# Focus october 2021



We are the only PARKINSON'S FOUNDATION CENTER OF EXCELLENCE in the region with comprehensive care including doctors specialized in the diagnostics, treatment, research, and education of Parkinson's disease. We have a large multi-disciplinary team including healthcare professionals specialized in Parkinson's disease in the areas of psychology, speech, physical therapy, occupational therapy, dietetics, social work, pharmacy, neuropsychology, and neurosurgery, including a large deep brain stimulation program.

## We would like to introduce Emily Hunt, Social Worker, for the Parkinson's Disease & Movement Disorder Center!

Emily was born and raised in Nevada, MO. She has a Master's in Social Work from KU. Emily is a Licensed Clinical Social Worker in KS and MO and has been practicing for 12 years. Emily joined KU in May of 2021. She is married to TJ, a UPS delivery driver of 22 years. They have a son, Tucker who is 6.

Emily and her family live in Parkville, MO. She enjoys reading, embroidery, spending time outdoors, and spending time with friends and family. As a Clinical Social Worker in the Parkinson's Disease and Movement Disorder Clinic, Emily can assist with locating resources, making referrals, reviewing care options, insurance or financial questions, completing DPOA paperwork, and providing support to patients and their families.



RAJESH PAHWA, MD Laverne and Joyce Rider Professor of Neurology Director, Parkinson's Disease and Movement Disorder Center



KELLY LYONS, PhD

Research Professor
of Neurology

Director, Research and
Education, Parkinson's Disease
and Movement Disorder Center

#### TREMOR CORNER

At least 7 million persons in the USA are diagnosed with ET; however, propranolol is the only approved medication for ET. Other treatment options are primidone, gabapentin, and topiramate. Research has shown that at least 30% of persons with ET cannot tolerate the current medications due to side effects and another 30% do not receive significant benefit. There are also surgical options for ET including deep brain stimulation and focused ultrasound thalamotomy; however, not all patients are comfortable with having surgery. Soon, KU will be conducting 4 studies of new treatment options for ET, if you are interested in participating in a research study, please email pdetcenter@kumc.edu or call 913-588-7159.

#### **CLINICAL STUDIES RECRUITING**

We have multiple ongoing and upcoming studies for Parkinson's disease and essential tremor. There is no cost to participate in studies. We are currently enrolling patients in studies of the following areas:

- 1. Newly diagnosed PD patients
  - a. NLY01 PD patients diagnosed within the last 5 years and not taking any PD medications
  - b. K0706 PD patients diagnosed within the last 3 years and not taking any PD medications
  - c.  $\underline{\text{CVL-751}} \text{PD}$  patients diagnosed for < 3 years and taking no PD medications except for an MAO-B inhibitor
- 2. Stable PD patients
  - a. PADOVA PD patients taking only an MAO-B inhibitor OR levodopa diagnosed within the last 3 years
- 3. PD patients experiencing OFF time (poor control of symptoms) during waking hours
  - a. ND0612 PD patients with at least 2.5 hours of OFF time per day
  - b. Earstim-PD PD patients with at least 2 hours of OFF time per day
  - c. CVL-751 PD patients with at least 2.5 hours of OFF time per day
- 4. PD patients experiencing at least 2 hours of dyskinesia (wiggling movements from levodopa)
  - a. ADX-301 PD patients with at least 1 hour of dyskinesia between 9 a.m.
     and 4 p.m. daily and not currently taking amantadine or willing to discontinue
  - b. BK-JM-201 PD patients with at least 1.5 hours of troublesome dyskinesia daily and not taking or willing to stop amantadine
- PD Generation Mapping the Future of Parkinson's Disease Testing for 7 genes associated with Parkinson's disease. Anyone diagnosed with Parkinson's disease in our region can participate.

If you are interested or have patients who are interested in learning more about any of these research studies, please contact <a href="mailto:PDETCenter@kumc.edu">PDETCenter@kumc.edu</a>.

#### **RESEARCH FOCUS**

TOPAZ - Trial of Parkinson's and Zoledronic Acid As PD progresses, the risk of falling increases, resulting in a greater incidence of broken bones. The Parkinson's Foundation is conducting a study to determine if the risk of broken bones can be reduced by treatment with zoledronic acid. This drug is an injection approved by the FDA for the treatment of osteoporosis or in postmenopausal women to prevent osteoporosis. Its use is investigational in this study. Anyone with PD or other forms of parkinsonism that are at least 60 years of age can participate. A nurse will come to your home for the injection of the study drug. It is possible that you may receive placebo (injection that does not contain the drug). You will be followed every 4 months to report occurrence of fractures. You will be compensated for your participation. If you are interested, please visit www.topazstudy.org or click on TOPAZ in the title above and enter the invitation code KUMC.

### KU PARKINSON'S DISEASE ANNUAL SYMPOSIUM View Now At:

https://www.youtube.com/watch?v=rsWwmG2D4uU

We welcome any feedback, questions, or comments at PDETcenter@kumc.edu.

Visit our website: KUMC.EDU/PARKINSON