

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 had a wonderful Thanksgiving and we wish each of you a safe, happy, and healthy holiday season and all the best for 2023! In 2022, we had many accomplishments. We are studying more new treatment options for PD and ET than ever before and are continuing to get new research studies. We welcomed Dr. Andrea Lee, our newest movement disorder specialist, and Dr. Angela Richmond our movement disorders fellow, we now have a physical therapist in our clinics, and we have implemented a formal palliative care program to help persons with PD and their families live well throughout the disease course. We had over 600 attendees at our live PD symposium and over 1400 attending our virtual PD educational series; both of which we plan to repeat in 2023.

If you would like to make an end of year donation to support local PD & ET research click [HERE](#) for online donation or send a check payable to KU Endowment Association (KUEA) 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 & 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.

**PRAX-944** - ET for at least 3 years with at least moderate tremor of the arms/hands. Cannot be taking primidone.

**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 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**  
**UCB0599** - diagnosed < 2yrs, never taken PD medications  
**K0706** - diagnosed 3 years, not taking any PD medications  
**ANVS-22001** - < 2 hours of OFF time  
**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
- 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 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

### What Is OFF Time?

If you have PD, one question your doctor may ask is if you have OFF time. This can be difficult for many to answer. OFF time is when your medications are not working to adequately control your symptoms. OFF time can involve your motor symptoms, so your tremor may be worse, it may be more difficult to walk, write, speak clearly, perform daily activities or do fine movements, and your muscles may feel more stiff. OFF time can also affect non-motor symptoms where your mind may feel cloudy or it is harder to think of the words you want to say, you may feel more anxious or have less motivation. ON time is when your medicine is working well and your symptoms are under good control. OFF time can occur any time throughout the day. It may be when you first wake up and your medicines have not yet started to work, it could occur at the end of each medication dose where you may feel like your medication effect is wearing OFF before your next dose, or it can occur in the evenings or throughout the night. OFF time can be predictable where you have certain times throughout the day that your medications always wear OFF or it can be random with no clear pattern. It is important to monitor your OFF time so your doctor can make necessary adjustments to avoid it. A study is currently ongoing to monitor OFF time in more detail, it does not involve any medications or changes to your current treatment. If you think you have OFF time and would like to participate please email [PDETcenter@kumc.edu](mailto:PDETcenter@kumc.edu).

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