Anxiety and Worry in Parkinson’s Disease

By Greg Pontone, MD
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Severe anxiety and worry occurs in up to half of people diagnosed with Parkinson’s disease (PD). Most often, the anxiety is new and out of character, with individuals reporting, “I never considered myself an anxious person before Parkinson’s disease.” In addition to causing emotional distress, anxiety has also been shown to worsen PD symptoms, lower quality of life, and cause people to avoid activities they once enjoyed.

Anxiety related to Parkinson’s often has unique features and requires specialized treatment compared to anxiety not related to PD, including anxiety experienced before the onset of PD in the same individual. The two most common Parkinson’s-related anxiety disorders are, 1) fluctuation-associated anxiety and 2) anticipatory anxiety.

Fluctuation-associated anxiety occurs as Parkinson’s disease medication wears off at the end of dose. Typically, this is an episodic anxiety with physical symptoms of racing heart, sweating, increased tremor, a feeling of restlessness, panting or trouble drawing a full breath, and even the fear that one might die. Being aware of the timing of anxiety episodes in relation to the timing of your PD medications is the key to treating fluctuation-associated anxiety. With this information, your doctors can adjust your medications to improve this type of anxiety.

Anticipatory anxiety is excessive worry about an upcoming event, such as an appointment or trip. Fear is out of proportion to the situation and there is the concern that the worst may happen. This type of anxiety is often due to a breakdown in the ability to organize, sequence, and plan. Treatment often involves the cooperation of family and caregivers and sometimes talk-therapy and medications.

Anxiety is not a sign of weakness or a lack of ‘mental toughness’, instead it is thought to be part of the disease process or a complication of anti-Parkinson’s treatment. There is no need to suffer in silence or embarrassment as these anxiety problems are common in Parkinson’s and can often be successfully identified and treated in a matter of weeks.

Pacing 4 Parkinson’s: Exemplary Leadership

Paul DeLuca and his sister, Pat DeLuca Kaunitz, have been dedicated advocates, leaders, and volunteers for the Johns Hopkins Parkinson’s Disease and Movement Disorders Center and the Parkinson’s community. Pat and Paul have been the driving force behind Pacing 4 Parkinson’s (P4P) since its inception in 2008 to honor their father Gene DeLuca, who battled PD for over twenty years.

Paul has served as a Center Advisory Board Member since 2004 and the Pacing for Parkinson’s committee chair since 2008. Paul’s outstanding leadership and Pat’s enthusiastic support have recruited a growing team of 175+ members, making it one of the largest charity teams at the Baltimore Running Festival.

Over the past five years, P4P has raised over $200,000 for care, research, education, and outreach, with the DeLuca family contributing more than $30,000. The DeLuca family has brought enthusiasm to P4P that has created strong camaraderie among the team and community. Both the center and community are very appreciative of their ongoing support and leadership.

Learn more about P4P and how you can join the fight against PD on page 4.
**RESEARCH INITIATIVES**

**Biomarkers for PD and PD-Related Cognitive Impairment**

*Expansion of Initiative*

By Liana Rosenthal, MD

In collaboration with Ted Dawson, MD, PhD, and the NIH’s Parkinson Disease Biomarker Program, the MARK-PD study was initiated in September, 2012. The study seeks to find biomarkers to improve diagnosis and treatment of individuals with PD and PD-related cognitive impairment. A biomarker is a test that can diagnose PD or provide information about disease progression, fostering the development of new and better treatments. We are recruiting both people with PD and healthy volunteers without PD. To learn more, please contact Nadine Yoritomo, RN, at 410-616-2822.

**New Research Initiative**

**Seeking Those Without Parkinson’s**

*Michael J. Fox PPMI Launches New Prodromal Cohort*

By Arita McCoy, RN, BSN

The Michael J. Fox Foundation has created an addition to the Parkinson Progression Markers Initiative (PPMI) to identify those who may be at risk of developing PD. Individuals who are over the age of 60 and do not have PD, but may have hyposmia (lack of smell), REM behavioral sleep disorder, or LRRK2 genetic mutation, are invited to participate. The goal is to examine the biomarker progression prior to onset of motor symptoms. To learn more, please contact Arita McCoy, RN, at 410-955-2954.

