

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.

**KU Designated the Parkinson's Foundation Krupp Smith Family Foundation Center of Excellence and the Gary A Smith Super Site for PD GENERation: Mapping the Future of Parkinson's Disease**

The Krupp Smith Family Foundation made a \$1 million donation in memory of Gary Smith Sr. to the Parkinson's Foundation to advance research, expand clinical care and help meet the rising demand for community-based services in the Heartland.



Dr. Rajesh Pahwa, Director, KU PD Center of Excellence (COE)  
Dr. Kelly Lyons, Director, Research & Education, KU PD COE  
Gary Smith, Jr., Chairman, Krupp Smith Family Foundation  
John L Lehr, Parkinson's Foundation President and CEO



**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 3 years, 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 primidone.

**JZP385** - Moderate to severe arm/ hand tremor. Cannot be taking primidone.

Two studies of wrist-worn devices providing stimulation to reduce tremor will begin in the next few months.

To participate in a research study or for more information, email [pdetcenter@kumc.edu](mailto: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](http://www.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
- PD patients with LRRK2 Gene**
- Early PD - Control of Symptoms**  
CVL-751 - diagnosed < 3 years, no PD medications except for an MAO-B
- Stable PD patients**  
STEM-PD - Moderate non-motor symptoms affecting daily activities
- PD patients experiencing OFF time (poor symptom control)**  
CVL-751 - at least 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
- PD Patients with memory issues**
- PD patients with medication resistant tremor**
- 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
- The Parkinson's Progression Markers Initiative (PPMI)**
  - Parkinson's Disease cohort** (PD diagnosed within the last 2 years, not on or expected to need PD medication for 6 months)
  - Prodromal cohort** (1st degree relative with PD, REM sleep behavior disorder (RBD), or known genetic variants; 60+ years of age),
  - 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](mailto:PDETCenter@kumc.edu) or call 913-588-7159.

**RESEARCH HIGHLIGHT**

**Medication Resistant Parkinson's Disease Tremor**

PD medications generally control the primary motor symptoms of tremor, slowness and stiffness. However, in some patients, tremor of the hands/arms is not well controlled by carbidopa/levodopa or other PD medications. In some cases, the tremor may be reduced, but is still bothersome and in other cases it may not be reduced at all. This tremor is referred to as medication resistant tremor. There is a new medication being studied for medication resistant PD tremor.

If you have PD tremor that is not currently controlled by your medications and are interested in participating in this study or would like more information please email [pdetcenter@kumc.edu](mailto:pdetcenter@kumc.edu) or call 913-588-7159.

**MEDICATION NOTIFICATIONS**

**KYNMOBI (apomorphine sublingual film)**

As of June 30, 2023 Kynmobi will be withdrawn from the market and prescriptions will not be filled or refilled after this date. This is related to limited use, not any sort of side effect or issue with the drug. If you are taking Kynmobi, please contact your Parkinson's physician to discuss alternate treatment options.

**Carbidopa/levodopa subcutaneous infusion was not approved by the FDA and is not available at this time. Updates will be provided as more information is available.**

Visit our website: [KUMC.EDU/PARKINSON](http://KUMC.EDU/PARKINSON) for more information about PD and ET