

19

FALL/ WINTER

MOVEMENT DISORDER

DIGEST

News from the Johns Hopkins Parkinson's Disease and Movement Disorder Center | Fall/ Winter 2019

DIRECTOR'S
CORNER



DO I NEED TO SEE A NEUROLOGIST SPECIALIZING IN MOVEMENT DISORDERS IF I HAVE PARKINSON'S DISEASE? KELLY MILLS, MD, MHS

One question that is commonly asked at our center is whether or not people with Parkinson's Disease need to see a neurologist specializing in Movement Disorders like Parkinson's Disease (PD) or whether a general neurologist is sufficient. The answer is complicated, and depends a lot on where the patient lives, the resources in that area, the hardship required to travel, and the experience of local providers. General neurologists are often amazing clinicians who have knowledge about everything from carpal tunnel syndrome to multiple sclerosis to stroke and Alzheimer's disease. However, their experience in managing Parkinson's Disease (PD) may vary from provider to provider based on his/her/their prior exposure and training.

Some general neurologists feel fairly comfortable managing many different medications and therapies used for treatment of Parkinson's symptoms while others may feel comfortable with only starting a "first-line" therapy and then referring to a Movement Disorders Specialist. Either way, it is very important for a PD patient to ask his or her neurologist about their comfort with managing their stage of PD and whether or not a referral is needed at that time. A neurologist with fellowship training in Movement Disorders means that he or she has spent 1-2 years specifically training in the management of Parkinson's Disease and other disorders, including advanced therapies such as surgical treatments, infusion therapies, and knowledge about the latest and greatest treatments for Parkinson's. They are also trained in making the appropriate referrals to other team members, including PD-trained physical, speech and occupational therapists; neurologists; neurogastroenterologists; neurosurgeons; psychiatrists; neuropsychologists; and other providers who can help with PD management.

Patient organizations like the Parkinson's Foundation generally recommend seeing a Movement Disorders Specialist at some point to help facilitate a multidisciplinary approach. One important factor in whether or how often to see a Movement Disorders Neurologist is the location and ease of access to a specialist. Patients who live several hours away from a specialist and/or who have difficulty with travel might see their local neurologist more frequently and only travel to see a Movement Disorders Neurologist once every 6 or 12 months for input on management. If this is the case, it is important for the local neurologist and Movement Disorders Specialist to communicate regarding updated recommendations and to be allied as a team for the patient. While this has traditionally been a challenge, electronic medical records are starting to "talk" to each other, making this communication a bit easier. The goal of patient-oriented healthcare is for the system to focus on the outcome of the patient, incorporating their preferences into our treatment plan and focusing on what is important to that specific patient. At our center, we practice this by partnering with community neurologist and all other types of providers to deliver comprehensive care to each individual based on his or her specific circumstances. To find a Movement Disorder Specialist near you, contact the free **Parkinson's Foundation Helpline at 1.800.4PD.INFO (1-800-473-4636) or Helpline@Parkinson.org.**

FACULTY HIGHLIGHT

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.



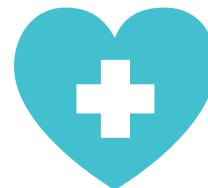
WHAT IS YOUR WHY?

MAITREYI MURTHY, MD



I recently graduated from Neurology residency however, I had the opportunity to work with Parkinson's patients for at least a year before beginning my training. I have to say I had a calling that this was going to be my forte. Working as a Movement Disorders Specialist allows me to combine my two passions: neuroscience and fostering the doctor-patient relationship. I feel a great deal of responsibility and pride when I talk with patients and their families. I like to provide them with the right kind of information and medical care that is tailored to their needs. It gives me a sense of fulfillment that we are here as a united team to help improve the quality of life for our patients. I consider myself extremely fortunate to have the opportunity to work and learn from an excellent team of healthcare providers who are dedicated to nurturing and improving the quality of care provided to our patients. I look forward to serving you all!

Yours truly,



Maitreyi Murthy, MD

Clinical and Research Fellow

*Johns Hopkins Parkinson's Disease and Movement Disorders Center
School of Medicine*

COMMUNITY SPOTLIGHT

PACING FOR PARKINSON'S

The Johns Hopkins Parkinson's Disease and Movement Disorders Center would like to sincerely thank all of those who supported Pacing for Parkinson's during the Baltimore Running Festival. The Baltimore Running Festival will take place on October 17, 2020. To join the team or donate, visit www.pacing4parkinsons.org



196: FINAL NUMBER OF PARTICIPANTS ON THIS YEAR'S P4P TEAM.

11: NUMBER OF YEARS WE'VE BEEN A CHARITY TEAM WITH THE BRF!

\$85,452: AMOUNT OF MONEY RAISED BY THIS YEAR'S TEAM SO FAR.

