

Parkinson's & Movement Disorder Digest

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

Spring 2015

FEATURE ARTICLE

Partnering for Parkinson's

The Importance of Team Work Among Neurologists

By Zoltan Mari, MD



Effective partnership between the (usually community based) general neurologist and the (usually academic center based) movement disorder specialist has never been more important than today, when several novel and advanced diagnostic, therapeutic, and care delivery options have become available to those who diagnose and treat Parkinson patients.

It is obvious to everyone involved with the patient's care that such effective partnership will only serve the patient's best interest. It is important to understand what the challenges are to successfully creating and maintaining inter-physician collaborations and how to best address them.

The ever-changing field of Parkinson's disease care demands that physicians update their knowledge constantly. New diagnostic methods are being developed, new medications and more advanced therapeutic solutions keep hitting the market, new discoveries are being made, and new guidelines on existing treatments and practice parameters are being published. It is generally not physically possible and reasonably expected from a general neurologist to delve into the nuances of highly detailed knowledge of each subspecialty of neurology, as they have to see so many patients with so many diverse problems as varied as the field of neurology is. They therefore should rely on the partnership with the subspecialist's assistance to ensure they can always offer the most up-to-date advice, diagnostics, and treatments to their patients.

Likewise, it is not generally possible to have the infrastructure for these advanced options at the community based private practice setting or hospital – for such options the general neurologist will need to rely on the availability of a larger center and their movement disorder team.

Further, many patients are interested in volunteering for clinical trials and other research studies, which are generally

available at academic centers. It is to the patients' benefit if their general neurologist is connected with an academic center and acts as the community based member of the larger team, in order to properly inform and advise their patients. On the other hand, movement disorder specialists can only offer these advanced diagnostic and therapeutic options if they successfully partner with their community based generalist colleagues, their referral base, and their link to the community. Without those referrals and the help of their community based counterparts, the infrastructure and the advanced knowledge could not be put in use. Similarly, the success of their research depends on the referrals of appropriate patients, from their general neurology colleagues.

From the patient's perspective, successful partnership between their physicians in general is a win-win situation. On the one hand they enjoy the easy accessibility of their local neurologist for day-to-day management and advice, on the other hand they also benefit from highly specialized advice and options, when they need those.

The potential challenges include the lack of trust: on the generalist's side there may be concern over losing patients once referred; and on the subspecialist's side there may be questions about co-managing versus counter-managing patients. These challenges should be actively addressed through bilateral proactive and continuous communication. One great and tried option to help avoid communication breakdowns is through outreach and education initiatives.

The outreach team can educate patients and care partners about the importance of having their local neurologist and the movement disorder specialist on the same page. Outreach should also include connecting with the community neurologists as well as primary care physicians. Support group meetings and larger community symposia provide an excellent forum where both community and academic neurologists could present to the audience, meet each other, and their patients. This could also strengthen the patients' impression of team work and further improve trust among all parties.



JOHNS HOPKINS
MEDICINE

ABOUT THE CENTER

Johns Hopkins Parkinson's Disease and Movement Disorders Center



The Johns Hopkins Parkinson's Disease and Movement Disorders Center is dedicated to comprehensive patient care, research, and outreach and education for those living with PD and related movement disorders.

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<i>Associate Director:</i>	Becky Dunlop, RN, MS
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<i>Website:</i>	www.hopkinsmedicine.org/neuro/movement
<i>Phone:</i>	410-502-0133

Specialty Centers for Movement Disorders

A National Parkinson Foundation Center of Excellence - Johns Hopkins is one of thirty-nine leading medical centers worldwide that has been identified by NPF as a site with outstanding performance in Parkinson's research, care, and outreach. *Director: Zoltan Mari, MD*



Ataxia Center - Ataxia is typically defined as the presence of abnormal, uncoordinated movements and may result from abnormalities in different parts of the nervous system. The Ataxia Center offers a multidisciplinary approach to the identification and treatment of cerebellar ataxia. *Director: Liana S. Rosenthal, MD*

Atypical Parkinsonism Center - Atypical parkinsonism refers to a variety of neurological disorders that share some features of PD but are not idiopathic PD. These disorders include Progressive Supranuclear Palsy (PSP), Corticobasal Syndrome (CBS), Multiple System Atrophy (MSA) and Dementia with Lewy bodies (DLB). *Director: Alexander Pantehyat, MD*

