Focus APRIL 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.

April is Parkinson's Disease Awareness Month! Kansas Governor, Laura Kelly, signs proclamation to officially make April 2022 Parkinson's Disease Awareness Month in Kansas



Kim Nitz,
Parkinson's Foundation
Lou Eisenbrandt,
PD Advocate
Governor Laura Kelly
Kim Lee
KU PD Parkinson's Foundation
Center of Excellence Coordinator
John Reinhart
PD Advocate, Davis Phinney
Foundation



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



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

KELLY LYONS, PhD

TREMOR CORNER

ET Studies Starting This Month!

<u>JZP385</u> – ET with moderate to severe arm/ hand tremor. Cannot be taking ET medications

PRAX-944 – ET for at least 3 years with at least moderate arm/hand tremor. Cannot be taking primidone.

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

If you are interested in participating in a research study or would like more information, please email pdetcenter@kumc.edu or call 913-588-7159.

CLINICAL STUDIES RECRUITING

We have multiple ongoing and upcoming studies for PD. We are currently enrolling for the following studies:

1. Newly diagnosed PD patients

- a. <u>K0706</u> PD patients diagnosed within the last 3 years and not taking any PD medications
- b. <u>CVL-751</u> PD patients diagnosed for < 3 years and taking no PD medications except for an MAO-B inhibitor

2. Stable PD patients

- a. <u>PADOVA</u> 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. 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. <u>BK-JM-201</u> 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.

6. 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 meds for 6 months)
- b. Prodromal cohort (1st degree relative with PD, REM sleep behavior disorder (RBD), or known genetic variants; 60+ years),
- c. Healthy Controls (30+ years).

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



Parkinson's disease was first described by James Parkinson in 1817. Since that time, a number of medical and surgical treatments have been approved, allowing people to live well with PD! Yet, a lot of work is still needed to prevent, reverse, and ultimately cure PD!

There are many ways for you to get involved in PD Awareness month! Participate in a clinical trial to help advance treatment options, join a support group or exercise program, raise awareness of PD in your community, have a fundraiser for PD or donate to advance PD research!

Living With Parkinson's: Beyond the Diagnosis – Surgical Options

Presented by Dr. Kelvin Au and Crystal Cramer, BSN from the KU PD Center of Excellence. Click on the link below to watch now:

https://voutu.be/67wW-0VUaNY

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

Visit our website: KUMC.EDU/PARKINSON