

# Parkinson's & Movement Disorder Digest



Newsletter for the Johns Hopkins Parkinson's Disease and Movement Disorders Center

## How Are You Sleeping?

*Seema Gulyani, PhD, CRNP*

*Senior Nurse Practitioner*

*Johns Hopkins Movement Disorders Center*

*Johns Hopkins Center for Sleep*



A good night's sleep is crucial to our health and well-being. Adequate rest is especially important for those with Parkinson's disease (PD) to restore and repair the body. However, **sleep-related problems affect more than 75% of individuals with PD.** It has been estimated that 67% of PD patients have problems initiating sleep and 88% have difficulties maintaining sleep.

### Common PD Related Sleep Complaints

- Difficulty falling and staying asleep
- Waking up to go to the bathroom
- Excessive daytime sleepiness
- Sleep apnea
- Leg movements, cramping, or jerking
- Vivid dreaming
- Difficulty turning over in bed

Some of the symptoms of PD that can make it more difficult to initiate sleep include frequent urination, painful cramps, stiffness, pain, vivid dreaming, involuntary leg movements, and hallucinations. It is also common for those with more severe daytime symptoms to have worse sleep. Even though tremor disappears at the onset of sleep, it may reappear during brief awakenings and for short intervals during light non-REM (rapid eye movement) sleep to potentially disturb sleep.

One of the most common and troublesome barriers to a good night's rest for people with PD is the increased need to get up to urinate (nocturia). In fact, nocturia affects more than 60% of those with PD and is a result of over activity of the bladder muscles. Management tools for nocturia may consist of limiting liquids after 5 p.m. or placing a portable commode at the bedside. Sleepiness during the day is also very common, affecting 30 - 50% according to the National Parkinson Foundation (NPF). Excessive sleepiness may arise in PD due to a poor night's sleep or dopaminergic medications.

Other sleep disorders commonly associated with PD that may interfere with restful sleep include sleep apnea, restless leg syndrome, periodic limb movements, and REM sleep behavioral disorder. According to the NPF, obstructive sleep apnea affects 40% of individuals with PD. Signs and symptoms can include loud snoring, pauses in breathing noticed by a bed partner, waking up with headaches, waking up choking, gasping for air, or waking up with dry mouth. Restless leg syndrome is an urge to move the legs usually caused by an unpleasant or uncomfortable sensation. Symptoms of restless leg syndrome have a tendency to worsen at night and can infringe with restful sleep.

Another common sleep disorder is periodic limb movements which is described by repetitive movements of one or both legs. Some people with PD can also be affected by REM sleep behavioral disorder, causing them to experience abnormal movements during vivid dreams. This is due to the loss of muscle control that does not occur during REM or "dream" sleep.

While issues with initiating and maintaining sleep can be disruptive to daily life, there are many medical treatments and therapies available. In addition to these treatments, some of the most effective therapies for improving sleep include better sleep hygiene and simple lifestyle adjustments. Tips for improving sleep hygiene can be found through the *American Academy of Sleep Medicine* at [www.sleepeducation.com](http://www.sleepeducation.com).

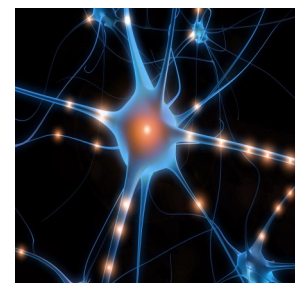
If you or someone you love is affected by sleep-related problems, make sure you discuss them with your doctor. To make an appointment with the **Johns Hopkins Center for Sleep**, please call **410-715-1060** or **1-800-WE-SLEEP**.

### *American Academy of Sleep Medicine* Healthy Habits of Good Sleep

- Set a sleep schedule - get up at the same time each day
- If you do not fall asleep in 20 minutes, get out of bed
- Avoid naps longer than 30 minutes and after 3 p.m.
- Avoid excessive liquids in the evening
- Make your bedroom comfortable - free from light and noise
- Exercise regularly
- Limit caffeine after lunch

## ABOUT THE CENTER

The Johns Hopkins Parkinson's Disease and Movement Disorders Center is comprised of a multidisciplinary team that seeks to fulfill the tripartite mission of patient care, research, and education. Movement disorders can be progressive and disabling conditions and include ataxia, dystonia, essential tremor, and Parkinson's disease. Untreatable a mere 50 years ago, there has been steady progress in the treatment of these conditions since. Recent advances in our understanding of the mechanisms of these disorders have led to tremendous progress in treatment — both medical and surgical. Our ever expanding team and facilities are committed to advancing this progress and achieving our mission of improving the lives of patients suffering from these disorders.



