

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.

**April Is Parkinson's Disease Awareness Month!**

**Shop for Jewelry & Support Parkinson's Research at the KU Parkinson's Foundation Smith Krupp Family Foundation Center Of Excellence**

**KENDRA GIVES BACK PARTY!**

Enjoy sips, sweets, & jewels while supporting Parkinson's disease research! Kendra Scott is hosting "Shop For Good" in-store or online, April 14th & 15th, **20% of your purchase will be donated to the KU PD Center**

Online: [kendrascott.com](http://kendrascott.com)

enter code GIVEBACK-DWMCI in your cart or at checkout

In person: Mention at Check-Out Counter

April 14th 4:00-6:00pm at Kendra Scott, KC Country Club Plaza, 412 Nichols Road, Kansas City, MO 64112

April 15th 3:00-5:00pm at Kendra Scott, Town Center Crossing, 4533 W 119th Street, Leawood, KS 66209

KENDRA SCOTT



**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**

1. **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
2. **Early PD - Control of Symptoms**  
**CVL-751** - diagnosed < 3 years, no PD medications except for an MAO-B inhibitor
3. **Stable PD patients**  
**STEM-PD** - Moderate non-motor symptoms affecting daily activities
4. **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
5. **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](mailto:PDETCenter@kumc.edu) or call 913-588-7159.

**RESEARCH HIGHLIGHT**  
**Reducing Fractures After Falls**

Persons living with Parkinson's disease or other forms of parkinsonism, such as MSA, PSP, vascular parkinsonism, or dementia with Lewy bodies, are at a high risk of broken bones due to the increased risk of falls. In fact, persons with PD or other forms of parkinsonism are 4 times more likely to have a hip fracture than persons of the same age without parkinsonism. Broken bones can increase disability, reduce independence, and may lead to nursing home placement.

The Parkinson's Foundation, in collaboration with several PD Centers nationally, is conducting the TOPAZ study with the goal of reducing fracture risk in persons with PD or other forms of parkinsonism. The study involves taking a single treatment of zoledronate, which is an FDA approved treatment for osteoporosis (loss of bone mass). You do not need to have osteoporosis or currently having falls to participate. The study is done completely from your home and does not require you to come to the clinic. Anyone, male or female, who is 60 years or older, has not had a hip fracture and has PD or another form of parkinsonism may participate.

If you are interested in participating in this study or would like more information please visit [TOPAZstudy.org](http://TOPAZstudy.org) or call 415-387-5748. Please indicate that you heard about the study from the KU Parkinson's Center.

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