Deep Brain Stimulation Center - Deep brain stimulation (DBS) is a FDA-approved neurosurgical procedure that involves surgically implanting electrodes into the brain to alleviate the symptoms caused by movement disorders. The multidisciplinary team at the DBS center has established a clinical comprehensive assessment to evaluate possible DBS candidates and determine if surgery will benefit a patient. *Director: Zoltan Mari, MD*

Dystonia Center - Dystonia is a neurological condition with a very broad range of manifestations and defined as a sustained muscle contraction. There are many treatment options for dystonia that the center explores with patients, including botulinum toxin injections, pharmacological treatments, and in some cases, deep brain stimulation. *Director: Zoltan Mari, MD*

Morris K. Udall Center - Congress created the Morris K. Udall Centers of Excellence for Parkinson's Disease Research to help develop new clinical treatments for PD. The center at Johns Hopkins engages in various research initiatives to study the disease process and includes a brain donation program. *Director: Ted Dawson, MD, PhD*



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 *Parkinson's & 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.

MEDICAL TREATMENT

New Tricks for the Old Dog

New Carbidopa/Levodopa Formulations for PD

By Kelly Mills, MD

Carbidopa/levodopa IR (Sinemet) has been the most potent medication therapy available for the movement symptoms of Parkinson's disease (tremor, stiffness, slowness). Unfortunately, progression of Parkinson's disease may eventually make symptom control difficult using Sinemet. For instance, each dose may only last a few hours at a time and "wearing-off" might occur between doses, leaving patients stranded with severe tremor or immobility during this "off" time. Some patients also develop side effect movements or "dyskinesias" that occur even when the medication is helping to treat the Parkinson's symptoms. Fortunately, several new medications use the same potent active ingredient (carbidopa/levodopa) in *new* formulations that last longer and cause less dyskinesia than Sinemet.



Now FDA Approved Treatments

IPX066 (brand name RYTARY™) has microcapsules that slowly release carbidopa/levodopa so that each dose lasts longer. In a large trial, this medication reduced the average number of doses per day by 2 and the number of "off" hours per day by about 2.2 when compared to Sinemet. This was FDA approved in January of 2015.

Levodopa/carbidopa intestinal gel (LCIG; brand name DUOPA™) is a gel form of carbidopa/levodopa that is infused by an external pump through an intestinal tube continuously throughout the day. The brain receives a constant supply of medication, reducing fluctuations in symptom control in people very sensitive to small changes in carbidopa/levodopa levels. Compared with Sinemet, LCIG reduced "off" time and dyskinesia time each by 2 hours a day on average in a large trial. The downside is that patients have to undergo placement of an intestinal tube and wear an external pump. This therapy is now FDA approved and Johns Hopkins will be one of the centers offering this treatment in the near future.

Droxidopa (brand name NORTHERA™) is a medication that helps to increase blood pressure and improve the sensation of lightheadedness in patients with neurogenic orthostatic hypotension, a symptom that can be present in Parkinson's disease or related disorders such as MSA. This medication has been on the market for 20 years in Japan and has established safety and efficacy.

Treatments Under Development

The "**accordion pill**" is a multilayer structure of biodegradable film that is lined with carbidopa/levodopa and folds into a capsule. This is not yet FDA approved, but preliminary studies showed about a 50% reduction in the amount of "off" time and less time with dyskinesia compared to Sinemet.

Inhaler-based levodopa is being researched as a rescue medication for use when oral medications "wear off" unexpectedly. Inhaling a medication is one of the fastest routes to the brain, so a compound called CVT-301 is being studied as a possible inhaled form of carbidopa/levodopa.

RESEARCH

Enrolling Research Studies

Please contact Becky Dunlop, RN, MS, *Associate Director* at **410-955-8795** if you are interested in research at the Johns Hopkins Parkinson's Disease & Movement Disorders Center or have any questions.