15: NUMBER OF TOP FUNDRAISERS, WHO RAISED \$1,000 OR MORE BY RACE DAY

5: NUMBER OF NEW RESEARCH PROJECTS INITIATED BY HOPKINS INVESTIGATORS - FUNDED BY THE MONEY RAISED

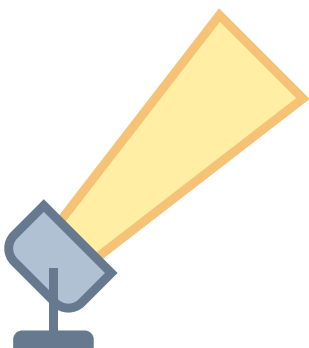
4: NUMBER OF COMMUNITY OUTREACH PROGRAMS FUNDED BY THE MONEY RAISED

2019 AWARDEE HIGHLIGHT YOGA FOR PD



THIS BI-WEEKLY (TUESDAYS AND THURSDAYS) YOGA CLASS WAS HELD AT THE YOGA CENTER OF COLUMBIA. THE GOAL OF THIS 10-WEEK CLASS WAS TO ASSIST PARKINSON'S PATIENTS IN COPING WITH THEIR SYMPTOMS OF BALANCE LOSS, REDUCED MOBILITY, PAIN, AND ANXIETY.

DUE TO THE PROGRAM'S SUCCESS, THE YOGA CENTER OF COLUMBIA IN PART WITH THE RETREAT CENTER OF MARYLAND WILL BE CONTINUING THIS PROGRAM FREE OF CHARGE BEGINNING IN JANUARY. FOR MORE INFORMATION, VISIT: WILDFLOWERYOGA.COM OR CALL (410) 720-4340.





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. 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, MD **Contact:** Laura Shinehouse: lshineh1@jhmi.edu

2. Evaluation of the Personal KinetiGraph (PKG) to improve insight into Parkinson's disease symptoms

Objective: To understand the utility of the data of a wearable Personal KinetiGraph in the clinical management of PD in routine clinical care

Eligibility: PD patients in NPF registry; responsiveness to dopaminergic medications; No DBS/DUOPA

P.I.: Kelly Mills, MD **Contact:** Seneca Motley: 410-955-6672

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, PhD **Contact:** Adrian Paez: 443-923-9551

4. 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, MD, PhD

Contact: Catherine Bakker: 410-616-2814

5. 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, MD **Contact:** AJ Hall: 410-616-2813

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, MD

Contact: Sydney Baybayan: 410-955-6692

7. 4RTNI-2 (NA_00130505)

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

P.I.: Alex Pantelyat, MD

Contact: Diane Lanham: 443-287-4156

8. 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, MD

Contact: Vanessa Johnson: 410-616-2815

9. Randomized, Double-Blind, Placebo-Controlled, Parallel-Group Study to Evaluate the Efficacy and Safety of BHV-3241 in Subjects with Multiple System Atrophy (M-STAR Study)

Objective: To evaluate the efficacy, safety and tolerability of BHV-3241, compared to placebo, in patient with Multiple System Atrophy.

Eligibility: Male and female patients, >40 to <75, with a diagnosis of possible or probable MSA

P.I.: Jee Bang, MD

Contact: Kori Ribb: 410-614-2216

10. Swallowing Function in Parkinson's Disease

Objective: To evaluate swallowing problems in participants with a neurological disease or stroke.

Eligibility: Male and female patients diagnosed with a neurological disease or stroke.

P.I.: Dr. Marlis Gonzalez-Fernandez, MD, PhD

Contact: Rachel Brenowitz : 410-502-2245

EDUCATION



ART THERAPY FOR PARKINSON'S

CHELSEA GANC, MS, CHES



According to the American Art Therapy Association, "Art Therapy is a mental health discipline, facilitated by a credentialed art therapist, who uses various art forms and materials to engage in the creative process as a way to explore feelings, increase self-esteem and develop social skills. Its many goals include improving physical functioning and well-being."

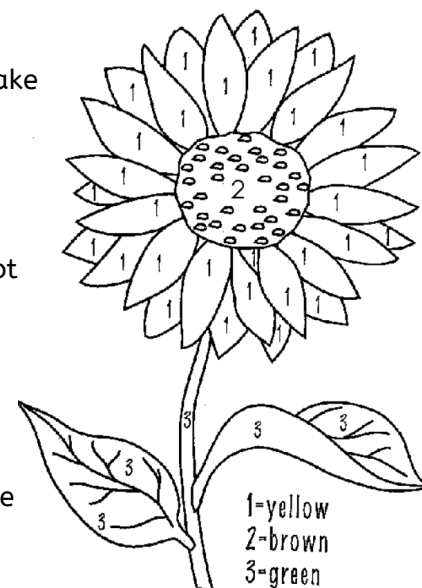
Art therapy may help restore some functional independence and improve the quality of life for people with Parkinson's. In treating Parkinson's Disease and other conditions, it has been reported to improve mood, self-confidence, creativity and motor skills. The Parkinson's Foundation reports ways in which art therapy helps to improve symptoms related to PD:

Tremor: About 70 percent of people with PD experience tremor at some point of the disease. Stress, as well as fatigue and intense emotions, can temporarily make tremor worse. Most people find art therapy relaxing, and therefore an effective way to reduce tremor in times of stress.

