

Movement Disorder Digest

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

Fall 2017

Pacing for Parkinson's

Thanks For Another Amazing Year!

The Johns Hopkins Parkinson's Disease and Movement Disorder Center would like to sincerely thank all the participants who participated in Pacing for Parkinson's at the Baltimore Running Festival!

This year was one of our best successes to date - over \$137,000 was raised for Parkinson's disease research, community outreach and education. None of this would have been possible without the amazing members of the planning committee - **Don Long, Aliya Reich, Paul Deluca, Wendy Long, Kathy Hobart, Julie Bullock, Brandon Bullock, Andy Fish, Ryan Dreibelbis, Jenna Scott, Andy Katz, Kaylin Kopcho, Arita McCoy and Jennifer Eklof.**

Everyone who participated by raising money, running, volunteering or supporting us - your kindness is unmatched! The dedication, morale and awareness that was displayed the day of the event was incredibly inspiring.

A big, heartfelt thank you to everyone, and stay tuned for P4P 2018!



I Am More Than My Diagnosis

Julie Bullock's Journey with Parkinson's Disease

By GiGi Gray

Julie Bullock has always enjoyed working in the community, giving back, and making a difference wherever she goes. This lifestyle has prepared her for what is next to come - never knowing there would be a major plot twist.

One of Julie's proudest moments was getting the opportunity to help with Hurricane Katrina recovery and rebuilding in Gulfport, MS. By being a part of this program, she was able to help build homes for individuals in need. Due to the physical activity that was involved in this project, Julie damaged some muscles in her right arm and began experiencing occasional jitters.

In 2010, Julie joined the Johns Hopkins Department of Psychology and Brain Science, working with professors and graduate students who study all aspects of the human brain. Julie's right arm was still bothersome and she decided it was time to get it looked at. She had her primary care doctor examine her, but they found no connection to Parkinson's disease. After speaking with some of her colleagues, she was encouraged to visit a neurologist. Within minutes of seeing the neurologist, they were sure she had early-onset Parkinson's. This news numbed Julie, and as soon as she got to her car she Googled "Will Parkinson's disease kill me?" She got her answer: "not fatal." She called her husband, then went back to work. Like many, Julie sought a second opinion and with the help of her boss, she was given the contact information for the Johns Hopkins Parkinson's Disease and Movement Disorder Center. She was diagnosed in 2011, confirming the original diagnosis.

Julie had a great sense of humor and she used that to inform her family about her diagnosis, knowing that a flood of bad images would fill their minds. After all, she had those same images of Parkinson's disease. It never crossed her mind to keep her illness a secret, especially at her workplace with all the resources around her. Julie stated, "I cannot imagine

having to live the past 6+ years having to balance my current and future health with the reality of not knowing what lies ahead without my husband. He is my voice of reason, strength, and compassion. Even though I am the one with the diagnosis and taking the medication, we are both dealing with this disease together."



One day at work Julie happened to read the "Today at Hopkins" email message, and the announcement was about Pacing 4 Parkinson's and the Baltimore Running Festival. Julie got very excited; here was something she could do. Julie and her husband immediately got involved.

Julie's involvement with Johns Hopkins PDMDC and Pacing 4 Parkinson's has helped her to feel secure in what she knows about her diagnosis. She volunteers each year to work with the medical students, to let them "try and diagnose her." She uses her diagnosis to help educate the students on PD and to better treat PD patients.

Julie and her husband have been involved with P4P for 4 years and have served on the Committee Board for two years. Together, they have raised \$24,234 and, as always, they watched to see how their dollars would be used. "After all, I'm not just a fundraiser; I am a stakeholder in my future treatment. It's in my best interest to stay involved," stated Julie.

Julie is now 49, and has great hopes that by 60 she will be on a medication that halts the progression of this disease. She hopes that newly diagnosed PD individuals will accept help from the people around them because they too want to know more about PD. She encourages them to learn what they can and ask questions freely. Julie ends by saying, "This isn't the end... it's a plot twist."

CENTER UPDATE

Emily Carman is a new Research Nurse in our center who joined in May 2017. Emily has worked at Johns Hopkins since 2011 where she started her nursing career as a bedside nurse in the Neurology/ Neurosurgery department. She has a passion for the Neurology field and was interested in expanding her knowledge beyond the bedside. Emily enjoys working with Parkinson's Disease and Movement Disorders patients in this new role as it provides her the opportunity to become an active part of each patient's individual journey.