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	Zoltan Mari, MD (NA_00036863)	Becky Dunlop 410-955-8795
Parkinson's disease	MARK-PD	Identify biomarkers for PD and PD-related cognitive impairment	Individuals without PD	Liana Rosenthal, MD (NA_00031749)	Nadine Yoritomo 410-616-2822
Parkinson's disease	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 and are of Ashkenazi Jewish decent 2.) Individuals without PD who are of Ashkenazi Jewish decent AND have a first degree relative with PD	Zoltan Mari, MD (NA_00039232)	Arita McCoy 410-955-2954
Parkinson's disease	STEADY-PD	Determine if isradipine alters disease course	Individuals with PD who are not treated	Kelly Mills, MD (NA_00038373)	Becky Dunlop 410-955-8795
Parkinson's disease	Adamas 302 (blinded) and 304 (placebo control)	Determine safety and effectiveness of new extended release formulation of Amantadine (Amantadine HCL) to treat dyskinesia	Individuals with PD who have untreated dyskinesia	Kelly Mills, MD (NA_00056431) (NA_00056432)	Becky Dunlop 410-955-8795
				Shawn Smyth, MD (ADS-AMT-PD304) <i>(Adjunct Faculty, PDMD Center in Howard County)</i>	Erica Stacy 443-755-0030
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_00092041)	Carrie Speck 410-955-5057
Parkinson's disease	Transcranial Direct Current Stimulation	Test the therapeutic relevancy of non-invasive brain stimulation for improving motor symptoms	All individuals diagnosed with PD	Reza Shadmehr, PhD (NA_00081426)	Yousef Salimpour 410-350-6241
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

RESEARCH

Enrolling Research Studies

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Condition	Title	Objective	Eligibility	PI	Contact
Dystonia	Dystonia Coalition	Create repository to learn more about dystonia	Individuals over the age of 18 who have primary dystonia	Zoltan Mari, MD (NA_00074297)	Becky Dunlop 410-955-8795
Sialorrhea (drooling or excessive salivation)	Mystical	Investigate the efficacy of Botulinum toxin type B injection to treat troublesome sialorrhea	Individuals who have untreated excessive salivation due to any cause	Zoltan Mari, MD (NA_00084484)	Becky Dunlop 410-955-8795
				Joseph Savitt, MD, PhD (SN_SIAL_301) (<i>Adjunct Faculty, PDMD Center in Howard County</i>)	Erica Stacy 443-755-0030

RECENT DEVELOPMENTS

Music and Rhythm-Based Interventions for Parkinson's Disease

Exploration of Complimentary Therapies

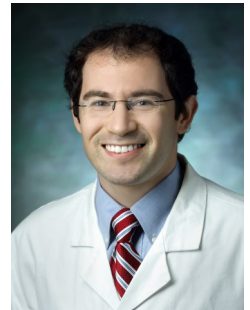
By Alexander Pantelyat, MD

Several music and rhythm-based therapies for Parkinson's disease have been explored in recent years. Some of the best evidence to date has been found for Argentine Tango. This ballroom dance involves big steps in multiple directions, and has been shown to significantly improve walking and balance in Parkinson's disease. It appears to have some additional benefits when compared with other ballroom dance forms such as Foxtrot. Also, when researchers compared traditional partnered Tango to non-partnered Tango, a similar degree of benefit for walking and balance was observed; however, those dancing alone found it less enjoyable, and therefore less motivating.

Argentine Tango has its origins in African rhythms, and I recently studied group West African drumming (while seated) in 10 patients over 6 weeks. Compared to baseline, patients in the drumming group experienced a significant improvement in their overall quality of life, and also tended to walk faster after the drumming classes; this was not observed in the control group of patients who did not attend drumming classes.

The loss of voice volume and clarity is a common problem in Parkinson's disease, and several studies have evaluated the effects of singing in a choir on patient's voice quality and several other outcomes. While results so far have not been conclusive, the proliferation of Parkinson's disease choirs throughout the world and in the U.S. (see parkinsonvoiceproject.org; a choir in Texas, for example, has been meeting regularly since 2007, with yearly performances involving >100 patients) indicates that patients are experiencing benefits. A study of group choir-based singing for Parkinson's disease at Johns Hopkins (**Parkinsonics**) is about to get under way.

The mechanisms of how these therapies work for Parkinson's Disease need to be investigated. What we know is that all of these interventions have in common a prosocial aspect, and are fun, thereby **fighting isolation** and motivating people to continue. Music and rhythm-based interventions are being actively evaluated at our center. Please contact Becky Dunlop at **410-955-8795** to learn more!