Freezing: Some people with PD experience the temporary, involuntary inability to move, called freezing. Because art therapy introduces novel motions that are not part of everyday life, it conditions your body to operate less on autopilot, which decreases likelihood of freezing.

Impaired speech: Art therapy is a powerful communication tool that creates avenues of self-expression that are invaluable to those struggling with speech problems. Even if participants do not have speech problems, it can sometimes be easier to express difficult thoughts and feelings visually instead of verbally.

Isolation and depression: About half of people with PD can experience some form of depression during the course of the disease. Art therapy creates a sense of community and emotional support that can alleviate feelings of isolation that often make depression more likely.



Paint by Number Example

The Johns Hopkins Parkinson's Disease and Movement Disorders Center will be hosting a Painting for Parkinson's night on May 20th from 6-8PM at Saint Johns Lutheran Church in Parkville, MD. Participants will use a paint by number canvas board to help guide their painting. To register, please contact Chelsea Ganc at **410-955-6684** or by email at **cganc1@jhmi.edu**.

PROGRAM CALENDAR

SPONSORED IN PARTNERSHIP WITH BY THE JOHNS HOPKINS PDMD CENTER, PACING FOR PARKINSON'S AND THE MARYLAND ASSOCIATION FOR PARKINSON SUPPORT.

PAINTING FOR PARKINSON'S

THIS FREE EVENT IS DESIGNED FOR THOSE WITH PARKINSON'S DISEASE AND THEIR CARE TAKERS. PARTICIPANTS WILL SELECT A PAINT BY NUMBERS CANVAS OF THEIR CHOICE TO PAINT.

JANUARY 15TH

MAY 20TH

NOVEMBER 18TH

6-8PM

SAINT JOHNS LUTHERAN CHURCH

8808 HARFORD RD, PARKVILLE, MD 21234



PARKINSON'S DISEASE EDUCATIONAL SERIES

APRIL 15TH

PRESENTER: DR. KELLY MILLS/ DISEASE MODIFYING THERAPIES

JULY 15TH

OCTOBER 21ST

6-8PM

SAINT JOHNS LUTHERAN CHURCH

8808 HARFORD RD, PARKVILLE, MD 21234

NEWLY DIAGNOSED SERIES

THIS **FOUR- PART** SERIES IS DESIGNED FOR THOSE NEWLY DIAGNOSED WITH PARKINSON'S DISEASE (1-2 YEARS) AND THEIR CAREGIVERS. THIS SERIES WILL OFFER VALUABLE INFORMATION AND RESOURCES ABOUT PARKINSON'S DISEASE.

(SPRING SESSION) (FALL SESSION)

MARCH 16TH

SEPTEMBER 28TH

APRIL 20TH

OCTOBER 26TH

MAY 20TH

NOVEMBER 16TH

JUNE 15TH

DECEMBER 14TH

10AM-1PM

JOHNS HOPKINS COMMUNITY

PHYSICIANS (WHITE MARSH LOCATION)

4924 CAMPBELL BLVD #200,

NOTTINGHAM, MD 21236

LEWY BODY AND PARKINSON'S DISEASE DEMENTIA SUPPORT GROUP

THIS IS DESIGNED FOR THOSE WITH DEMENTIA WITH LEWY BODY AS WELL AS THOSE EXPERIENCING COGNITIVE CHALLENGES SECONDARY TO PARKINSON'S DISEASE AND THEIR CAREGIVERS.

1ST MONDAY OF EVERY MONTH

1-3PM

SAINT JOHNS LUTHERAN CHURCH

8808 HARFORD RD, PARKVILLE, MD 21234

ATYPICAL PARKINSONISM SUPPORT GROUP

THIS IS DESIGNED FOR INDIVIDUALS WITH MULTIPLE SYSTEM ATROPHY (MSA), CORTICOBASAL DEGENERATION (CBD), AND PROGRESSIVE SUPRANUCLEAR PALSY (PSP), AS WELL AS THEIR CAREGIVERS.

