





PDU-13 (04.12.2021)

PDUpdate No. 13

JFK's Parkinson's Newsletter

NEXT Parkinson's Support Group – Monday, April 19th

Topic: JFK's New "Inpatient" Parkinson's Program

Date/Time: Monday, April 19th at 4:05 pm

Speaker: Janice Dibling, Manager of Speech Pathology at HMH JFK Johnson

Rehabilitation Institute

Venue: ZOOM Meeting

Join Zoom Meeting at https://us02web.zoom.us/j/2128260907

Next Monday, Janice Dibling will present JFK's newest program to treat People with Parkinson's Disease (PwPs). The program is based on the proven inpatient program at Northwell Health's Glen Cove Hospital, initiated in 2019.

During an extended stay at JFK, patients with chronic PD symptoms will be evaluated and treated with multi-disciplinary "intervention" therapies designed to lead to better quality, more independent lives.

Please tune in on Monday to hear more about this exciting new advancement in treating Parkinson's at JFK.

<u>UPCOMING Parkinson's Care Partner Support Group – Monday, April 26th</u>

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

<u>Support Group Dates for 2021 - Mark your calendars!):</u>

<u>Parkinson's Support Groups</u> (3rd Monday of every month) April 19, May 17, June 21, July 19, August 16, September 20, October 18, November 15 & December 20

<u>Care Partner Support Groups</u> (4th Monday of Even months) April 26, June 28, August 23, October 25, December 27

<u>DBS Support Groups</u> (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@hmhn.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 it's 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

If you fit this profile and are willing to become a PD Mentor, contact **Donna Mastropolo** (dmastropolo@yahoo.com), **program coordinator**.

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=wNCMJO8UJqk&t=1s

Article - How Exercise Affects People with PD - by Dr. Roger Rossi, D.O.

https://www.hackensackmeridianhealth.org/HealthU/2021/02/05/how-exercise-impacts-parkinsons-disease/

<u>Did You Know...</u>In the next 10 years the number of Parkinson's sufferers in the world's most populous countries will double to almost 30 million! These escalating statistics are real, and they are fueled by a continuously aging population. We are on the cusp of an emerging Parkinson's pandemic. Imagine what Parkinson's research can do if it was afforded the same focus as the COVID-19 pandemic?

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

https://www.ifkmc.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!

John Kolaya, JFK Parkinson's Patient Advocate (914) 837-6910; jkolaya@aol.com

PDUpdates are distributed as needed to keep HMH JFK clients informed of important information about Parkinson's Disease and HMH JFK's Comprehensive Parkinson's Program. For your privacy, your name will not appear on any of the email documents. You may opt out of this free service by replying to this email with your desired intentions.