*Interim Director:* Zoltan Mari, MD  
*Associate Director:* Becky Dunlop, RN, BSN  
*Contact:* 410-502-0133, option 2

## SPECIALTY CENTERS

### Ataxia Center

The Ataxia Center at Johns Hopkins offers a multidisciplinary approach to the identification and treatment of cerebellar ataxia. Ataxia is typically defined as the presence of abnormal, uncoordinated movements and may result from abnormalities in different parts of the nervous system. Neurologists familiar with the nuances of these disorders work with speech therapists, swallowing experts, physical and occupational therapists as well as genetic counselors, ophthalmologists, and psychiatrists to see the patient as a whole person.

*Medical Director:* Liana S. Rosenthal, MD  
*Contact:* 410-502-0133, option 1

### Deep Brain Stimulation Center



This center is focused on helping appropriate patients with movement disorders, including essential tremor, dystonia, and Parkinson's disease. Deep brain stimulation (DBS) surgery has been conducted at Johns Hopkins for over 15 years, making it one of the most experienced DBS centers in the U.S. The team of neurologists, neurosurgeons, physician assistants, and nurses can tap into the expertise offered by other Johns Hopkins specialists including psychologists, psychiatrists, and electrophysiologists. DBS is a FDA-approved neurosurgical procedure that involves surgically implanting electrodes into the brain to alleviate the symptoms caused by movement disorders. The team at the DBS center has established a clinical comprehensive assessment to evaluate possible DBS candidates and determine if surgery will benefit a patient.

*Surgeons:* William Stanley Anderson, MD, PhD & Frederick Lenz, MD, PhD  
*Contact:* 410-502-0133, option 2

### Dystonia Center

Dystonia is a neurological condition with a very broad range of manifestations and defined as a sustained muscle contraction. The basic underlying problem involves over-activity of the main muscles needed for a movement, extra activation of other muscles that are not needed for the movement, and simultaneous activation of muscles that work against each other. There are many treatment options for dystonia, including botulinum toxin injections, pharmacological treatments, and in some cases, deep brain stimulation.

*Physicians:* Zoltan Mari, MD & Liana S. Rosenthal, MD  
*Contact:* 410-502-0133, option 2

# NATIONAL PARKINSON FOUNDATION CENTER OF EXCELLENCE



## Center of Excellence Leadership Conference Winter 2014 Update

Paige Nichols, BA, Research Assistant

On January 16 - 18, 2014, representatives from Johns Hopkins and 38 other Parkinson's Disease and Movement Disorders Centers from around the globe travelled to Miami, Florida to participate in the National Parkinson Foundation's (NPF) 2014 Center of Excellence (COE) Leadership Conference. The goal of this annual conference is to gather leaders in the Parkinson's field to update the academic community on current research and clinical breakthroughs as well as innovations in care delivery. The NPF Center of Excellence network represents Parkinson's specialists at top medical institutions who are leading the way to advance care through research and through identifying, understanding, and teaching the management strategies that deliver the best results for patients. As a group, NPF COE provide care to more than 50,000 patients in the United States and 8 other countries around the world.

Some of the topics on the agenda at this year's conference included ongoing research initiatives such as the NPF Parkinson's Outcomes Project. With 20 Centers of Excellence participating in the study, including our center at Johns Hopkins, the NPF Parkinson's Outcome Project is the longest and largest longitudinal Parkinson's disease study of real-world care ever attempted. The overall goal of this comprehensive study is to develop best care practices for Parkinson's disease, with additional goals to involve patients in their care, create transparency within the NPF Center of Excellence network, fund comparative research, and inform education and outreach efforts. Initiated in 2009, there are currently 7,200 patients in the study with over 14,300 clinical evaluations. In Miami, ongoing results from the study were analyzed by study investigators and have been made available to the public through the NPF website ([www.parkinson.org](http://www.parkinson.org)) in a report entitled, "**Parkinson's Outcome Project: Report to the Community.**" One of the key findings is the conclusion that negative mood and depression has the greatest impact on health status.