In her free time, Emily enjoys fundraising for Hurricane Katrina victims and has been on 8 mission trips to New Orleans since 2009 to help rebuild homes and bring families home. Since joining the Center, her favorite experience has been participating in Pacing 4 Parkinson's at the Baltimore Running Festival. Emily also enjoys participating in support groups to educate the community.

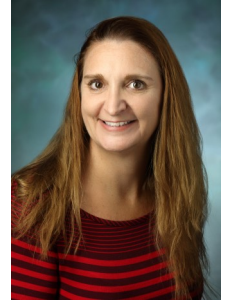
Diane Lanham joined the Parkinson's Disease and Movement Disorder Center in September as a Senior Clinical Research Coordinator. Diane is a Virginia Tech "Hokie" with degrees in Psychology, English and Education, and an MA in Experimental Neuropsychology from George Mason

University. Diane spent 17 years in study coordination and research management at Kennedy Krieger in the fields of developmental cognitive neurology, behavioral neurogenetics, neuroimaging, neuropsychology, and psychiatry.

Her experience in MRI, DTI, fMRI and MRSI image analysis, and background in neuropsychological testing, led to interests in brain-behavior relationships in neurogenetic and neurological disorders. Diane has co-authored a number of manuscripts and actually *enjoys* writing and performing statistical analysis.

After co-founding the Clinical Trials Unit in 2011, Diane became the "go-to" resource for regulatory-related issues, taking great pride in her color-coded binders. She is relentless in her efforts to protect patient safety, ensure study compliance, and preserve data integrity.

Diane is very excited and honored to now be part of the PDMD team, and thanks everyone here for such a warm welcome! She very much looks forward to learning more about movement disorders, PET imaging, and supporting all aspects of the research studies... as long as she doesn't have to draw blood.



EDUCATION

Dystonia - A Complex Movement Disorder

By *Ankur Butala, MD*

Dystonia is a complex movement disorder syndrome in which parts of the body spasm and twist into unusual positions and postures. As a syndrome, dystonia may occur in isolation or as a secondary manifestation of another condition, such as Parkinson's disease (most commonly in the legs when the medication wears off) and, when starting early in childhood, is often presumed to have a genetic cause. Dystonic movements can involve the whole body (i.e., generalized), contiguous parts of the body (segmental) or specific focal regions (such as the neck in "spasmodic torticollis" or "cervical dystonia"). Movements can be quite diverse from brief jerks, twitches or tremors, to back-arching "opisthotonic" postures. Sometimes difficult to diagnosis, dystonia can sometimes only emerge with action or a specific task, such as a task-specific hand-dystonia (when writing) or while playing a musical instrument (an embouchure dystonia when playing a wind instrument).

Treatment can vary based on what causes the dystonia. For example, high-potency antipsychotics can induce a medication-induced acute dystonia which might be stopped once the medication is discontinued. However, most of the time, particularly with genetic dystonia, there is not a *cure*, though there are very effective treatments, which vary from medication to surgery. Medication such as levodopa or trihexyphenidyl is often tried with varied results, usually more helpful for children. At the opposite end of the spectrum, deep brain stimulation can significantly improve quality of life for people with generalized

dystonia or those in whom medication has failed.

There is wide consensus internationally that the most broadly effective treatment is botulinum toxin (BoNT). Discovered in *Clostridium botulinum*, a bacteria implicated in home canning-related sickness, when purified and administered focally in particular muscles, it can dramatically improve dystonia. Though dystonia originates in abnormal electrical activity in the brain, BoNT reduces nerve-muscle (or nerve-gland) signaling which weakens the muscle allowing normal movement. Rather than the cosmetic targeting of crows' feet, the primary use of BoNT is for dystonia, and it had FDA approval for 30+ years.

