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Hackensack
Meridian Health
JFK Medical Center



Hackensack
Meridian Health
JFK Johnson
Rehabilitation Institute

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JFK's Parkinson's Newsletter

**RESCHEDULED SUPPORT GROUP – FOCUSED ULTRASOUND, MONDAY, SEPT 13TH
AT 5PM**

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>

Important News from our friends at the Michael J Fox Foundation

Parkinson's Advocacy is a joint effort by many organizations and individuals across America. The Parkinson's Foundation collaborates regularly with the Michael J. Fox Foundation on research and other advocacy efforts to educate members of Congress about Parkinson's disease. Please read on and decide to **take action** on these decisions on the budget to pass the Appropriations bills that fund Parkinson's research. **I certainly did!** JK

Updates from Washington

Advocacy Works: Capitol Hill Is Buzzing About Parkinson's

September 9, 2021

Policy advocates of The Michael J. Fox Foundation (MJFF) have been busy, and it shows!

One of the most important things Congress does is set the federal government's budget every year. In their planning for Fiscal Year 2022, which starts on October 1, **the House of Representatives approved two important annual spending bills along with accompanying committee report language that specifically highlights Parkinson's disease (PD) as a priority for the coming year.** This is due, in part, to the work MJFF advocates have done over the years in educating their members of Congress about PD. Thank you!

One of the annual spending measures, the Labor, Health and Human Services, and Education (Labor, HHS) Appropriations bill, includes four mentions of PD we want to tell you about:

1. The committee will **continue to fund the National Neurological Conditions Surveillance System (NNCSS) at the Centers for Disease Control and Prevention with a \$5 million infusion in Fiscal Year 2022.** The NNCSS will collect data from already existing and new data resources about Parkinson's disease and other neurological conditions and provide it to researchers so they can have a better understanding of how, when, where, and why Parkinson's happens and what patterns might emerge.
2. The committee also **encourages the National Institute of Neurological Disorders and Stroke (NINDS)** — the institute within the National Institutes of Health (NIH) where there is significant funding for Parkinson's research — **to rededicate their efforts toward finding a cure.** Since its founding, MJFF has funded \$1 billion in PD research, and we need the federal government to continue to partner with us on funding the most promising work. NINDS will be expected to inform Congress in the following year's budget process how they plan to prioritize Parkinson's research funding.
3. Research suggests that Parkinson's is caused by a combination of genetic and environmental factors. The committee **urges the National Institute of Environmental Health Sciences (NIEHS)** — another institute within NIH that plays a role in PD research — **to collaborate with appropriate partners on researching the effects of chemicals and other toxins on Parkinson's development and progression.** NIEHS also is expected to inform Congress in the following year's budget process how they plan to prioritize Parkinson's research funding.
4. Last, and certainly not least — in fact, this is huge! Congress has recognized that Parkinson's is not just a movement disorder but could also include dementia and that PD research should be prioritized in overall dementia studies. The committee **"strongly urges" NINDS and the National Institute on Aging** — another institute within NIH — **to highly prioritize PD research both before, during, and after the onset of dementia.**

Oh, wait. Did you think we were done? We're not. There's more.

The House-approved Military Construction, Veterans Affairs, and Related Agencies annual spending bill has accompanying committee report language recognizing the increasing number of veterans affected by PD. It directs the Veterans Administration to **significantly increase its investment to maintain and expand Neurology Centers of Excellence dedicated to further understanding of Parkinson's and its impact on veterans.**

These incredible policy "wins" could not have happened without advocates across America lifting their voices and speaking truth to power about the need for Parkinson's research to be a higher priority among all the federal entities that fund important research toward a cure.

Congress will be back in session full-time toward the end of September when they will make their final decisions on the budget and pass the Appropriations bills that fund Parkinson's research. [Please use our action alert to email your Members of Congress and ask them to prioritize research toward a cure for Parkinson's.](#) It's easy to do, takes about 90 seconds, and carries a lot of weight with Senators and Representatives as they prepare their votes.

Before we let you go, we have another update for you from Washington, D.C. Our community has been busy this summer! In August, MJFF advocates sent more than 6,400 emails to Capitol Hill which influenced **22 Members of Congress to sponsor the Credit for Caring Act** — the bill that provides tax credits for family caregivers. When Congress is back in session later in September, we'll have a better idea of what happens next with this bill, so stay tuned. ([Take action on this issue if you haven't yet.](#))

Our policy team is pumped and firing on all cylinders to continue this momentum into fall and winter.

Here's a heads up for October: We'll be focusing our advocacy efforts on Medicare because 90 percent of people with PD receive their health care coverage through Medicare. Medicare Open Enrollment starts on October 15, but we'll have several areas within Medicare where we will need your voice.

Thank you, again, to all the public policy advocates in our community who helped make all these important things happen. We couldn't do this work without you.

- **Carol Blymire**

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*)
October 25, December 27

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

Newly-Diagnosed Meetings (TBA) Next Meeting September 23rd at 5:00 pm

Newly-Diagnosed News – Last Thursday's joint ZOOM meeting with the Mentors and Mentees was very well attended with 14 members attending. We will have a follow-up meeting on **Thursday, September 23rd 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!

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

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 in-person post-COVID event! Everyone has the ability to form a team with friends, teams, clubs, and organizations OR, you may join an existing team. So far, we have raised over \$42,000 toward our goal of \$90,000 (and my personal goal of \$100,000!) There are only three weeks to go. **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>

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 HMM websites.

Check us out on Facebook!

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

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

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WE WILL NEVER QUIT!

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