Focus

JANUARY 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.

We hope you had a wonderful holiday and we wish each of you a safe, happy, and healthy 2023! The new year brings exciting opportunities for both persons with PD and ET. There are more ongoing studies than ever before. There are PD studies to identify PD earlier, slow disease progression, understand the cause, and better treat symptoms. There are also multiple studies of treatments to better control ET.

We are excited to announce our 2nd Virtual Series: Understanding PD featuring Dr. Pahwa from KU & Dr. Isaacson from the Boca Raton PD Center. There will be 8 courses that review PD diagnosis and alternate diagnoses, motor & non-motor symptoms, treatments for early & advanced PD, dyskinesia, OFF time, future treatments and pointers for living well with PD. The courses are free, but registration is required. Visit kansascitycns.org/programs for more information and to register. You do need to register for each course you would like to attend. You can also CLICK HERE to register or email KUPDETCenter@kumc.edu for more information.



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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.

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 or call 913-588-7159.

Essential tremor live educational conference featuring Dr. Rajesh Pahwa as the key note speaker coming in April. Watch for more information.

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

1. Newly diagnosed - Possible disease slowing

Disorder Center

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

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 lease 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
- 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 or call 913-588-7159.

RESEARCH HIGHLIGHT

A Vibrating Glove for Parkinson's Disease?

Many of you may have seen the story on the Today Show about the vibrating glove for PD. We have received many calls asking if this was a hoax or a new treatment for PD. There is not enough information at this time to answer if this glove may be beneficial for those with PD. The idea of vibration therapy is not new. In the 19th Century, the famous neurologist, Charcot, developed a vibrating chair for PD. He felt that after a carriage ride people slept better and were more comfortable and prescribed 30 minutes of his vibratory chair daily for those with PD. There have been many studies over the years examining whole body vibration therapy as a treatment for PD. Reviews of these studies have concluded that there were mixed results and not enough evidence to support use for PD. So what about the vibrating glove? The idea behind the glove is that it would be worn several hours a day and would provide some sort of vibration/stimulation to the fingertips and hands, which in turn is proposed to reduce the symptoms of PD. It is important to understand that although this may be a potentially exciting idea, there are not currently enough data to determine if it is effective. The gloves are in early development and rigorous studies are still needed before it can be fully evaluated as a treatment for PD. The gloves are not currently available to the general public or currently being studied at KU.

This information was adapted from an article by Dr. Okun from the Parkinson's Foundation. For full article click **HERE**.

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