COMMUNITY

Living with PD Outside of Clinic Walls

Local support groups are providing meaningful programs

A diagnosis of PD or related movement disorder can bring out so many difficult emotions. It is a challenge to learn how to cope with those feelings along with the stress of diagnosis and treatment. Education and support groups can be an essential key to successfully coping and managing the disease.

The Johns Hopkins PDMD Center has been collaborating with the community to develop more groups and specialty groups (ex. young onset, newly diagnosed, and women's groups); connecting support group leaders through quarterly meetings and conference calls; and providing resources and support to existing groups. Leaders are going beyond the standard format by establishing local exercise classes, caregiver groups, social gatherings, and much more.

If you are interested in finding a group locally, starting a new group, or volunteering; please contact Bailey Vernon at 410-616-2811 or bvernon1@jhmi.edu.

Congratulations Support Group Leaders!

Art Cooley of the Lower Shore Support Group of Salisbury for receiving the *Frank H. Morris Humanitarian Award* presented by the Community Foundation of the Eastern Shore.

Art Guyer of the Hagerstown Support Group for establishing the *Four-State Alliance for Parkinson's Support*.

Ruth Johnson of the PD Support Group at Landis Homes in Lancaster, PA for being nominated for the *Volunteer of the Year 2015* award by LeadingAge PA.

Dennis Leebel of the Parkinson's Education and Support Group of Sussex County, DE for being announced as a *Jefferson Award* winner by WBOC-TV.

Shirley McKinney of the Cumberland Support Group for receiving the title of *Wellness Ambassador* for the month of January by Western Maryland Health System.

Cheryl Reames of Winchester, VA for coordinating 3 support groups, 1 caregiver group, and information resources in the greater Winchester area.

Get Involved in 2015! Help Make a Difference!

Pacing 4 Parkinson's

Johns Hopkins PDMD Center

Saturday, October 17

Baltimore Running Festival

www.pacing4parkinsons.org

pacing4parkinsons@gmail.com

410-616-2811

The center invites you to participate in the **7th Annual Pacing 4 Parkinson's** at the Baltimore Running Festival this October. Join the fight against PD by running or walking, volunteering, or supporting the cause. All funds raised support the center's efforts to improve patient care, advance research initiatives, and expand outreach efforts.



Moving Day® DC

A Walk for Parkinson's

National Parkinson Foundation

Sunday, June 7

National Mall, Washington, D.C.

www.MovingDayDC.org

1-800-4PD-INFO

Moving Day® is the National Parkinson Foundation's annual fundraising walk event. It is a fun and inspiring fundraising event that unites families, friends, and communities in the fight against PD. To become involved in this great initiative, you can volunteer with NPF, sign up to participate, or support the cause. Visit the Johns Hopkins faculty and staff team page "Hop Squad" at <http://tinyurl.com/hopsquad>.



Maryland Association for Parkinson Support, Inc.

www.marylandparkinsonsupport.org

info@marylandparkinsonsupport.org

443-470-3223

Maryland Association for Parkinson Support, Inc. (MAPS) is a newly formed local non-profit organization dedicated to providing meaningful programs that will support the entire PD community. In 2015, MAPS will be hosting a variety of events to raise money for support groups, exercise programs, informational resources, and related services. Contact MAPS if you are interested in supporting the cause, volunteering, or receiving updates.



COMMUNITY

Outreach & Education Programs

Of the Johns Hopkins PDMD Center

Pre-registration is required for all programs listed below. Please contact Bailey Vernon at **410-616-2811** or bvernon1@jhmi.edu to register or learn more about these programs. To learn about the outreach calendar for ataxia and other movement disorders, please contact us.

◆ **Newly Diagnosed Parkinson's Disease Educational Forum**
Friday, March 13, June 26, October 23

9:00 a.m. - 12:00 p.m.

Green Spring Station, Foxleigh Building, Room 101
2330 W Joppa Road, Lutherville, MD 21093

◆ **Deep Brain Stimulation Information Session**
Wednesday, April 1 & November 4

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

Green Spring Station, Pavilion II, 1st Floor Conference Room
10753 Falls Road, Lutherville, MD 21093

◆ **Managing Parkinson's Disease Symposium: 2015 Update**
Saturday, April 11

9:30 a.m. - 12:30 p.m.

