

Parkinson's & Movement Disorder Digest



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

Center Update from the Interim Director

By Zoltan Mari, MD

These are exciting times at the Parkinson's Disease and Movement Disorders Center! Recently our center has exponentially extended its clinical and research operations and experienced a "jump start" with respect to its educational mission too!

First of all, our new team members are outstanding and we are very excited about them. On July 1, 2014 our center welcomed two new faculty members who are simply brilliant. They both have completed a thorough two year movement disorder fellowship curriculum at some of the best training programs in the world and are already contributing to all of our core missions. You will continue to read and learn more about them in future issues of the newsletter.



Dr. Alexander Pantelyat has joined our center from the University of Pennsylvania where he trained under the prestigious Movement Disorder Society's current president, Dr. Matt Stern and his team. His research explores atypical parkinsonian

disorders, cognitive aspects of movement disorders, biomarkers for Parkinson's disease (PD) and music-based rehabilitation of neurodegenerative diseases. The team is looking forward to Dr. Pantelyat setting up an Atypical Parkinsonism Center at Johns Hopkins.



Dr. Kelly Mills completed his training at the University of California, San Francisco, by arguably the best deep brain stimulation (DBS) team in the world. His research focuses on DBS therapy in dystonia and other movement disorders, cognitive dysfunction in movement disorders

and how certain treatments might impact cognitive and

psychiatric problems. Dr. Mills is already spearheading DBS operations and contributing to medical student, resident and fellow education in movement disorders.

Thanks to our fundraising initiative, **Pacing 4 Parkinson's**, we are able to support the training of excellent fellows (see page 5). This year we are fortunate to have two exceptional clinical fellows and one research fellow. **Dr. Laura Tochen** joined the team as our first pediatric movement disorder fellow. She completed her residency at Johns Hopkins where she developed a particular interest in Parkinson's disease and movement disorders. **Dr. Martin Kronenburger**, a former movement disorder attending from Germany, has joined us for a formal fellowship training. In addition to seeing patients clinically, his research will focus on the pathological changes of DBS surgery in PD as well as the pathophysiology of dystonia. **Dr. Faisal Alerwy** is our research fellow and recipient of the highly competitive Ministry of Education award by the Government of Saudi Arabia.

On account of the national shortage of experts, training and education are vital in the field of movement disorders. The medical students and neurology residents are attending our clinic more than ever. Our center continues to offer the undergraduate tutorial program "Neuroprotective Trials in Parkinson Disease". The accepted applicants learn about PD from our specialists and gain hands on experience. Education for our patients and the community is very important and we invite everyone to attend the **Movement Disorder Symposium** on November 8, 2014 (see page 7).

It is a golden age for movement disorders at Johns Hopkins. We are so pleased to share these exciting times with you. We hope you can continue supporting our operations to bring even better times with respect to research, outreach and education. Thank you.

Sincerely,

Zoltan Mari, MD

*To read Dr. Mari's unabbreviated letter, please visit http://zneuro.net/Files/FrontPageNewsletter_Fall2014.docx

Johns Hopkins Parkinson's Disease and Movement Disorders Center

A National Parkinson Foundation Center of Excellence

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

Zoltan Mari, MD, *Interim Director*

Becky Dunlop, RN, MS, *Associate Director*

Johns Hopkins Outpatient Center

601 N Caroline Street, Suite 5064, Baltimore, MD 21287

www.hopkinsmedicine.org/neuro/movement

410-502-0133 (Option 1 - Ataxia Center; Option 2 - Make an Appointment; Option 5 - Research)

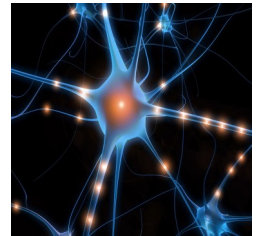
Please consider supporting our center!

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.

SPECIALTY CENTERS

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.



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 Degeneration (CBD), Multiple System Atrophy (MSA) and Dementia with Lewy bodies (DLB). This center is in the recent stages of development and will provide comprehensive care to those living with these disorders.

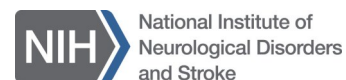
Deep Brain Stimulation Center

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.



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.



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.

A Look Into Current Research

By Zoltan Mari, MD

Our center is excited to be engaged in cutting edge research in the field of movement disorders and we are pleased to share some of these updates with you.

The *National Parkinson Foundation* sponsored **Quality Improvement Initiative** (Parkinson's Outcomes Project) remains fully funded and active. In fact, our center is very close to the 500-patient accrual goal.