4TH THURSDAY OF EVERY MONTH

2-4PM

SAINT JOHNS LUTHERAN CHURCH

8808 HARFORD RD, PARKVILLE, MD 21234

ADVANCED SURGICAL THERAPIES SEMINAR

EDUCATIONAL PROGRAM ADDRESSING DEEP BRAIN STIMULATION (DBS), CONTINUOUS LEVODOPA DELIVERY SYSTEM (DUOPA) AND OTHER ADVANCED THERAPIES IN MOVEMENT DISORDERS.

MARCH 18TH

JUNE 17TH

6-8PM

SAINT JOHNS LUTHERAN CHURCH

8808 HARFORD RD, PARKVILLE, MD 21234

FOR MORE INFORMATION ON THESE EVENTS, PLEASE CONTACT CHELSEA GANC @ 410-955-6684 OR BY EMAIL AT CGANC1@JHMI.EDU

ACTIVITIES & UPCOMING EVENTS

ACTIVITIES

PARKINSONICS COMMUNITY CHORUS

EVERY WEDNESDAY, 1:30-3:30PM

GOVANS PRESBYTERIAN CHURCH, SHARP HALL
5828 YORK ROAD
BALTIMORE, MD 21212
FOR MORE INFORMATION, VISIT:
INFO@MARYLANDPARKINSONSUPPORT.ORG

DANCE FOR PARKINSON'S

TUESDAYS @3:30PM; FREE CLASS

GOUCHER COLLEGE, DECKER SPORTS AND
RECREATION CENTER- TODD DANCE STUDIO
1012 DULANEY VALLEY ROAD
TOWSON, MD
FOR MORE INFORMATION, VISIT:
INFO@MARYLANDPARKINSONSUPPORT.ORG

ROCK STEADY BOXING

FOREST HILL

FOR MORE INFO, INCLUDING DAY AND TIMES,
CONTACT 410-893-4153 OR VISIT
WWW.FORESTHILLHEALTHFITNESS.COM



**MARYLAND
ASSOCIATION FOR
PARKINSON
SUPPORT, INC.**

Find your way with us

FOR MORE INFORMATION ON THESE
EVENTS, PLEASE CONTACT CHELSEA
GANC @ 410-955-6684 OR BY EMAIL
AT CGANC1@JHMI.EDU

UPCOMING EVENTS

PFNCA SYMPOSIUM

THIS EDUCATIONAL CONFERENCE IS AN INSPIRATIONAL
GATHERING FOR THOSE FACING PARKINSON'S AND
THEIR CARE PARTNERS. SYMPOSIUM LECTURES AND
BREAKOUT SESSIONS ARE PRESENTED BY MOVEMENT
DISORDER SPECIALISTS, NEUROLOGISTS,
NEUROSURGEONS AND HEALTH EDUCATORS.

APRIL 18, 2020

FALLS CHURCH, VA
TOWSON, MD
REHOBOTH BEACH, DE
WWW.PFNCA.ORG
(301) 844-6510 OR (703) 734-1017

CAREGIVER WELLNESS WORKSHOP

THIS EVENT IS OPEN TO CAREGIVERS OF THOSE WITH
PARKINSON'S DISEASE. PATIENTS ARE INVITED TO JOIN
THEIR CAREGIVERS BUT WILL PARTAKE IN DIFFERENT
ACTIVITIES.

APRIL 3RD

10AM-3PM

LOCATION TBD

SUPPORT GROUP LEADER EVENT

THIS EVENT IS OPEN TO THOSE WHO LEAD
SUPPORT GROUPS THROUGHOUT THE
PARKINSON'S COMMUNITY.

MAY 8TH

11AM-2PM

LOCATION TBD

PARKINSON'S FOUNDATION MOVING DAY

JUNE 13TH

WEINBERG YMCA IN WAVERLY
REGISTRATION OPENS @8:30AM
WALK STARTS @10:30AM

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 N. Caroline St., Suite 5064
Baltimore, MD 21287
Ph: 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**.

Disclaimer: The Movement Disorder 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.

Physician Faculty

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

Fellows

Gerson Suarez-Cedeno, MD
Maitreyi Murthy, MD
Jumana Alshaikh, 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

Allied & Research Team

Jana Arreola
Catherine Bakker, MS
Sydney Baybayon, BA
Emily Carman, BSN, RN, CNRN
Kathy Carney Sacco, LCSW-C
Amanda Gallagher, CCC-SLP
Kecia Garrett
Chelsea Ganc, MS, CHES
Anna J. Hall, BA
Vanessa Johnson, BS
Diane Lanham, MA
Arita McCoy, CRNP
Seneca Motley, BS
Jennifer Millar, PT
Kate Perepezko, BA
Regina Poole, BA
Kori Ribb, BSN, RN, CNRN
Donna Tippet, MPH, CCC-SLP

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