Focus

NOVEMBER 2022



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.

Introducing Molly Ray, RN, Movement Disorder Nurse On the Parkinson's Disease and Movement Disorder Team!

Molly received her RN from Kansas City Kansas Community College in May of 2021 and joined the Parkinson's Disease and Movement Disorder Center in June of 2021. Previously she worked with Alzheimer's disease patients and as a pediatric home health nurse. She is hoping to start working on her BSN at KU in 2023. She is currently working with Dr. Lee and Dr. Au, returning phone calls and taking care of patients with Parkinson's

returning phone calls and taking care of patients with Parkinson's disease, essential tremor and other movement disorders. Her favorite part of her job is getting to know patients and their families and being able to provide support through some of their toughest days. Her goal is to make at least one patient smile every day! Molly lives in Lee's Summit, MO and has 2 dogs, Lucy and Buddy. In her free time, she loves to read and take her dogs to the park.



RAJESH PAHWA, MD

Laverne & Joyce Rider
Professor of Neurology
Director, Parkinson's
Disease and Movement



KELLY LYONS, PhD

Research Professor
of Neurology

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

TREMOR CORNER

ET Studies Ongoing!

M21-471 - ET for at least 1 year, moderate to severe tremor of upper limbs. BOTOX injections for tremor. Can be taking tremor medications.

PRAX-944 - ET for at least 3 years with at least moderate tremor of the arms/hands. Cannot be taking primidone.

SAGE-324 - ET for at least 3 years with at least moderate arm/hand tremor. Cannot be taking other ET medications.

To participate in a research study or for more information, email pdetcenter@kumc.edu or call 913-588-7159.

The International Essential Tremor Foundation (IETF) provides education, support and resources for ET. Visit www.essentialtremor.org for more information.

PARKINSON'S STUDIES CURRENTLY RECRUITING

Disorder Center

 Newly diagnosed & Early PD - Possible disease slowing UCB0599 - diagnosed < 2yrs, never taken PD medications K0706 - diagnosed 3 years, not taking any PD medications CVL-751 - diagnosed < 3 years, no PD medications except for an MAO-B inhibitor

ANVS-22001- < 2 hours of OFF time

LUMA - diagnosed < 2 years, taking no PD medications or taking MAO-B inhibitor OR levodopa for no more than 3-12 months

2. Stable PD patients

PADOVA - taking only MAO-B inhibitor OR levodopa & diagnosed < 3 yrs **STEM-PD** - Moderate non-motor symptoms affecting daily activities

- 3. PD patients experiencing OFF time (poor symptom control) CVL-751 - at lease 2.5 hours of OFF time per day Diary Study - completing diaries to assess OFF time, diagnosed > 3 yrs & > 3 hours of OFF time
- 4. PD patients experiencing troublesome dyskinesia
 BK-JM-201 > 1.5 hours of troublesome dyskinesia, not taking amantadine
- 5. PD Patients with memory issues but not dementia
- 6. PD Generation: Mapping the Future of Parkinson's Disease Testing for 7 genes that may increase the risk of developing PD. Anyone diagnosed with PD in our region can participate in person or virtually
- 7. The Parkinson's Progression Markers Initiative (PPMI)
 - a. Parkinson's Disease cohort (PD diagnosed within the last 2 years, not on or expected to need PD medication for 6 months)
 - b. Prodromal cohort (1st degree relative with PD, REM sleep behavior disorder (RBD), or known genetic variants; 60+ years of age),

c. Healthy Controls (30+ years of age).

If you are interested or have patients who are interested in more information about any of these studies, please email PDETCenter@kumc.edu or call 913-588-7159.

RESEARCH HIGHLIGHT

Is Parkinson's Disease Genetic?

The cause of PD is currently not known. It is thought that it could be the result of an underlying genetic predisposition, triggered by an environmental factor like significant herbicide or pesticide exposure. The Parkinson's Foundation is conducting the PDGeneration study which is testing for 7 genes that could increase the risk of developing PD. KU has tested over 300 persons with PD and less than 15% have had one of the these 7 genes. This suggests that additional genes, not yet tested or identified may be related to the development of PD or that environmental factors are increasing the risk. Given the rural nature of our region, we are in a prime position to help determine the influence of genes and environment in causing PD. If you have not yet participated in the study, particularly if you are from or currently living in a rural area, please consider getting involved. The study does not require you to come to KU, it can be done virtually from a computer at your home or a public location near you. Determining the genetic influence in PD, not only helps to identify the cause of PD but also the development of new treatments targeting specific genes. KU is starting a study soon, that is testing a new treatment targeting the LRRK2 gene. If you have done genetic testing and have the LRRK2 gene, please contact us for more information about the study. If successful, this treatment would be the start of precision medicine, which would provide treatments specifically for your genetic makeup!

Visit our website: KUMC.EDU/PARKINSON for PD information