**Research Initiative**

**Seeking Those with Primary Dystonia**

*NH/NINDS and ORDR Sponsored Multi-Center Study*

By Abhimanyu Mahajan, MBBS

The National Institutes of Health (NIH), National Institutes of Neurological Disorders and Stroke (NINDS) and Office of Rare Disease Research (ORDR) is sponsoring Dystonia Coalition Projects with the overall goal to develop a better understanding of dystonia that may improve the treatment of affected patients. Project 1 involves the creation of a patient repository of biospecimens, videos, and clinical information that can aid future studies on dystonia. Individuals who are over the age of 18 and have primary dystonia are invited to participate. To learn more, please contact Becky Dunlop, RN, at 410-955-8795.

**Enrolling Research Studies**

**Biomarkers for PD and PD-Related Cognitive Impairment**

Seeking: Individuals with PD that are treated with PD medications and individuals without PD

Goal: To identify PD biomarkers

PI: Liana Rosenthal, MD (NA_00031749)
Nadine Yoritomo, RN, BSN, CCRP 410-616-2822

**Dystonia Coalition**

Seeking: Individuals with dystonia over the age of 18

Goal: To understand dystonia

PI: Zoltan Mari, MD (NA_00074297)
Becky Dunlop, RN, BSN 410-955-8795

**National Parkinson Foundation Parkinson’s Outcomes Project: Patient Registry**

Seeking: All PD patients seen at the center and their care partners

Goal: To develop quality care standards

PI: Zoltan Mari, MD (NA_00036863)
Becky Dunlop, RN, BSN 410-955-8795
Bailey Vernon, MPH 410-616-2811

**Longitudinal Study of PD and Related Disorders**

Seeking: All patients with movement disorders and their care partners

Goal: To maintain a database of those interested in future studies

PI: Liana Rosenthal, MD (NA_00032761)
Vanessa Johnson, BS 410-614-1480

**Safety and Efficacy of 18F-AV-133 PET Imaging**

Seeking: Individuals with symptoms of a movement disorder but who have not yet received a definite diagnosis

Goal: To determine if 18F-AV-133 can detect loss or damage of dopamine cells

PI: Dean Wong, MD (NA_00036863)
Becky Dunlop, RN, BSN 410-955-8795

**Transcranial Direct Current Stimulation**

Seeking: Individuals with PD

Goal: To test the therapeutic relevancy of non-invasive brain stimulation for improving motor symptoms

PI: Reza Shadmehr, PhD (NA_00081426)
Yousef Salimpour, PhD 410-614-3424
AWARE IN CARE

*Advocating for Medications ON TIME*

The National Parkinson Foundation’s *Aware in Care* program provides individuals living with Parkinson’s disease and their families with vital information designed to educate hospital staff about the need for the appropriate medication at the correct time. Did you know that 3 out of every 4 individuals with Parkinson’s do not receive their medications on time when hospitalized? Parkinson disease medication regimens are complex and individualized. The *Aware in Care* kit is a tool which has the potential to help you or your loved one during a hospitalization or during a regular physician visit. Be sure to order one today at 800-473-4636 or www.awareincare.org.

EXPANDING NURSING KNOWLEDGE OF PARKINSON’S FOR IMPROVED CARE

*Edmond Safra Visiting Nurse Faculty Training Program*

The Edmond Safra Visiting Nurse Faculty training in Parkinson’s disease has been offered by the Johns Hopkins University Parkinson’s Disease and Movement Disorders Center for four years. This program was originally developed by two Parkinson disease nurse specialists, Lisette Bunting-Perry, PhD and Gwyn Vernon, MSN, CRNP. Nationally over 50 nursing faculty have completed the program with the goals of expanding nursing knowledge, advancing nurse scholarship, and improving care. The program provides current information on Parkinson’s so that faculty instruction reflects recent advances in the field. Faculty has instructed over 6,000 undergraduate nursing students about PD. *A key lesson is the importance of medication timing.* More information is provided at www.parkinsonsnursing.com.

NEW ELECTRONIC PARKINSON’S DIGEST

The center released the first electronic Parkinson’s Digest in June, 2013 to provide additional information about center updates and community outreach programs. In order to receive updates from our center and the electronic newsletter, or be removed from our mailing list, please email your contact information to Bailey Vernon at bvernon1@jhmi.edu.

