Focus december 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 hope that you have a wonderful holiday and wish each of you a safe, happy and healthy new year! In spite of COVID-19 challenges, in 2021 we have added new staff members including Dr. Kelvin Au (movement disorder specialist), Sarah Luby (Tate), PharmD (pharmacist), Emily Hunt, MSW, LCSW, LSCSW (social worker) and Dr. Swarna Mandali (dietician); we have expanded our telemedicine services; we are developing a more formal palliative care program to help persons with PD live well throughout the disease course; and we have multiple new studies for all stages of PD as well as several new studies for ET. We hope to resume our live symposium and other programs in 2022. If you would like to make an end of year donation to support local PD & ET research click HERE for an online donation or send a check payable to KU Endowment Association to Kelly Lyons, PhD, University of Kansas Medical Center, Parkinson's Disease and Movement Disorder Center, 3599 Rainbow Blvd, MS 3042, Kansas City, KS 66160.



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

Alcohol and Essential Tremor

For many persons with ET, an alcoholic beverage may temporarily reduce tremor. This reduction in tremor may cause some to drink an excessive amount of alcohol which can lead to alcoholism. In addition, the consumption of large amounts of alcohol can lead to a "rebound" tremor the next day, which is often more severe than the typical tremor from ET. A drink prior to an event or get together may help to reduce tremor, but drink responsibly so the alcohol does not lead to a worsening of your tremor.

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. <u>CVL-751</u> PD patients diagnosed for < 3 years and taking no PD medications except for an MAO-B inhibitor
 - d. PPMI PD patients diagnosed within the last 2 years, not taking any PD medications, observational study
- 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. 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
 - 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 PDETCenter@kumc.edu.

RESEARCH FOCUS

Advances in PD Research in 2021!

Remote Programming: DBS

NeuroSphere Virtual Clinic, approved in 2021, allows for programming of deep brain stimulation parameters (Abbott device only) and system checks to reduce in office visits and provide symptom control through telemedicine.

MR-Guided Focused Ultrasound

MRgFUS thalamotomy has been approved for ET and parkinsonian tremor. MRgFUS pallidotomy (Insightec) was approved 11/2021 for PD to reduce OFF time and dyskinesia.

New Forms of Levodopa Delivery

Two investigational continuous subcutaneous infusion therapy studies have reported positive initial results with an increase in daily ON time without troublesome dyskinesia and a reduction in OFF time. Both therapies, ABBV-951 & ND0612, are still under study, but these results indicate promising new therapies for the future.

KU PARKINSON'S DISEASE ANNUAL SYMPOSIUM

Click Here to View

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

Visit our website: KUMC.EDU/PARKINSON