

Movement Disorder Digest

New Beginnings and a Sincere Farewell

By *Zoltan Mari, MD*

The Johns Hopkins PDMD Center has grown and matured in ways that have not been seen before. The size of our Center, (including the number of patient visits and active patients, full-time faculty and staff, sponsored research projects and outreach programs) are at their respective all-time highs, signaling the great impact our Center is making in both community and medical education, patient care, and scholarly goals.

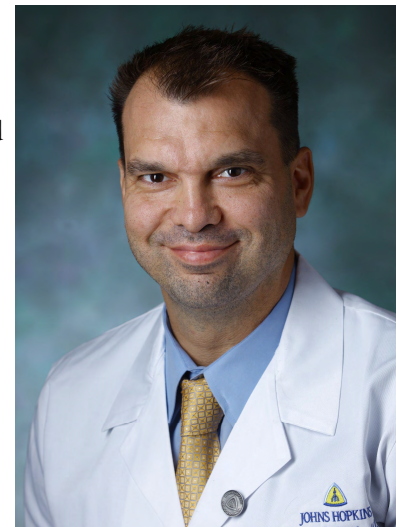
It is my pleasure to highlight our outreach and education mission first, as our Center successfully continues its designation and funding under the two most prestigious PD Center of Excellence networks: the NINDS Morris K Udall Centers of Excellence for Parkinson's Disease Research and the National Parkinson Foundation's Centers of Excellence. In the last year, we were fortunate to add **GiGi Gray** as our PD Health Educator and **Donna DeLeno Neuworth** as our Ataxia Center Health Educator, to help with our outreach and education efforts, and to continue with our support to the community through its phone, online, and social media presence. We also work closely with both the Maryland Association for Parkinson's Support (MAPS) and the Parkinson Foundation of the National Capital Area, helping organize their programs and symposia.

Our Center's clinical mission has also grown by leaps and bounds. In the last year, we added two outstanding providers. **Arita McCoy, CRNP**, has already been our long-term and beloved nurse before last year, when she graduated as a nurse practitioner. Now patients may further and directly benefit from her vast clinical experience, especially with PD and advanced treatments (such as DBS and Duopa); **Dr. Jee Bang**, joined us from UCSF and now serves as the Medical Director of our Huntington Disease Center. She is committed to our Atypical Parkinsonism Center, especially with focus on cognitive impairment, as well as our Ataxia Center. They join our existing squad of movement disorder neurologists. Their relentless commitment to our clinical mission and world-class movement disorder

expertise make our Center one of the most highly regarded PD and Movement Disorder Centers in the country. Our Center is also fortunate to have our affiliate community team members and Adjunct Professors, in **Drs. Howard Weiss, Stephen Grill, and Shawn Smyth**. We greatly appreciate them.

Our Center's scholarly accomplishments reached another historical best. Our faculty published over two dozen peer-reviewed publications in the last year alone, an all-time high, and received unprecedented levels of external funding. **Dr. Ted Dawson** and his team at the Institute of Cell Engineering have published ground-breaking discoveries regarding the cause and mechanism of PD pathology in the last year and **Dr. Hanseok Ko** and team have done work on a revolutionarily novel peptide that appears to dramatically slow the disease process in Parkinsonian animals.

Finally, it is with a heavy heart that I share the news that as of May 15th, I will leave the PDMD Center and JHU, to become the endowed chair for movement disorders at the Cleveland Clinic Lou Ruvo Center for Brain Health in Las Vegas, NV. A piece of my heart with forever stay with the PDMD Center I helped build, its wonderful people, the patients we cared for, our great Department of Neurology, and Johns Hopkins University. I thank all of you for the last eleven great years I had here.



Zoltan Mari, MD

CENTER UPDATE

Dr. Suraj Rajan will be starting his 2-year fellowship program at the Movement Disorders division at Hopkins in the summer of 2017. He is a graduate of the MBBS program at the Academy of Medical Science Pariyaram, from the South Indian state of Kerala. After a brief stint in primary care and emergency medicine in his home town in India, he moved to the UK to join the University College London's Institute of Neurology Queen Square as a research scholar. Dr. Suraj Rajan completed his MS in Clinical Neurology with his thesis focusing on the patterns of spread of alpha-synucleinopathy in the olfactory bulb. He moved to the United States in 2013 and completed his postgraduate neurology residency at the University of Missouri and at the Wright State University Neurology program in Ohio.