MARYLAND ASSOCIATION FOR PARKINSON’S SUPPORT (MAPS)

*Community Advocates Wanted*

The need for more support in the Parkinson’s community is growing in the form of support groups, education programs, exercise classes, and informational resources. Individuals with Parkinson’s disease, care partners, health professionals, the Johns Hopkins University, University of Maryland, and other community members are collaborating to incorporate Maryland Association for Parkinson’s Support (MAPS) as a community non-profit organization. This organization will provide valuable services to the entire community and aims to improve quality of life for people living with Parkinson’s disease. The board is seeking individuals in the community to support the initiative to improve services through volunteering, fundraising, advocating, and much more. To join the effort and receive updates, please contact Bailey Vernon at 410-616-2811 or maryland.parkinsons@gmail.com.

PACING 4 PARKINSON’S

*Momentous Year for Raising Funds and Awareness*

The JH PDMD Center is proud to present Pacing 4 Parkinson’s for the 5th year at the Baltimore Running Festival on **Saturday, October 12, 2013**. All motivated by the same cause, our team members raise funds and participate in the 5k, half marathon, marathon, or 4-person team relay. The money raised supports the center’s efforts to improve patient care, expand outreach efforts, and advance research initiatives for Parkinson’s disease. You can join the fight against Parkinson’s disease by joining the team, supporting a team member, or volunteering. Learn more about P4P at www.pacing4parkinsons.org or contact Bailey Vernon at 410-616-2811.
2013 FALL PROGRAM CALENDAR

SEPTEMBER

Ataxia Community Meeting & Picnic
Saturday, September 7
12:00 - 4:00 p.m.
Grace Fellowship Church
9505 Deerco Road
Lutherville-Timonium, MD 21093

Parkinson’s Disease 101
Monday, September 23
5:00 p.m. - 8:30 p.m.
Green Spring Station, Pavilion II
10753 Falls Road
Lutherville, MD 21093

OCTOBER

World Parkinson Congress
October 1 - 4
Montreal, Canada
www.worldpdcongress.org

Senior Expo
October 9  9:00 a.m. - 6:00 p.m.
October 10  9:00 a.m. - 4:00 p.m.
Maryland State Fairgrounds
2200 York Road
Timonium, MD 21093
www.seniorexpoonline.com

Pacing for Parkinson’s at the Baltimore Running Festival
Saturday, October 12
7:00 a.m.
M&T Bank Stadium
Baltimore, MD
www.pacing4parkinsons.org

Parkinson's Community Symposium
Saturday, October 26
8:45 a.m. - 4:00 p.m.
Farm and Home Center
1383 Arcadia Road
Lancaster, PA 17601

Bev’s Rally in the Valley for a Parkinson’s Cure
Saturday, October 26
7:00 p.m. - 11:00 p.m.
Valley Mansion
594 Cranbrook Road
Cockeysville, MD 21030
www.bevbattlesparkinsons.com

Parkinson’s Disease 201
Monday, October 28
5:00 p.m. - 8:30 p.m.
Green Spring Station, Pavilion II
10753 Falls Road
Lutherville, MD 21093

NOVEMBER

Sessions with your Neurologist
Saturday, November 9
10:30 a.m. - 12:00 p.m.
Green Spring Station, Pavilion II
10753 Falls Road
Lutherville, MD 21093

National Parkinson Foundation Moving Day
Sunday, November 10
11:30 a.m.
Nationals Park
Washington, DC
www.parkinson.org

Deep Brain Stimulation Information Session
Monday, November 11
6:00 p.m. - 7:30 p.m.
Green Spring Station, Pavilion II
10753 Falls Road
Lutherville, MD 21093

Ataxia Community Meeting
Saturday, November 23
12:00 p.m. - 2:00 p.m.
Green Spring Station, Pavilion II
10753 Falls Road
Lutherville, MD 21093

Contact Bailey Vernon at 410-616-2811 or bvernon1@jhmi.edu to register or learn more about these programs
Letter from the Division Director: Zoltan Mari, MD

As a clinician in the Department of Neurology, Movement Disorders Division, I believe I was given a unique opportunity to connect with patients and families, and understand their every day needs and fights. Parkinson’s disease changes lives, but we can offset most of those, by ‘changing lives’ too – treating PD. This slogan has been used before, but I truly mean it and strongly believe we can accomplish that here and now. I am humbled and honored to be trusted with this leadership role. With our teamwork and ever strengthening partnerships with patients, care partners, support groups, colleagues inside and outside Hopkins, and funding agencies, I am convinced we are better positioned than ever to start working toward that goal today.