Additionally, the topics of patient-centered care, gene therapy, telemedicine, and patient inspired clinical trials were discussed among the conference participants. At the conclusion of the conference, NPF leadership highlighted our collective mission to improve the lives of people with Parkinson's disease through research, education, and outreach. The Johns Hopkins Parkinson's Disease and Movement Disorders Center looks forward to continuing to serve the mission as a NPF Center of Excellence.

## Center Distributes National Parkinson Foundation's *Aware in Care* Kits

*Efforts to Help Families Advocate for Medications ON TIME while Hospitalized*

Did you know that 3 out of every 4 individuals with Parkinson's do not receive their medications on time when hospitalized? Parkinson disease medication regimens are complex and individualized. The NPF's *Aware in Care* kit provides individuals living with Parkinson's disease and their families with vital information designed to educate hospital staff about the need for the appropriate medication at the correct time.

Kit Contents:

- Hospital action plan
- Parkinson's disease ID bracelet
- Medical alert card
- Medication form
- Parkinson's disease fact sheet
- Magnet
- PD reminder slips for hospital staff



YOUR DOCTOR WANTS YOU TO GET YOUR MEDICATIONS ON TIME.

IN THE HOSPITAL  
**3** OUT OF **4**  
PEOPLE WITH PARKINSON'S DON'T.

**CHANGE THE ODDS.**

Order your kit today!  
1-800-473-4636  
[www.awareincare.org](http://www.awareincare.org)

## RESEARCH: CURRENTLY ENROLLING STUDIES

### DYSTONIA

**Dystonia Coalition** The overall goal is to develop a better understanding of dystonia that may improve the treatment of affected patients. The study is seeking individuals over the age of 18 who have primary dystonia.

Becky Dunlop, RN, BSN | 410-955-8795  
 PI: Zoltan Mari, MD | NA\_00074297  
*Funded by the National Institutes of Health, National Institutes of Neurological Disorders and Stroke, and Office of Rare Disease Research*

### SIALORRHEA

**Mysticol** The overall goal is to investigate the efficacy of MYOBLOC (Botulinum toxin type B) injection in the treatment of troublesome sialorrhea (drooling or excessive salivation) and to assess its safety and tolerability in adults. The study is recruiting individuals over the age of 18 who have untreated excessive salivation due to any cause in the last 3 months.

Becky Dunlop, RN, BSN | 410-955-8795  
 PI: Zoltan Mari, MD | NA\_00084484  
*Funded by US WorldMeds, LLC*

### MOVEMENT DISORDER WITH UNCLEAR DIAGNOSIS

**AVID** The goal is to determine if 18F-AV-133 PET imaging can detect loss or damage of dopamine cells. The study is recruiting individuals with symptoms of a movement disorder but who have not yet received a definite diagnosis.

Becky Dunlop, RN, BSN | 410-955-8795  
 PI: Dean Wong, MD | NA\_00071306

### PARKINSON'S DISEASE

**Longitudinal Study** The goal is to longitudinally follow individuals with PD and those without PD. This study is linked with the brain donation program that seeks to better understand the cause of PD. The study is recruiting those with and without PD.

Vanessa Johnson | 410-614-1480  
 PI: Liana Rosenthal, MD | NA\_00032761  
*Part of the Morris K. Udall Parkinson's Disease Research Center of Excellence and funded by the National Institute of Neurological Disorders and Stroke.*

### INDIVIDUALS WITHOUT PD

**Prodromal Cohort** This study is an addition to the Michael J. Fox Foundation Parkinson Progression Markers Initiative (PPMI) to identify those who may be at risk of developing PD. The goal is to examine the biomarker progression prior to onset of motor symptoms. The study is seeking individuals who are over the age of 60 and do not have PD, but may have hyposmia (lack of smell), REM behavioral sleep disorder, or LRRK2 genetic mutation.

Arita McCoy, RN, BSN | 410-955-2954  
 PI: Zoltan Mari, MD | NA\_00039232  
*Funded by the Michael J. Fox Foundation*

### PARKINSON'S DISEASE

**MARK-PD** This study is seeking to find biomarkers to improve diagnosis and treatment of individuals with PD. The study is recruiting individuals with PD that are treated with PD medications and individuals without PD.