Dr. Rajan is interested in DBS, gait and balance, atypical parkinsonian syndromes and functional movement disorders. In addition, he finds the clinical and pharmacological aspects of Movement Disorders most appealing. Outside of neurology, Dr. Rajan is a museum-buff, a history nerd, and hopes to be a clinical academician building a career as an educator.



Dr. Bonnie Kaas will also be joining the center for her two year fellowship in July of 2017. Bonnie completed her undergraduate training at Ursinus College in Pennsylvania, majoring in neuroscience and biochemistry. She attended medical school at the Johns Hopkins University School of Medicine and graduated in 2013. She subsequently completed her intern year with the Johns Hopkins Bayview

Internal Medicine program, followed by residency in adult neurology at the Johns Hopkins Hospital (2014-2017). She has interests in clinical research, medical education, quality improvement, and patient outreach. Bonnie is thrilled to have the opportunity to continue her subspecialty training at Johns Hopkins, and is excited to become part of our movement disorders team.

Donna DeLeno Neuworth has been with the Johns Hopkins Ataxia Center as the Health Educator since October 2016. Donna came to the Ataxia Center from the Johns Hopkins University Maximizing Independence at Home (MIND) research study providing outreach and recruitment that is designed to help keep people with dementia living safely in their own homes.



Prior to her employment at Johns Hopkins, Donna worked in the aging and disability field for over 15 years as an advocate and public policy staff member for the Maryland Department of Aging, AARP and the Alzheimer's Association, Greater Maryland Chapter.

She enjoys the working with people with ataxia and their care partners, and will be working on expanding the Ataxia Center's reach to people with ataxia in the Mid-Atlantic region. As the Health Educator, Donna develops social and educational events, support groups, newsletters, and assists with current ataxia research. To receive the Ataxia newsletter and information on upcoming events, please email Donna at ddeleno1@jhmi.edu.

Community Highlight

Tough "Tank" Hill

By GiGi Gray

"Tough Tank Hill, that's what they call him!"

It was all about boxing for Tank Williams - from amateur boxer, to pro fighter, trainer, and promoter. A natural warrior at heart, Tank now faces his toughest fight yet - Parkinson's Disease.

15 years ago in Washington DC, while training a boxer for a fight, Tank noticed that he was having problems walking. As Tank stumbled and to fell to his knees, a young man shouted, "Man, you're drunk!"

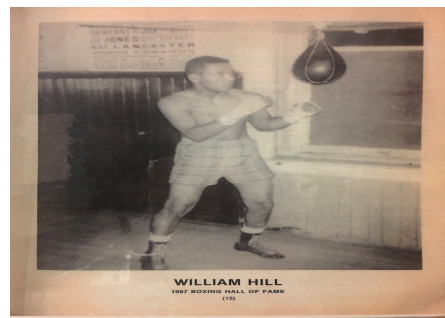
That week, Tank was diagnosed with Parkinson's Disease (PD). Never hearing of PD before, Tank relied on an explanation from the doctor. After receiving the answer, Tank went outside, looked up to the sky, and asked "What should I do now?"

Deciding not to give up and never having run from a fight, Tank approached PD as just another man in the ring. He applied the two rules that he lives by, "#1) Don't quit and #2) Don't forget rule #1."



Viola, Tank's wife and biggest supporter, threw herself into the ring with her husband. Researching treatments, support programs, top neurologists and specialists, Viola made certain that Tank could mount the best fight possible. Tank and Viola started attending support groups together, and Tank is now a member of the ParkinSonics Community Chorus, which meets every Wednesday at 1:30 p.m. at Govans Presbyterian Church in Baltimore, MD.

At 78, Tank is still in the boxing game, now giving back to the community by tutoring and training youth 8 years and older after school, providing a positive outlet for the youth of Baltimore City. Tank continues to thrive in the boxing world, spends time with family and friends, and gives back to the community, all while maintaining a positive disposition and caring for his mental and physical well being. He continues to live positively everyday and hopes to be an inspiration to others.



