



PDUpdate No. 30

01.30.2021

WELCOME TO THE JFK PARKINSON'S ADVOCATE WEBSITE

www.jfkpdadvocate.com

What's on the website?

- Timely information on Zoom Support Groups for all People with Parkinson's (PwPs), Newly Diagnosed, Young Onset, Caregivers, and DBS patients.

Support Groups link is <https://us02web.zoom.us/j/2128260907>

- The latest news on Parkinson's disease and research
- General Information about PD programs at JFK University Medical Center and Hackensack Meridian Health Network
- Answers to questions about PD medications, symptoms, diagnosis and therapy, including exercise and rehabilitation
- A Glossary of key PD terms
- Parkinson's Newsletters (PDUpdates)
- Articles written by local physicians
- Links to various PD resources
- Stories about PwPs and Caregivers
- Photos of various events
- Advertisers of PD services

February Support Group Meetings

- **Newly Diagnosed/Young Onset Support Group:** Thursday, Feb 3rd, Feb 17, Mar 3 at 5 pm**
- **Parkinson's Support Group:** Thursday, Feb 24th at 5 pm; Nicole Russo's Music with Movement
- **Care Partner Support Group:** Monday, Feb 28th at 4:05 pm

The link for all support groups is: <https://us02web.zoom.us/j/2128260907>

More Parkinson's Events

- **The LOUD CROWD:** Mondays at 3:00 pm and Thursdays at 11:00 am
For graduates of Speak Out only
- **ParkinSINGS:** Wednesdays at 3:00 pm (Zoom ID 828 270 48926)
- **Rock Steady Boxing:** Workouts on zoom Mondays, Wednesdays, and Fridays at JFK RSB also, zoom/in-person at Busacca's Gym and in-person at Garwood
- **Groovin' with Carol:** Thursdays at 1:30 pm in-person at Wall Municipal Building

PD Mentor-Mentee Program: Read about this Growing program at www.jfkpdadvocate.com

Our next DBS Support Group Meeting will be on Monday, January 31st at 4:05 pm immediately following Jessica's LOUD Crowd

Following a short video by Dr. Michael Okun from the Parkinson's Foundation and University of Florida, we will start the meeting off with Ginnie Long. A few years back, Ginnie was suffering from debilitating dyskinesia, so she made the choice to have Deep Brain Stimulation performed. As you will hear, it has dramatically changed her quality of life. Ginnie will share her DBS adventure with us and will be available to answer any questions you may have. The meeting will conclude with an open discussion from folks like Bill, Wilson and Ben who always add a new twist to the conversation. Please join this discussion if you are thinking of having DBS surgery or have already had it!

Please join us at 4:05 pm tomorrow, Monday, January 31st at:

<https://us02web.zoom.us/j/2128260907>

Don't miss the next PwP Support Group Meeting – Thursday, February 24th at 5:00 pm

Nicole Russo's Music with Motion

Nicole Russo is a Physical Therapist and the proprietor of SOAR Physical Therapy and Acupuncture at 2123 NJ-35 in Sea Girt, NJ, www.soarpt.com. With an extensive background in dance and singing, Nicole has been teaching dance to seniors for 30 years.

We will be fortunate to have Nicole as our guest educator on February 24th to teach a virtual dance and singing class for Parkinson's. Nancy and I attended her session last Thursday at ***Groovin' on a Thursday Afternoon*** at the Wall Township Municipal Building on Allaire Road. It was thoroughly enjoyable to join Nicole as we sang and moved to old favorites from the 60s and 70s. I can totally see this working on Zoom!

Newly Diagnosed/Young Onset Support Group – Thursday, February 3rd at 5:00 pm

In this meeting there is always engaging conversation about topics that the mentees want to know about. Our mentors are a group of determined and inspired people who keeps the conversation going!

Note that the Newly Diagnosed meetings are **not just for PD "Newbies."** They can ALSO help anyone on their PD journey, including those who need a **"refresher."** It's an excellent opportunity for those having difficulties after several years of living with Parkinson's to get back on track with your exercise, therapy, or attitude. We may pair you up with a motivated PwP who will give you tips on exercise, therapy and how to put some spring back in your step!