BoNT often requires dose titration early on as doctors may want to avoid unnecessary side effects. Usually, a minimal effective dose is found within 3-4 follow-up visits. After that, doctors rely upon specific feedback about the muscles and movements targeted with BoNT; pictures or brief video clips can be helpful to document response. Side effects are not uncommon and generally related to excess weakness of the muscle targeted or local spread in the muscle. Both the benefits and side effects of BoNT are temporary, about 3 months (ranging 2-6+ months). As a result, patients typically need to return every 3 months for repeat treatment. If you believe you might have a dystonia, pay attention to specific movements and triggers, perhaps recording a video clip to bring to follow-up visits. You can find more information at <https://www.dystonia-foundation.org/>.

RESEARCH STUDIES

Condition	Title	Objective	Eligibility	PI	Contact
Parkinson's Disease	National Parkinson Foundation Patient Registry	Develop quality care standards for PD	All PD patients and care partners seen at the center	Kelly Mills, MD (NA_00036863)	Nikki Mennucci 410-955-6684
Parkinson's Disease	APL-130277 for the Acute Treatment of OFF Episodes	Evaluate APL-130277 (sublingual version of Apokyn medication) in treatment of sudden "off-time" in PD	Individuals with PD, taking levodopa and having at least 2 hours of "off-time" daily	George Ricaurte, MD (NA_00086593)	Arita McCoy 443-287-7850
Parkinson's Disease	Anxiety in Parkinson's	One day visit to assess anxiety symptoms in PD	All individuals diagnosed with PD	Gregory Pontone, MD (NA_00092051)	Kate Perepezko 410-614-1242
Parkinson's Disease	Rotigotine for Anxiety in PD	8 week study of Rotigotine for the treatment of anxiety disorders in PD	Individuals diagnosed with PD experiencing anxiety	Gregory Pontone, MD (NA_00092051)	Kate Perepezko 410-614-1242
Progressive Supranuclear Palsy	PASSPORT	To determine if an investigational medication (BMS 986168) may potentially treat human tauopathies, such as PSP	Individuals diagnosed with PSP (possible or probable) <5 years	Alexander Pantelyat, MD (IRB00127218)	Emily Carman 410-955-8909
Parkinson's Disease and related disorders	Udall Center Longitudinal Study	Examine the relationship between the clinical symptoms of PD and the disease process in brain tissue (participation includes eventual brain donation)	Individuals diagnosed with PD or atypical PD and those without a neurological diagnosis	Liana Rosenthal, MD (NA_00032761)	Catherine Bakker 410-616-2814
Parkinson's Disease and related disorders	Udall Center Brain Donation Program	Examine the pathological changes in the brain tissue of individuals diagnosed with PD or related disorders as compared to controls	Individuals diagnosed with PD or atypical PD and those without a neurological diagnosis	Liana Rosenthal, MD (NA_00032761)	Catherine Bakker 410-616-2814
Movement Disorders	Genetic Characterization	To study the genetic risk factors involved in movement disorders	Individuals with PD, atypical parkinsonism, dystonia, ataxia, and Lewy body dementia	Jeffrey Rothstein, MD, PhD (NA_00055442)	Kecia Garrett 410-502-0133
Dystonia	Dystonia Coalition	Create repository to learn more about dystonia	Individuals over the age of 18 who have primary dystonia	Alex Pantelyat, MD (NA_00074297)	Aathman Swaminathan 410-955-6672
Parkinson's Disease	A Randomized Controlled Trial of OnabotulinumtoxinA for Depression in PD	To study if the drug OnabotulinumtoxinA (BOTOX®) is helpful for the treatment of depression in PD	All individuals diagnosed with PD who have symptoms of depression	Alex Pantelyat, MD (NA_00082708)	Nikki Mennucci 410-955-6684
Parkinson's Disease	Exploring Mechanisms for Neuropsychiatric Symptoms of PD using Transcranial Direct Current Stimulation (tDCS)	To study if tDCS helps depression, cognition, or other non-motor PD symptoms	All individuals diagnosed with PD who have symptoms of depression	Kelly Mills, MD (NA_0008795)	Yousef Salimpour 410-502-2666

RESEARCH STUDIES (continued)

Condition	Title	Objective	Eligibility	PI	Contact
Parkinson's Disease	Parkinson's Progression Markers Initiative Genetic Cohort	Identify genetic links to PD and learn how the LRRK2 mutation affects certain populations of people (<i>Part of the Michael J. Fox Foundation Parkinson's Progression Markers Initiative</i>)	1.) Individuals diagnosed with PD who are of Ashkenazi Jewish descent 2.) Individuals without PD who are of Ashkenazi Jewish descent AND have a first degree relative with PD	Liana Rosenthal, MD (NA_0003923)	Nikki Mennucci 410-955-6684