Friendship Heights Village Community Center
4433 South Park Avenue, Chevy Chase, MD 20815
202-364-7602

◆ **Caregiver Training for PD & Related Movement Disorders**
Friday, April 24

10:30 a.m. - 3:30 p.m.

Howard County Library, Miller Branch
9421 Frederick Road, Ellicott City, MD 21042
<http://tinyurl.com/PDCaregiver2015>

◆ **Parkinson's Disease 101**
Monday, May 4

In collaboration with the Carroll Hospital Center

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

Carroll Hospital Center, Dixon Building, Shauck Auditorium
291 Stoner Avenue, Westminster, MD 21157

◆ **Support Group Leader Networking Meeting**
Thursday, May 21

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

Towson Unitarian Universalist Church
1710 Dulaney Valley Road, Lutherville, MD 21093

Community Events

◆ **Parkinson's Symposium & Allied Professionals Conference**
Saturday, March 28

Presented by PFNCA

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

Fairview Park Marriott, Falls Church, VA
PFNCA, 703-734-1017

◆ **Continue the Conversation Dinners**
Thursday, April 2

Hosted by Drs. Zoltan Mari, Lisa Shulman & Howard Weiss to benefit PFNCA

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

Lebanese Taverna, Baltimore, MD
PFNCA, 703-734-1017

◆ **Mindful Motion; A Yoga & Pilates Event**
Sunday, April 12

To benefit MAPS, Inc.

12:00 p.m. - 2:00 p.m.

Four Seasons Hotel, Baltimore, MD
www.missiontix.com/mindfulmotion

◆ **Within Our Reach: Annual Parkinson's Community Symposium**
Friday, May 8

Presented by the University of Maryland

8:30 a.m. - 2:45 p.m.

BWI Airport Marriott, Linthicum, MD
Michelle Cines, 410-328-0157

◆ **Walk on the Boardwalk**
Saturday, May 16

To benefit the PD Support Group of Sussex County, DE

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

Rehoboth Beach Boardwalk
Patricia Slygh, 302-856-2978

◆ **Moving Day® DC**
Sunday, June 7

To benefit the National Parkinson Foundation

National Mall, Washington, D.C.

1-800-4PD-INFO

April is Parkinson's Awareness Month!

April 11th is celebrated annually as World Parkinson's Day to commemorate the birthday of Dr. James Parkinson's. This is a special day to increase awareness of PD. On April 11, 2005, the red tulip was announced as the worldwide symbol of Parkinson's disease.

World Parkinson Coalition. (2013).



JOHNS HOPKINS PARKINSON'S DISEASE & MOVEMENT DISORDERS TEAM

Physicians

Zoltan Mari, MD
Kelly Mills, MD
Alex Pantelyat, MD
George Ricaurte, MD, PhD
Liana Rosenthal, MD

Fellows

Faisal Alerwy, MBBS
Martin Kronenbuerger, MD
Laura Tochen, MD

Clinical Team

Nicole Bonsavage, BA
Jason Brandt, PhD
Becky Dunlop, RN, MS
Arita McCoy, RN, BSN
Jennifer Millar, PT
Gregory Pontone, MD
Katerina Salnikova, BA
Donna Tippet, MA, MPH, CCC-SLP
Bailey Vernon, MPH
Nadine Yoritomo, RN, BSN, CCRP

Deep Brain Stimulation Surgeons

William Anderson, MD, PhD
Frederick Lenz, MD, PhD

Udall Parkinson's Research Center

Catherine Bakker, MS
Vanessa Johnson, BS
Carrie Speck, BA

Adjunct Faculty

Stephen Grill, MD, PhD
Joseph Savitt, MD, PhD
Shawn Smyth, MD
Howard Weiss, MD

SAVE THE DATE

Newly Diagnosed PD Forum - Friday, March 13, June 26, October 23, 2015 - This program is for those diagnosed with Parkinson's disease in the past 1 - 2 years and will offer a comfortable forum for discussion.

Deep Brain Stimulation Information Session - Wednesday, April 1 & November 4, 2015 - This session will provide insight on the innovative technique that can help individuals with movement disorders.

Caregiver Training - Friday, April 24, 2015 - This educational program is for those who care for someone with PD or related movement disorder and want to learn more and connect with others.

Please look on page 7 for registration information.



Johns Hopkins
Parkinson's Disease and Movement Disorders Center
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