The Dawson Laboratory

The Dawson laboratory within the Institute for Cell Engineering, led by Ted Dawson, MD, PhD, studies molecular mechanisms of neurodegeneration of Parkinson’s disease, nitric oxide signaling and neuronal cell death, and neuroprotective and neurorestorative strategies in neurodegenerative diseases, stroke, and trauma. Dr. Dawson and his team are studying the genetic basis of Parkinson’s disease by investigating the mechanisms by which mutations in familial-linked genes cause PD, with hopes of identifying potential therapeutic targets for developing PD treatments. To study PD in human neurons, the laboratory is turning skin cells from people with different Parkinson’s disease mutations into stem cells and then turning them into neurons. With this stem cell technology, the lab can test hypotheses and discover drugs that actually work in human neurons rather than in mice and then hopefully be able to make the leap forward to get treatments to work in humans.

The Morris K. Udall Centers of Excellence for Parkinson’s Disease Research: The Clinical Core

The Morris K. Udall Centers of Excellence for Parkinson’s Disease Research were created by Congress more than 10 years ago. The primary goal of the Udall Centers is to develop new clinical treatments for Parkinson’s disease. The Udall Center at Johns Hopkins seeks to have an infrastructure in place that can efficiently facilitate a rapid translation from research to clinical practice when promising breakthroughs occur. One of the keys of this infrastructure is the Clinical Core. The Clinical Core currently recruits, evaluates, and follows patients with Parkinson’s disease and control participants and then obtains well-characterized postmortem brain tissue. In the coming year, the Clinical Core will add new assessments while continuing its current mission.

Welcome to the Team

Noha Saleh M. Alejhani, MBBS: Post Doctoral Deep Brain Stimulation Research Fellow to work in the movement disorders clinic.

Seema Gulyani, PhD, NP: Nurse Practitioner from the Johns Hopkins Sleep Disorders Center to focus on Parkinson’s disease clinical care and research.

Abhimanyu Mahajan, MBBS: Clinical research graduate assistant to work with Dr. Mari and focus on epidemiology of Parkinson’s disease and movement disorders.

Katerina Salnikova, BA: Research Assistant to work on the MARK-PD study with Dr. Rosenthal.

Nadine Yoritomo, RN, BSN, CCRP: Senior Research Nurse Coordinator from the Baltimore Huntington’s Disease Center at Johns Hopkins to assist Dr. Rosenthal with the MARK-PD study.
**Movement Disorders Team**

**Movement Disorders Physicians**  
Ted Dawson, MD, PhD  
Zoltan Mari, MD  
George Ricaurte, MD, PhD  
Liana Rosenthal, MD  
David Zee, MD

**Movement Disorders Allied Team**  
Amita McCoy, RN, BSN  
Paige Nichols, BA  
Katerina Salnikova, BA  
Bailey Vernon, MPH  
Nadine Yoritomo, RN, BSN, CCRP

**Movement Disorders Clinical Team**  
Noha Saleh M. Alejhani, MBBS, Fellow  
Jason Brandt, PhD  
Becky Dunlop, RN, BSN  
Seema Gulyani, PhD, NP  
Abhimanyu Mahajan, MBBS

**Deep Brain Stimulation Surgeons**  
William Anderson, MD, PhD  
Frederick Lenz, MD, PhD

**Parkinson’s Disease Research Center**  
Catherine Bakker, MS  
Susan Bassett, PhD  
Vanessa Johnson, BS  
Gregory Pontone, MD

**Adjunct Faculty**  
Stephen Grill, MD, PhD  
Joseph Savitt, MD, PhD  
Shawn Smyth, MD  
Howard Weiss, MD

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Disclaimer: The Parkinson’s Digest is published by the Parkinson’s Disease and Movement Disorders Center to provide timely and useful information to the Parkinson’s disease community. Every effort has been made to verify the accuracy of the content of the digest. However, the Digest is not intended to provide specific medical advice, and individuals are urged to follow the advice of their personal physicians. The Parkinson’s Disease and Movement Disorders Center is not responsible for the information or opinions expressed in its articles.

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