# Focus

September 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.

### Welcome Dr. Tyler Okelberry, Movement Disorder Fellow, to the Parkinson's Disease and Movement Disorder Team!

Dr. Okelberry attended medical school at the University of Texas Southwestern before moving to Kansas. He recently completed his residency training in Neurology. He has decided to continue a fifth year at KUMC to receive additional training from our movement disorder specialized neurologists to become a movement disorder specialist himself. He is excited to have joined the KU movement disorder team as the new movement

disorders fellow. His clinical interests include Parkinson's disease, essential tremor, atypical parkinsonian syndromes, deep brain stimulation and focused ultrasound. He enjoys getting to know his patients and making sure they feel seen and heard. He lives in Overland Park, Kansas with his wife and three children. He and his family love to swim, hike, read, and ride bikes.



RAJESH PAHWA, MD
Laverne & Joyce Rider
Professor of Neurology
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KELLY LYONS, PhD
Research Professor
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#### 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.

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

**FELIX** - Wrist-worn stimulation device to control moderate to severe ET

To participate in a research study or for more information, email 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 for more information.

#### PARKINSON'S STUDIES CURRENTLY RECRUITING

 Newly diagnosed - Possible disease slowing K0706 - diagnosed < 3 years, not taking any PD medications IkT-148009 - < 75 years of age, not taking PD medications</li>

Disorder Center

- Early PD Control of Symptoms
   CVL-751 diagnosed < 3 years, no PD medications except for an MAO-B</li>
- Non-Motor Symptoms (thinking, dizziness, fatigue, etc.)
   STEM-PD Headphone-like device to reduce non-motor symptoms
- 4. PD patients experiencing OFF time (poor symptom control) 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
- PD patients with medication resistant tremor Suvecaltamide -tremor persists, other symptoms controlled FELIX - Wrist-worn stimulation device to control PD tremor
- 8. 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)

   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),
- 10. Persons with Multiple System Atrophy (MSA)
- 11. Persons with Lewy Body Dementia (LBD)

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.

## Over 800 In Attendance For KU 15th Annual Parkinson's Disease Symposium!

We hope those of you that attended the symposium enjoyed the day and left with valuable new information. We are sorry to have missed those of you that were not able to attend. Dr. Andrea Lee, KUMC, spoke about new ways to help diagnose PD, like a picture of the brain, skin test, or spinal fluid. She also discussed the various treatment options currently available. Dr. Au discussed surgical procedures including deep brain stimulation, focused ultrasound, and infusion therapies; as well as new infusion therapies under study that would not require surgery. Dr. Whittaker reviewed the problems that can occur with vision in persons with PD such as blurry or double vision, dry irritated eyes, problems opening eyes and issues with color vision, and suggested https://eyewiki.aao.org/Visual\_Symptoms\_of\_Parkinson %E2%80%99s Disease for more information. Dr. Nashatizadeh discussed challenges during hospitalizations and advised to always have someone with you if possible, bring medications from home so they are sure of what you are taking and you have them if not available at the hospital, and to add the following as medications to avoid with PD: Reglan, Haldol, Compazine. Dr. Gibbons explained the importance of palliative care and that it is NOT hospice. Palliative care is an interdisciplinary approach, with the goal of improving the overall quality of life and reducing burden on the person with PD and their family, avoiding hospitalizations, and increasing communication and understanding of PD.

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