Nadine Yoritomo, RN, BSN, CCRP  
 410-616-2822  
 PI: Liana Rosenthal, MD | NA\_00031749  
*Part of the Parkinson's Disease Biomarker Program and funded by the National Institute of Neurological Disorders and Stroke.*

### PARKINSON'S DISEASE

**NPF Quality Improvement Initiative** The goal of this patient registry study is to develop models of excellent Parkinson's care for best health outcomes. The study is seeking all PD patients who are seen at an NPF Center of Excellence and their care partners.

Becky Dunlop, RN, BSN | 410-955-8795  
 Bailey Vernon, MPH | 410-616-2811  
 PI: Zoltan Mari, MD | NA\_00036863  
*Funded by the National Parkinson Foundation*



### PARKINSON'S DISEASE

**Transcranial Direct Current Stimulation** This study is testing the therapeutic relevancy of non-invasive brain stimulation for improving motor symptoms. The study is recruiting all individuals diagnosed with PD.

Yousef Salimpour, PhD | 410-614-3424  
 PI: Reza Shadmehr, PhD | NA\_00081426

## Researchers Uncover New Biological Target for Combating Parkinson's Disease

*Compounds already exist to potentially treat both inherited and non-inherited cases*

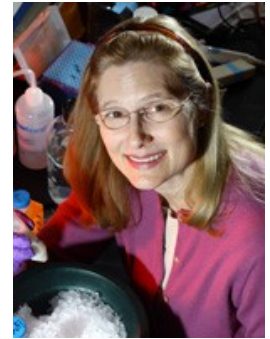
Researchers at Johns Hopkins and elsewhere have brought new clarity to the picture of what goes awry in the brain during Parkinson's disease and identified a compound that eases the disease's symptoms in mice. Their discoveries, described in a paper published online in *Nature Neuroscience* also overturn established ideas about the role of a protein considered key to the disease's progress.

"Not only were we able to identify the mechanism that could cause progressive cell death in both inherited and non-inherited forms of Parkinson's, we found there were already compounds in existence that can cross into the brain and block this from happening," says Valina Dawson, PhD, the director of the Stem Cell Biology and Neuroregeneration Programs at the Johns Hopkins University School of Medicine's Institute for Cell Engineering (ICE). "While there are still many things that need to happen before we have a drug for clinical trials, we've taken some very promising first steps."

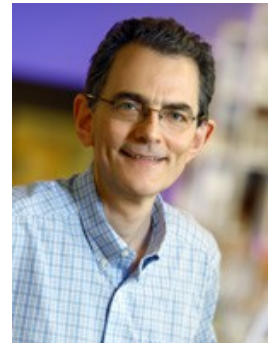
Dawson and her husband, Ted Dawson, MD, PhD,

the director of ICE, have collaborated for decades on studies of the molecular chain of events that leads to Parkinson's. One of their findings was that the function of an enzyme called parkin, which malfunctions in the disease, is to tag a bevy of other proteins for destruction by the cell's recycling machinery. This means that nonfunctional parkin leads to the buildup of its target proteins, and the Dawsons and others are exploring what roles these proteins might play in the disease.

**View the full article online at:**  
[www.hopkinsmedicine.org/news/media/releases/researchers\\_uncover\\_new\\_biological\\_target\\_for\\_combating\\_parkinsons\\_disease](http://www.hopkinsmedicine.org/news/media/releases/researchers_uncover_new_biological_target_for_combating_parkinsons_disease)



Valina Dawson, PhD



Ted Dawson, MD, PhD

## Sense of Smell and Parkinson's Disease: Are they Connected?

Arita McCoy, RN, BSN



Hyposmia, or the reduced ability to smell and detect odors, is a common complaint of Parkinson disease (PD) patients. However, the reasons for smell loss are currently unknown. Theories suggest that hyposmia may be related to an excess accumulation of the protein alpha-synuclein in the brains of people with PD. Heiko Braak, MD suggests that PD may not start in the movement control center of the brain, but in the gastrointestinal system and the olfactory bulb, the part of the brain that controls our sense of smell.

With these theories in mind, the Michael J Fox Foundation is very interested in hyposmia and how it may be a predictor of PD. Early detection is a crucial step to understand the causes of PD to develop better treatments. At Johns Hopkins, we are one of 32 international sites participating in the Parkinson Progression Markers Initiative, which has begun looking for individuals who are over the age of 60 and have a decreased ability to smell.

Studying the sense of smell in family members and friends of Parkinson's patients could help us get closer to the goal of discovering more about how PD starts – and how we can eventually stop it.

