

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 Kristin Nichols, Social Worker, to the Parkinson's Disease and Movement Disorder Team!

Kristin earned her master's in social work from the KU School of Social Welfare. She joined the KU Health System in June 2023, as a clinical social worker for the Movement Disorder Clinic. She also has a history of working in rehabilitation, as an Occupational Therapist, for the past 25 years, making her a multidisciplinary practitioner. Kristin is married with three teenage children. She enjoys time with family and friends, travel, reading, playing board games and doing jigsaw puzzles. Her extensive history in working with patients with neurological disorders drove her passion to come alongside patients and families, assisting them in navigating changes with disease progression, and understanding challenges that arise in what are often uncharted waters.



TREMOR CORNER

ET Studies Ongoing!

JZP385 – New medication for moderate to severe arm/ hand tremor. Cannot be taking primidone.

Several new studies for ET will be starting soon! Two studies will be continuing to assess non-surgical peripheral stimulation to control hand/arm tremor and another study will be assessing a non-surgical form of focused ultrasound. More information coming soon!

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 upcoming programs and more information.



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PARKINSON'S STUDIES CURRENTLY RECRUITING

- Newly diagnosed - Possible disease slowing**
IkT-148009 - < 75 years of age, not taking PD medications
- Early PD - Control of Symptoms**
CVL-751 - diagnosed < 3 years, no PD medications except for an MAO-B
- Non-Motor Symptoms (thinking, dizziness, fatigue, etc.)**
STEM-PD - Headphone-like device to reduce non-motor symptoms
- 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
- PD Patients with memory issues**
- PD patients with medication resistant tremor**
Suvecaltamide -tremor persists, other symptoms controlled
- 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).
- Simulated horseback riding for persons not exercising**
- Persons with Multiple System Atrophy (MSA)**
- Persons with Lewy Body Dementia (LBD)**
- Persons with Progressive Supranuclear Palsy (PSP)**
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.

Studies for Atypical Parkinsonism

Parkinson's disease is the most common form of parkinsonism; however, there are other, atypical, forms that can initially look very much like PD with slowness, stiffness and often tremor, but typically do not respond as well to PD medications and generally progress more quickly. Some signs that parkinsonism may be an atypical form are **early** symptoms (within the first 5 years of diagnosis) that include moderate problems with thinking and memory, hallucinations, balance problems, falling, dizziness when moving from a sitting or lying position to standing, increased urinary frequency and/or urgency, abnormal eye movements, abnormal sweating, difficulty swallowing, and speech problems. These symptoms can also be seen in PD, which can make diagnosis difficult, but in PD most of these symptoms occur later in the disease. Symptoms may also appear on both sides of the body, unlike typical PD in which one side is generally affected first.

There are currently no medications specifically for atypical forms of parkinsonism. Therefore, it is very exciting that there are studies currently ongoing for new treatments for multiple system atrophy (MSA), progressive supranuclear palsy (PSP), and Lewy body dementia (LBD), all of which are atypical forms of parkinsonism. If you have been diagnosed with atypical PD, parkinsonism, atypical parkinsonism, MSA, PSP or LBD you may qualify for one of these studies. If you are interested in more information about these studies please email pdetcenter@kumc.edu or call 913-588-7159.

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