Current Surgical Treatments for Parkinson's disease

By Kelly Mills, MD

Many patients living with Parkinson's disease find significant relief of their symptoms using oral medications such as Carbidopa/levodopa, pramipexole, ropinirole, or rasagiline, just to name a few. However, many patients who were once responding well to oral medications develop issues with symptom control over time and may require more advanced therapies. One issue that arises is "motor fluctuations," or when the beneficial effect of PD medications wears off after a few hours following each dose, leaving the patient slow, stiff, tremulous and fatigued before the next dose of medication takes effect. Another common issue is "dyskinesia," which is excessive involuntary movement that manifests as wiggling of the body or limbs and occurs when the medication is working at its best. Several therapies are available to address these complications of oral medical therapy in PD.

Carbidopa/levodopa enteral suspension (brand name: Duopa) can be infused at a constant rate from a pump through a small catheter that enters the part of the intestine that absorbs levodopa. This allows treatment with a constant rate of medication rather than the peaks and valleys associated with taking oral pills of Carbidopa/levodopa. It may also help non-movement fluctuating symptoms like fatigue. The catheter is placed through the abdominal wall in an outpatient surgical procedure and the cartridges of levodopa gel are shipped to the patient's home each month.

Another therapy to help with motor fluctuations and dyskinesia is deep brain stimulation (DBS). DBS works by improving function in the brain networks controlling movement that are disrupted by the lack of dopamine in Parkinson's disease. This effect is "downstream" from dopamine, so the effect of DBS persists even when the patient has not taken medications or when medications wear off between doses. DBS can also help tremor that does not respond to oral medications. DBS therapy involves a surgical procedure to implant small electrodes deep in the brain through small holes in the skull. In a brief, outpatient

second surgery, a device with the computer and battery is implanted in the chest like a cardiac pacemaker. While the traditional way of doing DBS surgery requires the patient to be awake so that his or her tremor or other movement symptoms can be tested to assure accurate placement of the electrode, we now also have the capability of doing DBS surgery under general anesthesia using real-time MRI guidance.



There is ongoing research into whether or not MRI-guided Focused Ultrasound (MRgFUS) can be used to treat medication-refractory tremor or dyskinesia in Parkinson's disease. While this therapy is FDA-approved for treatment of essential tremor, it is not yet proven safe or effective in Parkinson's disease, though trials are under way. There are still questions about how well this will work and how long the ultrasound lesion will last. If shown to be effective, this might be an option for patients with Parkinson's disease only affecting one side of the body.

Your movement disorder neurologist should be able to discuss all of these therapies with you. Or, visit the Neuromodulation and Advanced Therapies Clinic in the Johns Hopkins Parkinson's Disease and Movement Disorder Center for an evaluation.

Specialty Center

GUITAR- PD

By Emile Moukheiber, MD

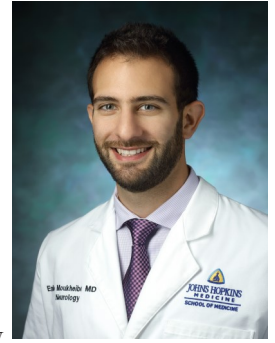
Engagement in musical activities has been found to improve symptoms in individuals with Parkinson's disease (PD), and physical therapy as well as music therapy have been demonstrated as viable non-pharmacological intervention methods that improve motor function in these individuals. Therapeutic instrumental music performance has the attributes of physical, rhythmic and social engagement, combined with immediate auditory feedback, and has the potential to bring in additional neuro-rehabilitative effects associated with musical engagement.

Previous research studies had suggested that music-based therapies may be helpful in individuals with Parkinson's disease. We therefore set forth in our study to assess the feasibility and the effects of non-traditional finger-style guitar classes on different parameters in individuals with Parkinson's disease.

We, in fact, postulate that a 6-week bi-weekly finger-style guitar group intervention (12 sessions in total) in addition to usual and

routine treatment, will be a feasible intervention in patients with Parkinson's disease (PD), and will result in significant gains in quality of life, mood, cognition, social engagement, upper extremity function and upper extremity dexterity, as compared to controls who receive only their usual and routine treatment.