If you are interested in learning more or would like to complete the smell survey, please visit [www.michaeljfox.org/ppmi](http://www.michaeljfox.org/ppmi) or contact Arita McCoy, RN, BSN at 410-955-2954 or [amccoy6@jhmi.edu](mailto:amccoy6@jhmi.edu).

## COMMUNITY PROGRAMS

### Center Announces Newly Diagnosed Series

Becky Dunlop, RN, BSN

Our Center is offering a series of classes, co-facilitated by our health educator and nurses, for individuals and families new to the diagnosis of Parkinson's disease. The class curriculum is based on the evidence from the Parkinson's disease patient education research literature. The series is designed to enhance knowledge and improve self-management so that individuals and families new to PD feel well prepared to partner with their providers along the disease trajectory.

In 2006, the Royal College of Physicians in London published the Parkinson's Disease National Clinical Guideline for Diagnosis and Management in Primary and Secondary Care (NICE). NICE stipulates that patient communication in chronic disease should be focused on two goals: the development of skills to enhance collaboration between the physician expert and the person living with the condition, and self-management skills which educate in problem solving. Another program offered in the United States, PROPATH, demonstrated the benefits of patient education and health promotion to those who received the intervention. If you are interested in this program, please see the yellow box to the right for more details.

*An Educational Series for  
Individuals Newly Diagnosed with  
Parkinson's Disease*

**Monday, June 16, 2014**

**Monday, June 23, 2014**

**Monday, June 30, 2014**

6:00 - 8:00 p.m.

Johns Hopkins at Green Spring Station  
2330 West Joppa Road, Foxleigh 101  
Lutherville, MD 21093

To register, please contact Bailey Vernon at  
410-616-2811 or [bvernon1@jhmi.edu](mailto:bvernon1@jhmi.edu).

Registration is required and space is limited.

Cost is \$20 per person. Please RSVP by June 4, 2014.

### *NPF Announces New Tool for the Newly Diagnosed First Connect My Page*

*My Page* is a free service developed by people with PD designed to empower those newly diagnosed by providing tools to lead a healthier, more independent life. Subscribers have access to articles, videos, and other online resources.

[www.parkinson.org/mypage](http://www.parkinson.org/mypage)

### Pacing 4 Parkinson's Hits New Milestones

*Join the 2014 P4P Team as a Participant OR Volunteer!*

Over the past 5 years, Pacing 4 Parkinson's (P4P) has become the largest community fundraiser for the Movement Disorders Center and supports the mission to improve patient care, expand outreach efforts, and advance research initiatives. P4P is a charity team at the Baltimore Running Festival (BRF) where team members have the opportunity to participate in one of the races and raise money for the cause. Over 300 participants raised over \$100,000 for the 2013 event, breaking all records and making P4P the second largest charity team at the BRF.

Join the fight on **Saturday, October 18, 2014** by becoming a P4P volunteer, participant, or supporter! Team members will create a personal fundraising page, pledge to raise a minimum of \$100, and participate in the BRF. All P4P team members receive registration to one of the BRF races (kids fun run, 5k, half marathon, marathon, or team relay), a P4P Under Armour t-shirt, training runs and special events, team camaraderie, and race day support. The P4P committee hosts a hospitality tent on race day to provide food, drinks, bag check, and support for all team members, families, and friends.

Registration is open until September 2014. Visit [www.pacing4parkinsons.org](http://www.pacing4parkinsons.org) or contact Bailey Vernon at 410-616-2811 or [pacing4parkinsons@gmail.com](mailto:pacing4parkinsons@gmail.com) to register, donate, volunteer or learn more.



2013 P4P Team Photos

# COMMUNITY CALENDAR

## Saturday, March 1

### Parkinson's Symposium

*Sponsored by the Parkinson Foundation of the National Capital Area (PFNCA)*

9:00 a.m. - 4:00 p.m.

Falls Church, VA

To register, call 703-734-1017

## Wednesday, March 5

### Dinner with the Doctors

*Dr. Zoltan Mari & Dr. Howard Weiss*

5:00 p.m. - 8:00 p.m.

Lebanese Taverna, Baltimore, MD

To register, call 703-734-1017

## Saturday, March 15

### Town Hall Meeting

*Sponsored by Maryland Association for Parkinson's Support (MAPS)*

Saturday, March 15

10:30 a.m. - 1:00 p.m.

