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JFK's Parkinson's Newsletter

FIRST, AN APOLOGY – Sorry about the mix-up with the Focused Ultrasound lecture on Monday! Dr. Azmi was tied up in the Operating Room and had to bail out of the 4 pm lecture. He was in the middle of performing an MRI-guided focused ultrasound procedure. Unfortunately, I was on another zoom call when he e-mailed me, so I didn't get his message. There was obviously much interest in this procedure as evidenced by the 35 or so who zoomed in on the call. We are rescheduling for <u>MONDAY, SEPTEMBER 13TH AT 5 PM.</u> We are holding the lecture one hour later in order to avoid clinic or O.R. time.

Here's why MRI-guided focused ultrasound procedure will be of interest to those of you who have tremors:

On June 14, 2021, Hackensack Meridian's Hackensack University Medical Center became the first and only center in New Jersey — and one of only a few in the country — to offer **noninvasive MRI-guided focused ultrasound** to treat hand tremors. If your meds haven't improved your symptoms, and you don't want to go through DBS surgery, **focused ultrasound** is a groundbreaking treatment that "can deliver immediate and outstanding results" according to **Florian Thomas, M.D., Ph.D.,** professor and chair of the Department of Neurology at Hackensack University Medical Center and at Hackensack Meridian School of Medicine.

Hooman Azmi, M.D., director, Division of Functional and Restorative Neurosurgery at the Hackensack University Medical Center Neuroscience Institute and associate professor of neurosurgery at Hackensack Meridian School of Medicine treats patients using focused ultrasound technology. "MR-guided focused ultrasound has the potential to instantaneously decrease or eliminate tremors and improve quality of life for millions of patients who are living with a movement disorder."

Join us as Dr. Azmi speaks to us about this amazing development on September 13th at 5 pm!

NOTE: You may join all of our Zoom meetings at https://us02web.zoom.us/j/2128260907

<u>Care Partner Support Group</u> – Thursday, September 2nd at 5 pm

Care Partner Fitness Study

Our Care Partner Support Group has been invited to participate in a study for family caregivers of older adults. This is a project from the Boston Roybal Center at Brandeis University. This is a fitness study to **find the best ways to help care partners increase their physical activity.** You will be using the fitness app designed for family care partners (Go&Grow) for 6 weeks and responding to weekly surveys.

Requirements:

-You are providing care to a loved one (e.g., relative, spouse, friend) who is 65 years or older. -You have an Android smartphone with internet access and Google Play Store.

Benefits:

You will be given a Fitbit to keep after the study! You will receive a \$25 Amazon Gift card by completing all aspects of the study.

To find out more about this new study, Xin Yau Lin of the Go&Grow Research Team of the Boston Roybal Center for Active Lifestyle Interventions at Brandeis University has agreed to speak to our Care Partner Support Group on Thursday, September 2nd at 5 pm.

Don't have an Android phone? No worries. The center's main focus is to improve health in middle-aged and older adults by fostering an active and engaged lifestyle. Xin Yau Lin will speak to other programs of interest to all.

If you have never been to a JFK Care Partner Support Group, why not start now?

You may join all of our Zoom meetings at https://us02web.zoom.us/j/2128260907

Support Group Dates for 2021 - Mark your calendars!

Parkinson's Support Groups (3rd Monday of every month except as noted*) September 13* @ 5 pm, October 18, November 15 & December 20

Care Partner Support Groups (4th Monday of Even months except as noted*) September 2* @ 5 pm, October 25, December 27

DBS Support Groups (4th Monday of Odd months) September 27, November 22

Newly-Diagnosed Meetings (TBA) Next Meeting September 9th at 5:00 pm

Newly-Diagnosed News – Last Thursday's joint ZOOM meeting with the Mentors and Mentees was very successful. In fact, it was so well-received by the mentees that we will have a follow-up meeting on **Thursday, September 9th at 5:00 pm**. For those mentees who were unable to attend last time, please make every attempt to attend the next one. You will find the atmosphere low-key and enlightening, and you will definitely find that you are not alone with your diagnosis!

Moving Day New Jersey is on Saturday, October 2, 2021

Moving Day is right around the corner! Let's begin some serious fundraising for our first inperson post-COVID event! Everyone has the ability to form a team with friends, teams, clubs, and organizations. This will result in wider coverage and will increase our fundraising efforts. OR, you may join an existing team.

Let's get to work! https://movingdaywalk.org/event/moving-day-new-jersey/

Parkinson's Foundation HelpLine and Website

The Parkinson's Foundation's HelpLine at 1-800-473-4636 is always a great resource for all PD-related questions and resources. The Parkinson's Foundation Website is at:

https://www.parkinson.org

Check us out on Facebook!

For topics, details, photos, and updates, go to **Facebook:** Public Groups, Parkinson's Support Group at HMH JFK University Medical Center.

COMING SOON - **Our Brand New Website** for People with Parkinson's (PwPs) will be flying under the banner, **The JFK Parkinson's Advocate!** The website will advocate for PwPs by offering basic information about the disease, its diagnosis and treatment. In addition, it will contain helpful resources about local programs, support groups, special events, and webinars that will be of importance to the newly-diagnosed, the young-onset, and those living with the disease for a number of years. Finally, we will point you in the right direction for clinical trials and fundraising opportunities so that one day, this will all seem like a distant chapter in our lives. This site is intended to supplement the JFK and HMH websites.

Get the Latest Parkinson's News from JFK University Medical Center

PDUpdates will be e-mailed directly to you. All you need to do is send me your name and your e-mail address indicating you would like to receive your own copy when it is published. As noted below, your information will remain confidential, and you may opt out at any time.

Stay Safe and *Keep Moving*! John Kolaya, JFK Parkinson's Patient Advocate (914) 837-6910; jkolaya@aol.com

WE WILL NEVER QUIT!

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