 2:00 pm

Mid-Shore PD Support Group

2nd Tuesday @ 11:00 am

Baltimore County PD Support Group

2nd Thursday @ 1:30 pm

Atypical Parkinsonism Group

4th Thursday @ 2:00 pm

Lewy Body Dementia Support Group

1st Monday @ 1:00 pm

Harford County Caregivers Group

4th Thursday @ 11:00 am

Hagerstown PD Support Group

1st Thursday @ 11:00 am

Conversations With A Doc

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

June: Memory and Cognitive Issues

September: GI System and Parkinson's

December: Sleep & Parkinson's

Register at www.marylandparkinsonsupport.org

Pacing for Parkinson's

October 2-9 Virtual "Race at Your Place"

Registration is open at pacing4parkinsons.org

Newly Diagnosed PD Educational Series

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

Surgical Therapies Seminar May 25th

Contact sphelan2@jhmi.edu

For more information on these or any other classes or resources, please contact The JHPDMD Health Educator Sarah Phelan at sphelan2@jhmi.edu

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.

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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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MEDICINE