Similarly high profile, the Michael J. Fox Foundation sponsored **Parkinson Progression Markers Initiative (PPMI)** will continue. Our center has accomplished a perfect retention rate and remains one of the top centers with respect to patient/healthy control ratio. Not only that, but the study has recently added new additional cohorts to study predictors of PD (see image and caption).

Our team is enthusiastic that the *Clinical Core of the Morris K. Udall Parkinson's Disease Research Center of Excellence* has moved to our department, under the new leadership of Dr. Rosenthal. The Clinical Core will continue to oversee the research registry, longitudinal study and brain donation program.

The **MARK-PD** study under the leadership of Drs. Dawson and Rosenthal is currently recruiting healthy controls (see page 5). This NIH-sponsored effort is critical in identifying biomarkers relevant to non-motor manifestations of Parkinson's disease (PD).

The clinical efficacy of **Transcranial Direct Current Stimulation** (tDCS) in PD continues to be tested and should be ready for prime time in the near future.

It is exciting to announce that the **MYSTICOL** trial is fully approved and enrolling. This is a very important trial that hopes to formally establish clinical efficacy of rimabotulinumtoxinB for sialorrhea (drooling). Sialorrhea can be a disabling problem for many individuals and enrollment is open to those with PD, ALS, stroke or any condition that causes drooling.

STEADY-PD III is a recently approved clinical trial that will test potential disease modification effects of isradipine. The study is looking for individuals with de novo (untreated/early stage) disease to volunteer.

Our specialty centers (page 2) are busier than ever with additional providers and new research projects. One of those research efforts includes DBS in unapproved movement disorders and other syndromes, an entirely novel territory! Under this research protocol, DBS is now offered not only for Tourette syndrome, but also for a number of other diseases.

Dystonia research efforts have doubled up and we are now part of the NIH-sponsored **Dystonia Coalition** as a fully funded site. Our team is working on a number of investigator initiated studies trying to decipher the mystery of network physiology to explain dystonic motor behavior.

A special thank you to the participants who generously contributed to the former neuroprotective trials, **NET-PD LS1**, **QE3** and **FS-ZONE**. Thank you to all of our research participants for dedicating their time and contributing to future advancements in the field of movement disorders.

If you are interested in learning more about our current research studies, please refer to page 4.

SMELL & YOUR BRAIN

1 IN 2 PEOPLE OVER AGE 60 ARE LIVING WITH SMELL LOSS

100% OF MAJOR BRAIN DISORDERS ARE ASSOCIATED WITH SMELL LOSS

96% OF NEWLY-DIAGNOSED PARKINSON'S DISEASE PATIENTS HAVE LOST SOME ABILITY TO SMELL

7 IN 10 PEOPLE LIVING WITH SMELL LOSS DON'T KNOW IT UNTIL THEY ARE TESTED

ESTIMATES SUGGEST SMELL LOSS MAY PRECEDE A PARKINSON'S DISEASE DIAGNOSIS BY UP TO 10 YEARS

People over 60 who **DO NOT** have Parkinson's disease are needed

TAKE THE **SMELL SURVEY**

www.michaeljfox.org/takethesmellsurvey

The Michael J. Fox Foundation is very interested in hyposmia and how it may be a predictor of PD. The study is looking for individuals over the age 60 who have a decreased ability to smell. Please see page 4 to learn more or contact Arita McCoy at 410-955-2954.

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	PD patients treated with PD medications and individuals without PD	Liana Rosenthal, MD (NA_00031749)	Nadine Yoritomo 410-616-2822
Parkinson's disease	Prodromal Cohort	Identify those who may be at risk of developing PD (<i>Part of the Michael J. Fox Foundation Parkinson's Progression Markers Initiative</i>)	Those over the age of 60 who do not have PD, but have lack of smell, REM behavioral sleep disorder or LRRK2 genetic mutation	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	Zoltan Mari, MD (NA_00038373)	Becky Dunlop 410-955-8795
Parkinson's disease	High resolution neuroimaging in Parkinson's	Examine cognitive functioning and memory in those with PD	Individuals diagnosed with PD who have a mild memory complaint	Gregory Pontone, MD (NA_000887276)	Carrie Speck 410-955-5057
Parkinson's disease	Anxiety in Parkinson's	Comparison of on/off anxiety to identify effective treatments	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
Sialorrhea (drooling or excessive salivation)	Mysticol	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
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
Abnormal involuntary movements (tardive dyskinesia)	SD-809 (Deutrabenzazine) for Tardive Dyskinesia	Test the efficacy of an investigational drug to decrease abnormal involuntary movements	Individuals diagnosed with abnormal involuntary movements who have had symptoms for at least 3 months	Joseph Savitt, MD Pro00009599 (<i>Parkinson's Disease and Movement Disorders Center of Maryland</i>)	Erica Stacy 443-755-0030

Healthy Controls Wanted!

