

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 to the first issue of our exciting newsletter. We will provide you with the latest news and research related to Parkinson's disease (PD) and essential tremor (ET). In addition, we will offer patients an opportunity to be involved in clinical research and educational activities.

Due to our previous contact from research and educational events, we have taken the liberty to sign you for this newsletter. Hopefully you will continue with the subscription, but if you don't want to receive future newsletters please click unsubscribe at the bottom of the email. Please feel free to share with others.

We welcome any feedback, questions, or comments that you may have at PDETcenter@kumc.edu.



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TREMOR CORNER

The University of Kansas is the region's first provider to offer an innovative, treatment for essential tremor and PD tremor called Focused Ultrasound (FUS). This procedure uses sound waves to create a lesion in the VIM nucleus of the thalamus of the brain to improve hand tremor on one side of the body. The lesion destroys the tissue with minimal risk or damage to the surrounding healthy tissue. No surgical incisions are needed. To date over 25 procedures have been performed at KU with patients reporting over 90% improvement in hand tremor. Difficulty with balance following the procedure is the most common side effect reported.

CLINICAL STUDIES RECRUITING

We have multiple ongoing and upcoming studies for Parkinson's disease and essential tremor. There is no cost to participate in studies.

We are currently enrolling patients in studies of the following areas:

1. Newly diagnosed PD patients
 - a. NLY01 – PD patients diagnosed within the last 5 years and not taking any PD medications
 - b. K0706 – PD patients diagnosed within the last 3 years and not taking any PD medications
 - c. CVL-751 – PD patients diagnosed for < 3 years and taking no PD medications except for an MAO-B inhibitor
2. Stable PD patients
 - a. PADOVA – PD patients taking only an MAO-B inhibitor OR levodopa diagnosed within the last 3 years
3. PD patients experiencing OFF time (poor control of symptoms) during waking hours
 - a. ND0612 – PD patients with at least 2.5 hours of OFF time per day
 - b. Earstim-PD – PD patients with at least 2 hours of OFF time per day
 - c. CVL-751 – PD patients with at least 2.5 hours of OFF time per day
4. PD patients experiencing at least 2 hours of dyskinesia (wiggling movements from levodopa)
 - a. ADX-301 – PD patients with at least 1 hour of dyskinesia between 9 a.m. and 4 p.m. daily and not currently taking amantadine or willing to discontinue
 - b. BK-JM-201 – PD patients with at least 1.5 hours of troublesome dyskinesia daily and not taking or willing to stop amantadine
5. PD Generation Mapping the Future of Parkinson's Disease – Testing for 7 genes associated with Parkinson's disease. Anyone diagnosed with Parkinson's disease in our region can participate.

If you are interested or have patients who are interested in learning more about any of these research studies, please contact PDETcenter@kumc.edu.

RESEARCH FOCUS

KU PD Center Joins Landmark PPMI Study

We are pleased to announce that KU is now part of Parkinson's Progressive Makers Initiative (PPMI) which is an observational study to better define and measure Parkinson's disease and to speed new treatment development. PPMI makes its data set and biorepository—the most robust in Parkinson's to date—available to researchers and industry to accelerate breakthroughs. The study will collect clinical, brain imaging and biological specimens (blood, skin biopsy, spinal fluid) from PD participants who have not started medication for PD, PD patients with GBA or LRRK2 gene mutations and healthy participants who do not have PD or any family history of PD. There is no cost to participate in the study.

KU PARKINSON'S DISEASE ANNUAL SYMPOSIUM

August 14 // 10 - 12 a.m.

Virtual program / no cost / register now
Parkinson.org/KUsymposium

KUMC.EDU/PARKINSON