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	MARK-PD	Identify biomarkers for PD and PD-related cognitive impairment	Individuals diagnosed with PD or atypical PD and those without a neurological diagnosis	Liana Rosenthal, MD (NA_00031749)	Nadine Yoritomo 410-616-2822
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)	Erica Stacy 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
Parkinson's Disease	MRI PD Study	One day visit to explore the relationship between cognition (e.g. memory) and emotion in PD	Individuals diagnosed with PD and those without PD	Gregory Pontone, MD (NA_00087276)	Kate Perepezko 410-614-1242
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	Jeffery Rothstein, MD, PhD (NA_00055442)	Sonja Scholz, MD, PhD 240-271-5297
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	DUOGLOBE	Measure the additional benefits of Duopa® therapy in post market analysis	Individuals eligible and cleared for Duopa® Therapy	Kelly Mills, MD (NA_00088106)	Erica Stacy 410-287-7850
Parkinson's Disease	SURE-PD Study	Determine if treatment with inosine can slow the worsening of Parkinson's disease.	PD patients diagnosed 3 years or less, taking no medication or only rasagiline or selegiline	Liana Rosenthal, MD (NA_00090505)	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

RESEARCH STUDIES (continued)

Condition	Title	Objective	Eligibility	PI	Contact
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
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)	Erica Stacy 410-287-7850

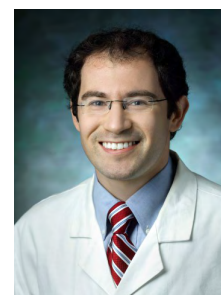
Atypical Parkinsonism Center - Research Updates

By Alex Pantelyat, MD

There are a number of research studies on the horizon for patients suffering from atypical parkinsonian disorders (progressive supranuclear palsy (PSP), corticobasal syndrome (CBS), multiple system atrophy (MSA), and dementia with Lewy bodies (DLB).

The Johns Hopkins **Longitudinal Biomarkers of Atypical Parkinsonian Disorders** study (all atypical parkinsonian disorders) gives participants the option of undergoing regular clinical assessments, magnetic resonance imaging, spinal taps, or all of the above. The goal is to determine how these disorders can be diagnosed earlier and more accurately. The **Genetic Characterization of Movement Disorders** study, in collaboration with Dr. Sonja Scholz from the National Institutes of Health (NIH), seeks to discover genetic changes associated with atypical

parkinsonian disorders. The **Natural History of Synucleinopathies** study is a national study that will focus on MSA, whereas the NIH-funded **4-repeat Tauopathy Neuroimaging Initiative-2** study will focus on PSP and its several variants by using clinical examinations, eye movement analysis, retinal thickness measurements, brain MRI and other imaging studies. With regard to treatment, we have been selected as a trial site for one of the first **anti-tau antibody trials for PSP** (to start later in 2017), and we also hope to start a pilot trial of **noninvasive brain stimulation** to improve movement symptoms in atypical parkinsonian disorders.



Social Functioning in Parkinson's Disease

Kate Perepezko, MSPH & Greg Pontone, MD

Parkinson's disease impacts several aspects of individual functioning— physical (gait, balance, tremor, rigidity) and mental (mood and cognition). However, the disease can also influence your interactions with others or your “social role functioning.”

Social roles refer to specific responsibilities that you take on in your regular relationships, including spouse, parent, employee, and friend. It is important to understand the symptoms of Parkinson's disease as well as how these symptoms can change your position in your family, workplace, community, and your ability to continue your leisure activities. Changes in your social roles can greatly impact your quality of life. Having strong relationships and maintaining activities can help many symptoms of the disease, including depression and cognition. Therefore, it is important to maintain and support important relationships in your life and consider whether there is room for improvement.

We are currently conducting a survey study investigating factors that impact ability to perform different social roles and satisfaction with performance in these roles. We are distributing the survey to participants in our Anxiety in Parkinson's study. This study involves a one-time, 2-3 hour visit in which participants complete an on/off evaluation. If you are interested in contributing your time to this research, please call Kate Perepezko 410-614-1242.

Thank you so much for dedicating your time for this project, we greatly appreciate it. This research will help us better understand the impact of Parkinson's disease on multiple aspects of life and hopefully inform new treatments to improve quality of life!

