



PDUpdate No. 31

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WELCOME TO THE JFK PARKINSON'S ADVOCATE WEBSITE, www.jfkpdadvocate.com

Please visit our new website for all your immediate Parkinson's needs. The website is rich in information about PD, and it is hoped that it will soon become your "go-to" resource for PD-related news, research, support group meetings, articles and basic Information related to Parkinson's disease.

Will This Stem Cell Breakthrough Spell the End of Parkinson's?

A story...

By Sebastian Skov Andersen (Published Feb. 09, 2022, in The Daily Beast)

Someday, soon the phrase "I will never quit" may "no longer be just a motivational saying. A new Parkinson's treatment that uses stem cells to artificially create new dopamine-producing nerve cells is expected to enter clinical trials on human patients later this year". Due to their longevity living with the disease, "many patients who receive a diagnosis today may live long enough to be eligible for this kind of treatment and find their lives spared from the harsh advanced stages of the disease—and perhaps see their motor function restored."

For Sebastian Skov Anderson's complete story, visit <https://www.thedailybeast.com/clinical-trials-for-new-danish-stem-cell-treatment-could-usher-the-end-of-parkinsons?ref=scroll>

February Support Group Meetings

- **Newly Diagnosed/Young Onset Support Group:** Thursday, Feb 17th, 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 is also zoom/in-person at Busacca's Gym and in-person at Garwood
- **Groovin' with Carol, Nicole and Matt:** Thursdays at 1:30 pm **in-person** on the lower level of the Wall Municipal Building on Allaire Road (wear a mask, please)

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

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. Your information will remain confidential, and you may opt out at any time.

Newly Diagnosed/Young Onset Support Group – Thursday, February 17th 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 that 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).

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

Nicole Russo's *Music with Movement*

Nicole Russo is a Physical Therapist at **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 50s, 60s, and 70s. I can totally see this working on Zoom!

Please have an armless chair or folding chair handy!!

Next Care Partners Support Group – Coming on Monday, February 28th! (a separate link is required)**

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\](https://www.parkinson.org/blog/caregiver-corner/top-caregiver-resources)

Our next DBS Support Group Meeting will be on Monday, March 28th at 4:05 pm immediately following Jessica's LOUD Crowd (a separate link is required)**

**Again, the link for all Support Groups is <https://us02web.zoom.us/j/2128260907>

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

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.

- 1st and last Thursdays – Carol Krakow from Cornerstone
- 2nd Thursday – Nicole Russo from SOAR
- 3rd Thursday – Matt Busacca

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>

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 www.jfkpdadvocate.com

- **PD does not DEFINE us** – The “Get to Know Us” Section of the website is ready and waiting to contain information about **YOU!** Send us your name, the town you live in and tell us your volunteering pursuits, interesting hobby, little known fact or accomplishment that makes you proud and keeps you sane!
- Your Parkinson's Care Team (Arrived – see PD Basics)
- Parkinson's and Nutrition (Arrived – see PD Basics)
- Dance for PD
- Drum Circles and Music
- Completion of the Index (Arrived – see Where Can I Find it?)
- 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!*

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WE WILL NEVER QUIT!

🌐 www.jfkpdadvocate.com