The study will take place at the Peabody Institute of the Johns Hopkins University as part of the Center for Music and Medicine, which provides cutting-edge multidisciplinary clinical care for musicians and research on music-based interventions for non-musicians. This study will continue to drive the Center's mission of driving research in music and medicine and developing music as well as rhythm-based therapies that improve patient quality of life and address symptoms. For more information, please email Diane Lanham - dlanham1@jhmi.edu



Medicinal Use of Cannabis

By Ankur Butala, MD

Medicinal use of cannabis has had a revival in recent times as states across the country have lifted prohibitions in place since the early 20th century. Largely, however, this has been the result of a populist initiative rather than compelled by scientific merits, and illustrates the pendular nature of scientific discovery (and rediscovery). Though referenced by traditional healers and apothecaries for much of history, it was not introduced to Western physicians until 1800s when it rapidly joined the pharmacopeia. Doctors recommended cannabis tinctures and elixirs as a treatment for insomnia, seizures, rheumatism, and migraines until the 1930s, when outlawed as a backlash to increased immigration and the "new" jazz craze.

Research continued, at a snail's pace, through the 20th century, with the isolation of the primary psychoactive cannabinoids, delta-9 tetrahydrocannabinol (THC) and cannabidiol (CBD). Later, the discovery of an endogenous cannabinoid, anandamide, and the retrograde activity of the cannabinoid receptor expanded our understanding of nerve signaling. As with much of science, discovery rarely leads to clear-cut answers and, generally, more questions needing clarification before cannabis-based treatments can be broadly implemented.

Cannabis plants come in three varieties: *Cannabis sativa*, *Cannabis indica* and *Cannabis ruderalis* (minimal amount of cannabinoids and used for industrial hemp production). These differ in their concentration of THC and CBD; the greater amount of THC in

C. sativa causing a more psychoactive experience with "spacy" or "cerebral" effect, whereas *C. indicas* are associated with somatic (i.e. appetite-stimulating, hypnotic) effect. In truth, effects are difficult to generalize since more than 250 unique cannabinoids are interacting with individual specific genetic differences.

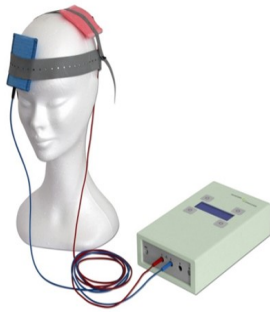
There is little data regarding the use of cannabis and cannabinoids in movement disorders with conflicting observations. Summarizing the available evidence, cannabis seems to worsen bradykinetic (i.e. Parkinson OFF symptoms) by impairing dopamine's activity. Though many people report reduced tremors, this is not consistently seen and it is likely that benefits observed relate to anxiolytic properties. There is more evidence for hyperkinetic (or fast) movement symptoms such as dyskinesia or chorea. Other disorders which might be amenable to treatment are Tourette Syndrome, Huntington Disease and Dystonia.

Currently, cannabis remains prohibited federally despite being decriminalized in 13, authorized medicinal use in 27 and recreational use permissible in 9 states. Also, it cannot be overstated that many reports of improved symptoms are based on anecdotal evidence and physicians *cannot* and *should not* rely on that alone. Nonetheless, medicinal cannabis and cannabinoid based treatments are ripe for further study.



Featured Parkinson's Disease Studies

Exploring mechanisms for Neuropsychiatric Symptoms of Parkinson's Disease using **Non-Invasive Brain Stimulation**



You may be eligible to participate if you have Parkinson's disease and:

- Depression
- Anxiety
- Apathy
- Cognitive problems such as memory loss, word finding or inattention

For more information, please contact:
Ankur Butala MD (Ankur.Butala@jhmi.edu) or
Kelly Mills MD (kmills16@jhmi.edu)
T 410 502 0133

Randomized Controlled Trial of Botulinum Toxin against Parkinson's Disease Depression



Currently, recruiting people with Parkinson's disease in a randomized clinical trial of whether a fixed amount of botulinum toxin can improve the symptom of depression in Parkinson's disease

If interested in learning more, please contact:

Ankur Butala MD
(Ankur.Butala@jhmi.edu) or Arita
McCoy APRN (Amccoy6@jhmi.edu)
T 410 955 2954

Center Distributes Parkinson's Foundation's Aware in Care Kits

The *Parkinson's Foundation* launched the **Aware in Care** campaign in 2011 to help people with Parkinson's disease (PD) get the best care possible during a hospital stay. According to a recent study, three out of four people with Parkinson's do not receive medications on time when staying in the hospital. With more frequent hospital visits and a high sensitivity to the timing and dosing of PD medications, people with Parkinson's face great risks in the hospital.