Specialty Center

Neurological Rehabilitation

By *Amanda Gallagher, MA, CCC-SLP*

The Johns Hopkins Brain and Stroke Rehabilitation Program (BSRP) is an interdisciplinary outpatient therapy program that provides neurological rehabilitation for people with Parkinson's disease. The BSRP team is comprised of physical therapy, occupational therapy, speech-language pathology, neuropsychology and psychiatry (rehabilitation physicians) services. Our providers have over 75 years of combined clinical experience.

Physical Therapy (PT) focuses on helping people improve safety and ease of mobility by focusing on treatment techniques to promote the ability to move, reduce pain and restore function. PT will teach different ways to manage your condition through exercises and strategies customized to your needs.

Occupational Therapy (OT) focuses on activities that someone completes on a regular basis including dressing, bathing, eating, grooming, cooking, cleaning, navigating in the community and returning to work. OT will help to identify physical or cognitive limitations that create barriers to participation in tasks, then work with you to identify tasks and activities that are meaningful and create functional goals and develop a therapy plan to provide the

best opportunity to achieve them. Speech-language Pathology (SLP) focuses on thinking skills, swallowing, speech precision, and voice dysfunction. SLP works with each person to identify areas of concern or limitation and develop a therapy plan that provides the best opportunity for improvement. Our SLP team is certified in the LSVT LOUD program. We also offer swallowing x-rays as needed to further evaluate difficulty with chewing and swallowing.

Rehabilitation psychologists and neuropsychologists help patients and families understand and manage physical, cognitive, and emotional problems associated with Parkinson's disease. Rehabilitation Psychology services include cognitive evaluation as well as behavioral and psychological interventions.

The BSRP team is able to provide coordinated appointments if you require multiple therapies (physical, occupational and/or speech-language pathology). For additional information, or to schedule an appointment with one of our BSRP providers please call (410) 614-3234. A physician's referral is required for each therapy service.

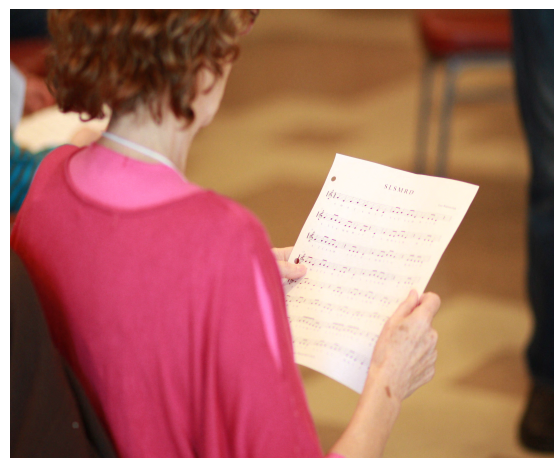
Parkinsonics Results

By *Alex Pantelyat, MD*

The Parkinsonics study, which concluded last year, aimed to assess whether weekly group singing improved Parkinson disease (PD) patients' voices, motor symptoms and quality of life. The study was led by Alexander Pantelyat, MD and Becky Dunlop RN, MS, and initially comprised 32 participants who were randomly assigned to either a weekly singing group or a weekly discussion group over 12 weeks. Participants then 'crossed over' to the other group and continued for another 12 weeks. Study assessments (while patients were taking their usual medications for PD) were performed every 6 weeks for 30 weeks. Data analysis is ongoing, but overall, participants' minimum voice volumes improved from baseline at 24 weeks and 30 weeks when reading a standard passage and describing a standard picture. Interestingly, overall motor function also improved at 24 weeks and 30 weeks, regardless of whether participants sang first. With the support of our center and the Maryland Association for Parkinson Support (MAPS), ParkinSonics weekly singing rehearsals are continuing under the leadership of Leo Wanenchak and Ellen Talles.

"Singing is healing on every level, fostering improvement of body, mind, and spirit. Immersing in ParkinSonics, participants' attention moves away from illness and toward creativity. While learning musical skills, singing fosters increased vocal volume and clarity, rhythmic movement, confidence, emotional expression, and a strong sense of community." - Ellen Talles

New singers are welcome to join and no experience is necessary. For details, contact Ellen Talles at (EllenTalles@comcast.net).



Community

Pacing for Parkinson's—Thank You!

Greetings from the Johns Hopkins Parkinson's Disease and Movement Disorders Center and the Pacing for Parkinson's committee!