Please make every attempt to attend this meeting. You will find the atmosphere low-key but

enlightening, and you will find that **you are not alone with your diagnosis!**

Advice for the Newly Diagnosed: <https://www.parkinson.org/Living-with-Parkinsons/Managing-Parkinsons/Advice-for-the-Newly-Diagnosed>

Read about Young Onset PD: <https://www.parkinson.org/Understanding-Parkinsons/What-is->

Parkinsons/Young-Onset-Parkinsons

You may join our Newly Diagnosed/Young Onset group by contacting me (jkolaya1127@gmail.com) or Donna(dmastropolo@yahoo.com).

Next Care Partners Support Group – Coming in March!

Dear Care Partners, we absolutely need and want your participation at our Care Partners' support groups. This is stuff that you won't necessarily hear or talk about at the PwP (People with Parkinson's) support groups. Please attend this meeting. You are very important to us and to your PwP. Let us know how we can help!

The Parkinson's Foundation has lots of great information about Care Partners. Click on this link to find the Top 10 resources for Care Partners:

<https://www.parkinson.org/blog/caregiver-corner/top-caregiver-resources/>

A Parkinson's Social Event – Thursdays from 1:30 pm to 3:00 pm

NOTE: GROOVIN' IS CANCELLED ON THURSDAY, FEBRUARY 3RD

Groovin' on a Thursday Afternoon!

for People with Parkinson's

A free social activity with gentle movement and speech exercises. Bring your significant other!

Every Thursday in the basement of the Wall Municipal Building!

Have some coffee and chat with your friends, then join a supplemental exercise designed to enhance your therapies. The program will change weekly. What will it be this week? Singing? A joke-telling contest? Gentle Tai Chi exercises? Groovin' dance steps? Come and find out!

Groovin' on a Thursday Afternoon is sponsored by **Cornerstone Speech and Language, SOAR Physical Therapy, and Busacca Fitness** and is free to the public.

*I can't imagine anything that's better
The world is ours whenever we're together*

There ain't a place I'd like to be instead of Groovin

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>

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 go to the Homepage at www.jfkpdadvocate.com, scroll down to OUR NEWSLETTER AND FILL OUT THE FORM. As noted below, your information will remain confidential, and you may opt out at any time.

JFK's Parkinson's Disease Center

Located in Edison, New Jersey, the JFK Parkinson's Disease Center is comprised of the **JFK Neuroscience Institute and the JFK Johnson Rehabilitation Institute**. Both Institutes are uniquely qualified to offer comprehensive services in a single location and work collaboratively to accurately diagnose PD and to create a care plan for each individual patient.

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

Did You Know?

1. People with Parkinson's need to hydrate themselves more frequently than those without PD? **Find Out Why at:** <https://www.neurologysolutions.com/parkinsons-disease/dehydration-in-parkinsons-risks-tips-2/>
2. The cause of Parkinson's is still unknown and there is no cure. What causes Parkinson's remains largely unknown. **Genetics** cause about 10 to 15 percent of all Parkinson's. The other 85 to 90 percent of cases are classified as sporadic (or occasional). Although there is no cure, treatment options vary and include medications and surgery.
3. No two people have the same exact symptoms. The progression of symptoms is often a bit different from one person to another due to the diversity of the disease. People with PD may

experience: tremor (mainly at rest); slowness of movements (bradykinesia); limb rigidity; gait and balance problems.

4. Small Handwriting and loss of smell are early signs of Parkinson's. A change in handwriting, specifically handwriting that's gotten smaller over time or crowded, are an early indicator of PD. Another common early sign is the loss of smell of foods like bananas, dill pickles and licorice.
5. The Parkinson's community is strong. The Parkinson's Foundation is here for our global Parkinson's community — that includes family members and caregivers. The Foundation hosts [Moving Day](#) walks across the nation and also provides additional ways to get involved — [donate](#), [volunteer](#), [host a fundraiser](#), join [PD Conversations](#) or [advocate](#).

If you answered four out of five questions correctly, you are qualified to be a Parkinson's Mentor. There are many Newly Diagnosed PwPs that can really use your advice and friendship! Contact John Kolaya or Donna Mastropolo and join our Newly Diagnosed Group.

Coming Soon on the JFK Parkinson's Website

- Your Parkinson's Care Team
- Parkinson's and Nutrition (Arrived – see Articles)
- Dance for PD
- Drum Circles and Music
- Completion of the Index and Glossary of PD terms
- More Doctors' Corner Articles
- What would you like to see on the website? – Contact me with your ideas and comments!

Stay Safe and *Keep Moving!*

John Kolaya,
JFK Parkinson's Patient
Advocate(914) 837-6910
john@jfkpdadvocate.com

WE WILL NEVER QUIT!