To protect, prepare and empower people with Parkinson's before, during and after a hospital visit, the Parkinson's Foundation developed the free **Aware in Care** kit with tools and information to share with hospital staff during a planned or emergency hospital visit.

Aware in Care kits can be requested from the Johns Hopkins PDMD Center, by contacting GiGi Gray at 410-955-6692. You may also visit the Parkinson's Foundation's website, www.parkinson.org to have a kit sent directly to your home.

*Excerpted from www.parkinson.org.



 **Parkinson's
Foundation**
CENTER OF EXCELLENCE

PARKINSON'S PROGRAM CALENDAR

These programs are presented by the *Johns Hopkins Parkinson's Disease and Movement Disorders Center* through various community partnerships and funding sources, including our Center's annual fundraising event, Pacing 4 Parkinson's. Pre-registration is encouraged for all programs listed below. Please contact our center at **410-955-6692** to learn more about these programs. Visit our website at www.hopkinsmedicine.org/neuro/movement for a full listing.

◆ Parkinson's Disease Educational Series

3rd Wednesday of Every Month

7:00 p.m. - 9:00 p.m.

St. Thomas Episcopal Church, 1108 Providence Road, Towson, MD 21286

December 20 - *Q & A Panel*

January 17 - *Kelly Mills, MD - Myths and Misconceptions about Parkinson's Disease*

February 21 - *Weiyi Mu, ScM - Genetic and Environmental Causes of Parkinson's Disease*

◆ Surgical Therapeutics for Parkinson's:

Deep Brain Stimulation & Duopa Information Session

Thursday, April 19th

6:00 p.m. - 8:30 p.m.

St. Thomas Episcopal Church, 1108 Providence Road, Towson, MD 21286

For more information contact GiGi Gray 410-955-6692 or ggray8@jhmi.edu

◆ Atypical Parkinsonism Support Group

4th Thursday of Every Month

2:00 p.m. - 4:00 p.m.

St. Thomas Episcopal Church, 1108 Providence Road, Towson, MD 21286

◆ Atypical Parkinsonism Support Group - Washington, DC

3rd Saturday of Every Month

2:00 p.m. - 4:00 p.m.

Sibley Memorial Hospital - Bldg. A, 2nd Floor, Room 5

Kristen Weidner, 715-821-3356 or weidner.kristen@gmail.com

◆ ParkinSonics Community Chorus

Every Wednesday

1:30 p.m. - 3:00 p.m.

Govans Presbyterian Church, Sharp Hall

5828 York Road, Towson, MD 21286

Supported in part by Johns Hopkins PDMDC

◆ Rock Steady Boxing

Forest Hill Health and Fitness

2217 Commerce Road, Forest Hill, MD 21050

410-893-4153 - Call for class times

Supported in part by Johns Hopkins PDMDC

◆ Dancing with PD

Every Tuesday

1:30 p.m. - 3:00 p.m.

Goucher College, Decker Sports and Recreation Center - Todd Dance Studio

1012 Dulaney Valley Road, Towson, MD

443-470-0279 or ellentalles@comcast.net

◆ Parkinson's Exercise Program - Brick Bodies at Padonia

2430 Broad Avenue, Lutherville Timonium, MD 21093

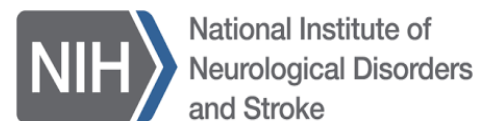
Free Class; members & non-members at Brick Bodies

Contact: info@marylandparkinsonsupport.org or 443-470-0279

Supported in part by Johns Hopkins PDMDC



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MAPS
Find your way with us

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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