As we approach this year's Pacing for Parkinson's charity event at the Baltimore Running Festival, we want to express a sincere thank you to all the past and current participants who have supported this events over these many years. The comradery and positive energy experienced during this public

awareness event is one of the true joys of being a part of this community campaign.

Once again, we look forward to your active participation to make this event a memorable one!

This year's event will be held on **Saturday, October 21, 2017**. Runners have the option to participate in the 5K, Half-Marathon, Full Marathon, Team Relay or Kids Fun Run events. Please join us for the best year yet!

2017 Registration is now open – www.pacing4parkinsons.org



For more pictures, check out Pacing for Parkinson's on Facebook!

Community Events

- ◆ **P4P at The Towson Spring Festival**
Saturday, May 6 - Sunday, May 7
44 W Chesapeake Ave, Towson, MD 21204
www.pacing4parkinsons.org

- ◆ **Quarter Auction**
Team Healing Maneuvers
Friday, June 2
To benefit JHU PDMD Pacing 4 Parkinson's
6:00 p.m.
Abingdon Fire Hall
3306 Abingdon Road
Abingdon, MD 21009

- ◆ **Moving Day® DC**
Saturday, June 3
To benefit the National Parkinson Foundation
National Mall, Washington, D.C.
www.movingdaydc.org or 1-800-4PD-INFO

- ◆ **Pacing 4 Parkinson's - Open to register**
Saturday, October 21
7:00 a.m.
Baltimore Running Festival
M&T Bank Stadium
www.pacing4parkinsons.org



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.

◆ 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

May 17 - *Alania Davis, PhD, SLP, Speech and Swallowing*

June 21 - *Attorney Elizabeth Green, Elder Law*

July 19 - *Dan Gold, DO, Vision*

August 16 - *Sonja Scholz, MD, PhD, Research*

September 13 (2nd Wednesday) - *Melissa Shepard, MD, Mental Health*

October 18 - *Liana Rosenthal, MD, Medication Management*

November 15 - *Howard Weiss, MD, "What Causes PD?"*

December 20 - *Q & A Panel*



◆ Surgical Therapeutics for Parkinson's:

Deep Brain Stimulation & Duopa Information Session

Wednesday, November 8

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

Register online - <http://tinyurl.com/DBS-Duopa-Nov2017>



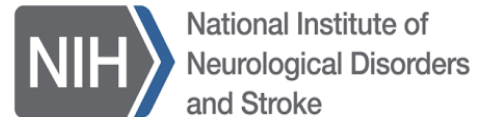
◆ Atypical Parkinsonism Support Group

4th Thursday of Every Month

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

St. Thomas Episcopal Church

1108 Providence Road, Towson, MD 21286



◆ ParkinSonics Community Chorus

Each Wednesday

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

Govans Presbyterian Church, Sharp Hall

5828 York Road, Towson, MD 21286



◆ Rock Steady Boxing

Each Tuesday and Thursday

11 a.m.

Forest Hill Health and Fitness

2217 Commerce Road, Forest Hill, MD 21050

410-893-4153



April is Parkinson's Awareness Month!

On April 11, 2005, the red tulip was announced as the worldwide symbol of Parkinson's Disease.

World Parkinson Coalition. (2013). www.worldpdcoalition.org

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**.

Physicians

Jee Bang, MD
Ted Dawson, MD, PhD
Zoltan Mari, MD
Kelly Mills, MD
Alex Pantelyat, MD
George Ricaurte, MD, PhD
Liana Rosenthal, MD

Fellows

Ankur Butala, MD
Emile Moukheiber, MD
Sonja Scholz, MD, PhD
Suraj Rajan, MD
Bonnie Kaas, MD

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Jason Brandt, PhD
Valina Dawson, PhD
Daniel Gold, DO
Stephen Grill, MD, PhD
Gregory Pontone, MD
Shawn Smyth, MD
Howard Weiss, MD

Neurosurgical Team

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

Allied & Research Team

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Marsha Davis, RD, LD
Amanda Gallagher, CCC-SLP
GiGi Gray, MS
Vanessa Johnson, BS
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Aathman Swaminathan, BS
Donna Tippet, MPH, CCC-SLP
Nadine Yoritomo, BSN, CCRP

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.

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