The Importance of Healthy Volunteers in Movement Disorders Research

Over the last several decades, the health of millions of individuals with Parkinson's disease and other movement disorders has been improved by therapies that were discovered as a result of biomedical research. Biomedical research includes the evaluation of new treatments for both safety and efficacy through clinical trials and all other research that contributes to the development of new treatments.

In order to realize future discoveries in the field of movement disorders, it is vital that both individuals with movement disorders and individuals without movement disorders volunteer to participate in research. Especially in clinical trials and natural history studies, the participation of healthy volunteers is important to define the limits of "normal." These volunteers are recruited to serve as controls for patient groups. They are often matched to patients on characteristics such as age, gender or family relationship. They are then given the same test, procedure or drug the patient group receives. Investigators learn about the disease process by comparing the patient group to the healthy control group.¹

Participating in research as a healthy control can be a great way to get involved and make a contribution towards identifying new treatments for those affected by movement disorders. Here at Johns Hopkins we are lucky to have multiple movement disorders studies taking place that are currently recruiting healthy participants. If you or someone you know may be interested in learning more about serving as a healthy volunteer in one of our current research trials, please refer to the list on page 4.

¹ NIH Clinical Center (February 25, 2014). *NIH Clinical Center: Patient Recruitment: Healthy Volunteers*. Retrieved from <http://clinicalcenter.nih.gov/recruit/volunteers.html>.

Study Seeking Healthy Controls

MARK-PD

Are you interested in participating in Parkinson's disease (PD) research that aims to improve both the diagnosis and treatment of the disease?

If so, you may be eligible to participate in the NIH sponsored MARK-PD study at Johns Hopkins as either a Parkinson's disease participant or as **an individual without neurological disease**. In this investigation, we are looking to identify biomarkers that have the potential to lead to a test to screen for PD and improve treatment of PD.

We are looking for participants both with and without PD. If you are over 30 years old and interested in learning more about the investigation, please contact Nadine Yoritomo, RN at **410-616-2822** or nyorito@jhmi.edu.

Liana Rosenthal, MD, PI; RPN: NA_00031749

Center Highlight: A P4P Volunteer Making a Difference

Jessica Stein, P4P team member since 2010 & P4P committee member since 2012



Jessica Stein and her grandfather Stanley

"About this time four years ago, I stumbled across P4P on Google when I was looking for a team to support during the Baltimore running festival. I couldn't be any luckier that I fell into such a fantastic group of people. The P4P family is everything you could ever ask for and has become a wonderful support system. My grandfather suffered from Parkinson's and it has been amazing to see the advancements that have been made by Johns Hopkins as a result of fundraising through P4P. Being part of the P4P family has been a

great avenue to extend my grandfather's legacy and support those who are living through similar experiences. There are so many ways to get involved in the cause, even for those that aren't able to participate in the race itself. I hope to see you on October 18!"



Support the Center's Largest Fundraising and Community Awareness Initiative!

6th Annual Pacing 4 Parkinson's at the Baltimore Running Festival Saturday, October 18, 2014

Support the Team!
Donate, Run, Walk or Volunteer

www.pacing4parkinsons.org

Managing a Movement Disorder

Welcome a New Non-Profit for Parkinson's!

Maryland Association for Parkinson Support, Inc. is a newly formed 501(c)(3) non-profit that will promote the well-being of people with Parkinson's disease, their families and friends, through support groups, informational resources, exercise programs and related services. Help this organization get moving by participating in events, donating or volunteering! Please call **443-470-3223** or email info@marylandparkinsonsupport.org to learn more.



Taking Medication On Time: Helpful Tips

Detach and Go Pill Organizer to the Rescue

Detach and Go is a detachable pill organizer that lets you organize your medication and create portable pill holders that you can take with you and easily place in a pocket or purse. Just like any other pill organizer, the medication can be organized into an individual compartment by the time of the day it needs to be taken. But what is nice about Detach and Go is that each compartment can then be detached and carried with you during your day without the need to take the entire pill organizer with you. With a disease like Parkinson's that requires a strict regimen of medication throughout the day, Detach and Go can be an easy way to transport and organize your daily medication. Detach and Go can be found easily on the internet by searching "Detach and Go Pill Organizer."