Columbia, MD

To learn more, call Deb Bergstrom at 301-712-5381

## Saturday, March 29

### Dystonia Educational Forum

*Sponsored by the Dystonia Medical Research Foundation & Johns Hopkins*

8:30 a.m. - 3:30 p.m.

Towson, MD

To register, call Julie Mack at 312-755-0198

## Friday, April 4

### Managing Parkinson's Disease

*Hagerstown Support Group & Johns Hopkins*

9:00 a.m. - 4:00 p.m.

Hagerstown, MD

To register, call Art Guyer at 240-625-2722

## Monday, April 7

### Deep Brain Stimulation

#### Information Session

*Presented by Johns Hopkins*

6:00 - 8:00 p.m.

Baltimore, MD

To register, call 410-616-2811

## Wednesday, May 7

### Support Group Leader

#### Networking Event

*Presented by Johns Hopkins*

Wednesday, May 7

10:00 a.m. - 2:00 p.m.

Towson, MD

To learn more, call 410-616-2811

## Monday, June 16, 23, 30

### Newly Diagnosed Series

*Presented by Johns Hopkins*

6:00 - 8:00 p.m.

Lutherville, MD

To register, call 410-616-2811

## Monday, September 8

### Deep Brain Stimulation

#### Information Session

*Presented by Johns Hopkins*

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

Baltimore, MD

To register, call 410-616-2811

## Saturday, October 18

### Pacing 4 Parkinson's

*Presented by Johns Hopkins*

Baltimore, MD

[www.pacing4parkinsons.org](http://www.pacing4parkinsons.org)

To learn more, call 410-616-2811

## Efforts to Expand Community Programs

### Town Hall Meeting Saturday, March 15

*Maryland Association for Parkinson's Support (MAPS) is a new community non-profit organization that aims to provide valuable services to the entire PD community. The meeting on March 15 will include presentations from movement disorder specialists to discuss the need for community collaboration. Details can be found on the calendar to the left.*

## Education & Support Groups

Community groups can be an essential key to successfully coping with PD or other movement disorders. Please contact Bailey Vernon at 410-616-2811 or [bvernon1@jhmi.edu](mailto:bvernon1@jhmi.edu) to find a group near you.

## Dancing with PD

Dancing with PD is a FREE, fun, and easy dance class based on the work of the Mark Morris Dance Group that focuses on balance, flexibility, and much more! Those with PD and their families and friends are invited to attend.



### Every Tuesday, 2:00 - 3:20 p.m.

Roland Park Place  
830 W 40th Street  
Baltimore, MD 21211

### Every Thursday, 4:00 - 5:20 p.m.

Megan Rich Physical Therapy  
9492 Deereco Road  
Lutherville, MD 21093

Ellen Talles, LCSW-C, BC-DMT, BFA  
410-878-7164 | [ellentalles@comcast.net](mailto:ellentalles@comcast.net)

## The Johns Hopkins University Parkinson's Disease and Movement Disorders Center

Interim Director: Zoltan Mari, MD

Associate Director: Becky Dunlop, RN, BSN

### *National Parkinson Foundation Center of Excellence*

Director: Zoltan Mari, MD

### *The Morris K. Udall Parkinson's Disease Research Center of Excellence*

Director: Ted Dawson, MD, PhD

Clinical Core Director: Liana Rosenthal, MD



JOHNS HOPKINS  
MEDICINE



Movement Disorder Clinical Appointments | 410-502-0133, option 2

Becky Dunlop, RN, BSN, Associate Director | 410-955-8795

Bailey Vernon, MPH, CHES, Health Educator | 410-616-2811

*Parkinson's Digest* Editor | Bailey Vernon

Please contact us at 410-616-2811 or [bvernon1@jhmi.edu](mailto:bvernon1@jhmi.edu) to be added to our mail or email list, or to update or remove your address. We also welcome your comments and letters.

Disclaimer: The *Parkinson's Digest* is published by the Johns Hopkins University 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, the *Parkinson's Digest* is not intended to provide specific medical advice, and individuals are urged to follow the advice of their personal physicians. The PDMD Center is not responsible for the information or opinions expressed in its articles.

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[www.hopkinsmedicine.org/neuro/movement](http://www.hopkinsmedicine.org/neuro/movement)



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