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 DeLena 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.
**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 MacMillan 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.

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**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 sure that Tank could mount the best fight possible. Tank and Viola started attending support groups together, and Tank is now a member of the Parkinson’s 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.
<table>
<thead>
<tr>
<th>Condition</th>
<th>Title</th>
<th>Objective</th>
<th>Eligibility</th>
<th>PI</th>
<th>Contact</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parkinson’s Disease</td>
<td>National Parkinson Foundation Patient Registry</td>
<td>Develop quality care standards for PD</td>
<td>All PD patients and care partners seen at the center</td>
<td>Kelly Mills, MD (NA_00035863)</td>
<td>Nikki Mennucci 410-955-6684</td>
</tr>
<tr>
<td>Parkinson’s Disease</td>
<td>MARK-PD</td>
<td>Identify biomarkers for PD and PD-related cognitive impairment</td>
<td>Individuals diagnosed with PD or atypical PD and those without a neurological-diagnosis</td>
<td>Liana Rosenthal, MD (NA_0731749)</td>
<td>Nadine Yoritomo 410-615-2822</td>
</tr>
<tr>
<td>Parkinson’s Disease</td>
<td>APL-130277 for the Acute Treatment of OFF Episodes</td>
<td>Evaluate APL-130277 (sublingual version of Apokyn medication) in treatment of sudden &quot;off-time&quot; in PD</td>
<td>Individuals with PD, taking levodopa and having at least 2 hours of &quot;off-time&quot; daily</td>
<td>George Ricciare, MD (NA_00086533)</td>
<td>Erica Stucy 443-287-7859</td>
</tr>
<tr>
<td>Parkinson’s Disease</td>
<td>Anxiety in Parkinson’s</td>
<td>One day visit to assess anxiety symptoms in PD</td>
<td>All individuals diagnosed with PD</td>
<td>Gregory Pontone, MD (NA_00092051)</td>
<td>Kate Perepezko 410-616-1242</td>
</tr>
<tr>
<td>Parkinson's Disease and related disorders</td>
<td>Udall Center Longitudinal Study</td>
<td>Examine the relationship between the clinical symptoms of PD and the disease process in brain tissue (participation includes eventual brain donation)</td>
<td>Individuals diagnosed with PD or atypical PD and those without a neurological-diagnosis</td>
<td>Liana Rosenthal, MD (NA_00032761)</td>
<td>Catherine Bakker 410-616-2814</td>
</tr>
<tr>
<td>Parkinson’s Disease and related disorders</td>
<td>Udall Center Brain Donation Program</td>
<td>Examine the pathological changes in the brain tissue of individuals diagnosed with PD or related disorders as compared to controls</td>
<td>Individuals diagnosed with PD or atypical PD and those without a neurological-diagnosis</td>
<td>Liana Rosenthal, MD (NA_00032761)</td>
<td>Catherine Bakker 410-616-2814</td>
</tr>
<tr>
<td>Movement Disorders</td>
<td>Genetic Characterization</td>
<td>To study the genetic risk factors involved in movement disorders</td>
<td>Individuals with PD, atypical parkinsonism, dystonia, ataxia, and Lewy body dementia</td>
<td>Jeffrey Rosenthal, MD, PhD (NA_00054422)</td>
<td>Sonja Scholz, MD, PhD 240-271-5297</td>
</tr>
<tr>
<td>Dystonia</td>
<td>Dystonia Coalition</td>
<td>Create repository to learn more about dystonia</td>
<td>Individuals over the age of 18 who have primary dystonia</td>
<td>Alex Pantelyat, MD (NA_00074297)</td>
<td>Aarthman Swaminathan 410-955-6672</td>
</tr>
<tr>
<td>Parkinson’s Disease</td>
<td>DUOCLOBRE</td>
<td>Measure the additional benefits of Duopa® therapy in post-market analysis</td>
<td>Individuals eligible and cleared for Duopa® Therapy</td>
<td>Kelly Mills, MD (NA_00088106)</td>
<td>Erica Stucy 410-287-7859</td>
</tr>
<tr>
<td>Parkinson’s Disease</td>
<td>SURE-PD Study</td>
<td>Determine if entacapone with inosine can slow the worsening of Parkinson’s disease</td>
<td>PD patients diagnosed 3 years or less, taking no medication or only entacapone or selegiline</td>
<td>Liana Rosenthal, MD (NA_00090305)</td>
<td>Aarthman Swaminathan 410-955-6672</td>
</tr>
<tr>
<td>Parkinson’s Disease</td>
<td>A Randomized Controlled Trial of Osib contraceptoriminostin A for Depression in PD</td>
<td>To study if the drug osib contraceptoriminostin A (BTO038) is helpful for the treatment of depression in PD</td>
<td>All individuals diagnosed with PD who have symptoms of depression</td>
<td>Alex Pantelyat, MD (NA_00082708)</td>
<td>Nikki Mennucci 410-955-6684</td>
</tr>
</tbody>
</table>

RESEARCH STUDIES
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. The study 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.

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 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

Atypical Parkinsonism Center - Research Updates

By Alex Pantelyat, MD

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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. The 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!
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 physiatry (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.

Specialty Center

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.
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 event 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 Town 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 John 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 Schulz, MD, PhD, Research
  September 13 (2nd Wednesday) - Medina Shepard, MD, Mental Health
  October 18 - Liana Rosenthal, MD, Medication Management
  November 15 - Howard Wellin, 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.
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 Panteleyev, MD
George Ricarte, MD, PhD
Liana Rosenthal, MD

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

Additional Faculty
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 Lees, MD, PhD

Allied & Research Team
Catherine Bakker, MS
Carrie Berleant, BS
Marsha Davis, RD, LD
Amanda Gallagher, CCC-SLP
GiGi Gray, MS
Vanessa Johnson, BS
Anita McCoy, CRNP
Nikki Mennucci, BS
Jennifer Millar, PT
Kate Perepeko, MPH
Carrie Speck, BA
Erica Stacy, BSN
Aashman Swaminathan, BS
Donna Tippet, MPH, CCC-SLP
Nadine Yoritomo, BSN, CCRP

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