Focus NOVEMBER 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.

Welcome Dr. Swarna Mandali, Dietician, to the Parkinson's Disease & Movement Disorder Center!

Dr. Mandali earned a PhD in Nutritional Sciences from Oklahoma State University. She is a registered dietitian, licensed in Kansas and Missouri. She joined KU in June of 2021, as the director for the Doctorate in Clinical Nutrition Program, Department of Dietetics and Nutrition at the School of Health Professions at KU Medical Center. She lives with her husband, daughter and a German Shepard, in the country in Edgerton, KS. She enjoys music, likes to exercise, loves to cook spicy food, and spend time with friends and family. As a Clinical Dietitian in the Parkinson's Disease and Movement Disorder Center, Dr. Mandali counsels patients on nutrition and healthy eating for maintaining health and managing Parkinson's disease and related conditions.



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

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.

For additional information about essential tremor, please visit the International Essential Tremor Foundation (IETF). For those living with ET, there are a number of resources available, including educational materials, support groups, programs and events, listing of physicians specializing in tremor, recent findings, and ongoing studies. For healthcare professionals, there are also ET educational materials that can be sent to your offices. The IETF website is essentialtremor.org.

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

New Clinical Trials for Dyskinesia Enrolling Now!

Dyskinesia are wiggling, dancelike, involuntary movements that most typically occur during the ON state when peak concentrations of levodopa are in the blood or less typically at the end of a dose when turning OFF. Dyskinesia can affect the hands/arms, legs/feet, face, neck, or trunk. Dyskinesia can be treated with amantadine/ amantadine ER, by adjusting the levodopa dose or frequency, discontinuing PD medications like dopamine agonists or COMT inhibitors, or with deep brain stimulation. Dyskinesia should not be confused with tremor which is a rhythmical movement of typically the upper or lower extremities that worsens during the OFF state. If you have more than 2 hours of troublesome dyskinesia per day, meaning it interferes with the smooth performance of your activities, and are interested in being in a research study please call 913-588-7159 or email PDETcenter@kumc.edu

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