Find the Perfect Reminder Tool for You

E-pill is an online website that sells a variety of products that all serve to help remind you to take your medications. The products range from watches, to automated pill dispensers, alarm clocks, vibrating timers and so much more. Another useful product, the pill pouch, is a slender vinyl large wallet sized container which contains several compartments for pills and labels. Keeping a stable regimen of medication in Parkinson's disease is very important in keeping your symptoms at bay. If you think that these products may be useful to you, you can visit their websites at www.epill.com or www.pillpouch.net.



Simple Technology Offers Alternative Ways to Exercise

For people with Parkinson's disease and related movement disorders, research suggests that exercise can improve gait, balance, flexibility and motor coordination. If you are having significant trouble with your mobility or you are simply looking for a way to incorporate a low intensity workout into your daily routine, it may be beneficial to invest in an inexpensive folding exercise peddling machine. Stationary cycles are an excellent option for those with balance difficulties or a fear of falling. These peddling machines can be placed on the floor to exercise the legs in a manner that is similar to riding a bike or can be placed on a table top to exercise the arms. Most models require no assembly. Online retailers such as Amazon, Walmart and Target offer many different models that range in price from \$25 - \$50.



Dancing with Parkinson's Disease

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. There is a class held **every Thursday from 4:00 - 5:20 p.m.** at Megan Rich Physical Therapy, 9492 Deereco Road, Lutherville, MD 21093. Please contact Ellen Talles at 410-878-7164 to learn more about this class or contact Bailey Vernon at 410-616-2811 to find an exercise program near you.



Community Programs & Events

Community education & support groups

Find a group near you, start a new group or become more involved
Contact: Bailey Vernon, 410-616-2811



Monday, September 8 Deep Brain Stimulation Information Session

Presented by the Johns Hopkins PDMD Center

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

Johns Hopkins at Green Spring Station

10753 Falls Road, Pavilion II

Lutherville, MD 21093

Register: **410-616-2811** or [www.goo.gl/bMy09y](http://www.google.com/url?q=http://www.goo.gl/bMy09y)



Sunday, September 14

Walk Off Parkinson's

Presented by the Parkinson

Foundation of the

National Capital Area

Gates open 8:30 a.m., walk at 10:00 a.m.

Nationals Park, 1500 South Capitol Street, SE

Washington, DC 20003

Contact: **703-734-1017**

Register: www.walkoffpd.org

**Please consider supporting Dr. Mari by joining "Team Mari" or donating*



Saturday, October 11

Parkinson's Symposium on "Quality of Life"

Presented by the Parkinson's Education and Support Group of Sussex County, DE

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

Epworth United Methodist Church

19285 Holland Glade Road

Rehoboth Beach, DE 19977

Register: Dennis Leebel, **301-644-3465**

or www.delmarvaparkinsonsalliance.org



Saturday, October 11

Bev's Rally in the Valley

Fundraiser with dancing, raffles and more

7:00 pm - 11:00 p.m.

Parkville American Legion

Contact: Mike Bruno, 410-561-5112



Sunday, October 12

Partners in Parkinson's

Presented by the Michael J. Fox

Foundation & AbbVie

8:00 a.m. - 3:30 p.m.

Washington Hilton

1919 Connecticut Ave NW, Washington, DC 2009

Register: www.partnersinparkinsons.org



Saturday, October 18

Pacing 4 Parkinson's at the Baltimore Running Festival

Presented by the Johns Hopkins PDMD Center

8:00 a.m. - 2:00 p.m.

M&T Bank Stadium, Baltimore, MD 21230

Register or donate: 410-616-2811 or

www.pacing4parkinsons.org



Saturday, November 8

Movement Disorder Symposium

Presented by the Johns Hopkins PDMD Center

The symposium will provide educational seminars and breakout sessions for those with PD, Parkinson plus syndromes, essential tremor, dystonia and ataxia.

8:00 a.m. - 3:30 p.m.

BWI Airport Marriott Hotel

1743 W Nursery Road

Linthicum, MD 21090

Register: **410-616-2811** or www.hopkinsmedicine.org/neuro/movement_symposium



JOHNS HOPKINS PARKINSON'S DISEASE AND 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
Seema Gulyani, PhD, CRNP
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

Deep Brain Stimulation Information Session - Monday, September 8, 2014 - This session will provide insight on the innovative technique that can help individuals with movement disorders. Register at www.goo.gl/bMy09y.

Pacing 4 Parkinson's - Saturday, October 18, 2014 - P4P is a team at the Baltimore Running Festival that fundraises for the PDMD center. Register or donate at www.pacing4parkinsons.org.

Movement Disorder Symposium - Saturday, November 8, 2014 - This symposium will be held at the BWI Marriott and include a variety of educational seminars. Register at www.hopkinsmedicine.org/neuro/movement_symposium.



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