Focus

February 2023



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.

Please Welcome Sarah Kanaga, RN, BSN to the Parkinson's Disease and Movement Disorder Team!

Sarah received her BSN, RN from Rockhurst University in 2017 and joined the Parkinson's Disease and Movement Disorder Center in December 2022. Previously she worked at Research Psychiatric Center on the senior unit. She also worked at Research Medical Center on the stroke and brain floor, and Saint Luke's neurology clinic. She is currently working with Dr. Kelvin Au, KU Movement Disorder Specialist, and is managing patients with Parkinson's disease, essential tremor,

She loves working with patients, hearing their stories and learning about their lives. Sarah lives in Mission, Kansas with her sweet dog, Sadie, and sassy hedgehog, Petunia. In her free time, she loves to read, watch movies, and spend time with her loved ones.



and other movement disorders.

RAJESH PAHWA, MD

Laverne & 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

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.

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 information, email pdetcenter@kumc.edu or call 913-588-7159.

ESSENTIAL TREMOR EDUCATION FORUM

Saturday, April 1, 2023 9:00am - Noon, registration 8:00am The Pavilion at John Knox Village 520 NW Murray Road, Lee's Summit, MO 64081

CLICK HERE TO REGISTER NOW or call 888-387-3667

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

PARKINSON'S STUDIES CURRENTLY RECRUITING

- Newly diagnosed Possible disease slowing K0706 - diagnosed 3 years, not taking any PD medications LUMA - diagnosed < 2 years, taking no PD medications or taking MAO-B inhibitor OR levodopa for no more than 3-12 months
- Early PD Control of Symptoms
 CVL-751 diagnosed < 3 years, no PD medications except for an MAO-B inhibitor
- Stable PD patients
 STEM-PD Moderate non-motor symptoms affecting daily activities
- 4. 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
- PD patients experiencing troublesome dyskinesia
 BK-JM-201 > 1.5 hours of troublesome dyskinesia, not taking amantadine
- 6. PD Patients with memory issues
- 7. 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
- 8. 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.

FREE PARKINSON'S DISEASE VIRTUAL EDUCATION

Understanding Parkinson's Disease:

A Virtual Series For Persons Living With PD Featuring Dr. Rajesh Pahwa, KU PD Center

Each course has a short presentation followed by Q&A from the audience. There is no cost to attend but you do need to register for each course you plan to attend.

Treating Parkinson's Disease Psychosis, Dementia and Other Non-Motor Symptoms Feb 6, 2023, 7:00 PM

<u>Click Here to Register for Course 2</u>

What Are My Treatment Options After Diagnosis? Feb 13, 2023, 7:00 PM Click Here To Register for Course 3

Levodopa: Facts & Myths Feb 27, 2023, 7:00 PM
Click Here To Register for Course 4

Management of OFF and Dyskinesia Feb 28, 2023, 7:00 PM Click Here to Register for Course 5

Use of On-Demand Therapies Mar 6, 2023, 7:00 PM
Click Here to Register for Course 6

Role of Infusion Therapy, Deep Brain Stimulation and Focused Ultrasound Mar 14, 2023, 7:00 PM
Click Here To Register for Course 7

Pointers For Living Well With Parkinson's Disease Mar 15, 2023, 7:00 PM Click Here to Register for Course 8

You can also register at **kansascitycns.org/programs** or email your full name and which courses you would like to attend to PDETcenter@kumc.edu and we will register you.

Visit our website: KUMC.EDU/PARKINSON for more information about PD and ET