



PDU-14X (04.26.2021)



Hackensack
Meridian Health
JFK Medical Center



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Meridian Health
JFK Johnson
Rehabilitation Institute

PDUpdate No. 14-XTRA

JFK's Parkinson's Newsletter

Parkinson's Care Partner Support Group – TODAY - Monday, April 26th

This month's Care Partner Support Group will be a "square table" discussion-- comprised of rows of images of Zoom participants—ALL OF YOU! We're hoping that everyone will share their ideas for questions like these:

- How do you stay patient and positive?
- What keeps you going in the tough/challenging moments?
- What are your favorite activities to do with your partner with PD?

Make a list NOW—and please forward it to John Kolaya at jkolaya@aol.com. You will find that you are not alone. Make friends with other care partners and share your common questions and feelings!

You may join the Zoom meeting at <https://us02web.zoom.us/j/2128260907>

The Care Partner Support Group begins at 4:05 pm today

Support Group Dates for 2021 - Mark your calendars!):

Parkinson's Support Groups (3rd Monday of every month)

April 19, May 17, June 21, July 19, August 16, September 20, October 18,
November 15 & December 20

Care Partner Support Groups (4th Monday of Even months)

April 26, June 28, August 23, October 25, December 27

DBS Support Groups (4th Monday of Odd months)

May 24, July 26, September 27, November 22

Please forward any suggested topics for future support groups to John Kolaya

In Other Parkinson's News...

Check out the last ParkinSINGS concert

Once again, the ParkinSINGS choir recorded its concert at the Count Basie Theatre in Red Bank, NJ. The choir consists of about 2 dozen singers, many of which have never sung in a choir before. Singing is great exercise for your vocal chords and is lots of fun! We practice every Wednesday via zoom and put on four major concerts a year with mini-performances, such as Moving Day New Jersey whenever we can. The Parkinson's Awareness Month concert may be viewed at <https://www.youtube.com/watch?v=UDgQxwOxgW8&t=11s>

If you want to join in the fun, contact Aly Chananie, Senior Speech Pathologist at (732) 321-7063 or Alyson.chananie@hmn.org. No Experience Necessary!

Introducing THE PARKINSON'S MENTORING PROGRAM AT JFK

What does everyone diagnosed with Parkinson's have in common? All of us started with a symptom or symptoms that led us to a neurologist; we received our diagnosis; and then we asked, WHAT'S NEXT?

Do you remember how you felt back then? Were you fearful? Angry? Confused? In Denial? Maybe you still have some of these feelings. Did you wish you had a friend or confidante—someone else who had PD—who could help you move forward and cope with the maze of information about treatments, medications, and resources available?

JFK will begin its first-ever PARKINSON'S MENTORING PROGRAM on May 1st! We are looking to enroll enthusiastic, positive individuals who have already started their journey in the world of Parkinson's Disease—and pair them with Newly-Diagnosed JFK patients or those who are simply seeking additional support as they navigate their way around the JFK care and treatment campus.

Who is qualified to be a mentor?

We're looking for existing JFK patients who are able and willing to:

- Provide information about JFK and its various PD programs
- Provide resources about the Parkinson's Foundation and other sources of valuable information about PD
- Listen to a new patient's concerns and provide empathy and encouragement
- Share personal experiences about their own journey with Parkinson's Disease
- Promote positive behavior by setting a good example
- Be willing to laugh, look on the bright side, and remember to be grateful for everything that's good in life, including new treatments and medications on the horizon

Don't be shy! If you fit this profile and are willing to become a PD Mentor, contact **Donna Mastropolo** (dmastropolo@yahoo.com), **program coordinator**.

Note: Six PwPs have signed up so far.

IWNQ – Let's adopt a slogan that reflects our attitude about Parkinson's disease. A good friend of mine, Scott Rider, and fellow PwP, has coined the phrase **I WILL NEVER QUIT!** He offered to let me use it for our support groups and has donated 50 IWNQ bracelets to get us started. We now have 150 bracelets and 100 key chains which I will hand out to fellow PwPs when the in-person opportunity arises. Wear them proudly!

Hugh Never Quits!

Check out this short, inspirational video about Parkinson's, featuring our very own Hugh M. <https://www.youtube.com/watch?v=wNCMJ08UJqk&t=1s>

More on Hugh...Hackensack Meridian's Spring ***Spotlight on U*** features Hugh and **Roger Rossi, D.O.** talking about how Hugh is "mitigating his (PD) symptoms by doing everything from non-contact boxing to singing in a choir." Dr. Rossi, the Director of the Parkinson's Disease and Movement Disorders Program at JFK Johnson Rehabilitation Institute notes that "there is increasing evidence that exercise may not only improve symptoms but delay onset and decrease the progression of the disease."

“The right thing at the wrong time is the wrong thing”

----Joshua Harris

“Timing is important in life but critical in Parkinson’s Disease”

----Michael S. Okun, M.D.

PD Lecture, May 11th - Changes in thinking and memory can affect both people with Parkinson’s and their care partners, family and friends. The **Mind, Mood, and Motion** program will teach participants about these changes and the steps they can take in their daily lives to reduce the effects these symptoms might have. Together, with **Roger Rossi, D.O.** you will discuss treatment options, with a special focus on the benefits of exercise. Discover new exercise tips and learn more about the relationship between physical therapy and exercise – both proven to help manage the motor and non-motor symptoms of PD.

Click to register: <https://www.parkinson.org/events/2021/MMM-Hackensack>

To Learn More About JFK’s Comprehensive Parkinson’s Disease Program, click on:

<https://www.jfkmc.org/services/the-neuroscience-institute/movement-disorders/parkinsons-disease>

We’re now on Facebook!

For topics, details, photos, and updates, go to **Facebook**; Public Groups, Parkinson's Support Group at HMH 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.

Stay Safe and *Keep Moving!*

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