



*** Next Meeting ***

**“Living Your Best Life With Parkinson’s: What We Really Learn from
Personal Experience and Research”**

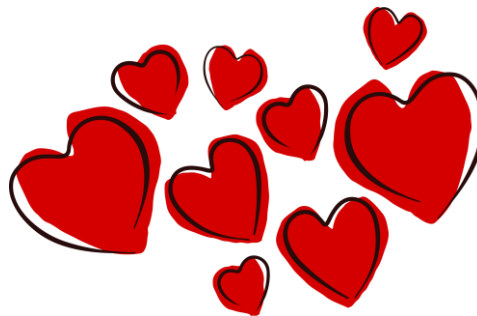
Karen Raphael, PhD, Professor Emerita, New York University, Person with Parkinson’s

Friday, February 23, 2024 10:00 am

Freedom Plains United Presbyterian Church, 1168 Rt. 55 (East parking lot)

(across from Arlington High school)

In Person ONLY



Cancellation Information for In-Person Meetings

As we do every year, we will follow the public schools in making weather-related cancellations. **If the schools are closed, we will cancel. If they are on delay, we may meet with those who can safely get out.** Our cancellation notices will be posted on www.whud.com and www.wspkfm.com storm closings/announced on **WHUD 100.7 FM** and **WSPK 104.7 FM** radio.

Monthly Meeting - Friday, February 23, 2024

“Living Your Best Life with Parkinson’s:

What We Really Learn from Personal Experience and Research”

Dr. Karen Raphael; Professor Emerita (NYU), Researcher, Psychologist, Person with Parkinson's

Come join us for our February program on living our "best life with Parkinson's!" In addition to her professional training and extensive experience in the field of movement disorders, Dr. Raphael is also a person with Parkinson's herself. This will be **in person** at our new venue, the *Freedom Plains United Presbyterian Church* (FPUPC) at 1168 Rt 55 Lagrangeville, NY. See the bottom of this page for driving details. Come help us explore this important topic!



Mark Your 2024 Calendar – Monthly Meetings

February 23, 2024 – *“Living Your Best Life with Parkinson’s: What We Really Learn from Personal Experience and Research”* – Dr. Karen Raphael

March 22, 2024 – *Discussion/sharing (wrong date in December newsletter)*

April 26, 2024 – *“What’s Behind Hallucination, Delusions, and Acting Out in Sleep?”*

Dr. Katherine Amodeo

May 24, 2024 - TBA

June 28, 2024 – *Discussion/Sharing*

Special Events:

March 9, 2024 – *“Parkinson’s Symposium;”* Freehold, NJ, in person or online (Dave Iverson, person with Parkinson’s, care partner, author, broadcast journalist, will be a speaker.)*

April 11, 2024 – *“Living Well with Parkinson’s”* Women’s Club of White Plains, White Plains, NY FREE, REGISTRATION required; (Dr. Amodeo will be one of the speakers)*

***Note:** *Details and registration instructions for the March and April events will be emailed to members or you can contact Nancy Nealon at nnealon@parkinson.org or (585)743-1266*

September 8, 2024 – Annual *“Walk over Water,”* Walkway Over the Hudson

We are now meeting at our easily accessible new venue, the ***Freedom Plains United Presbyterian Church (FPUPC), 1168 Rt. 55.*** Coming into Lagrangeville from Poughkeepsie on Rt. 55, go past the church on your right to the East parking lot. The entrance is at the far end of the lot, but, once in the lot, you can drive up very close to the building. Coming off the Taconic, you go towards Poughkeepsie and enter the parking lot just past the *Daily Planet* and the entrance to Tops Market. Handicapped rest rooms are across the hall from the meeting room, which is right inside the entry.

NOTE: 2024 DUES (\$15/INDIVIDUAL; \$20/COUPLE)

(Mail checks to: **PDSGMHV** P.O. Box 304 Lagrangeville, NY 12540)

Parkinson's News Today is strictly a news and information website about the disease. It does not provide medical advice, diagnosis or treatment. This content is not intended to be a substitute for professional medical advice, diagnosis, or treatment. Always seek the advice of your physician or another qualified health provider with any questions you may have regarding a medical condition. Never disregard professional medical advice or delay in seeking it because of something you have read on this website.

(Editor's note: The following news "shorts" came from *Parkinson's News Today*. Please note that mention of current trials or research "discoveries" are not to be taken as recommendations. These reports are merely to help keep you informed of Parkinson's in the news. Always consult your neurologist regarding medications.

Brain organoids derived from patients taken to space station

Studies in microgravity may help to better understand and treat Parkinson's
by [Patricia Inácio, PhD](#) | January 22, 2024



3D "mini-brains," or brain organoids, derived from people with [Parkinson's disease](#) and [primary progressive multiple sclerosis \(MS\)](#) are now at the International Space Station (ISS) as part of ongoing research in the unique effects of space on the human brain.

How brain cells interact in microgravity, a condition under which people or objects appear to be weightless, may help in understanding the mechanisms that underlie these and other neurodegenerative disorders. Such insights are paramount to finding novel biomarkers for an earlier [disease diagnosis](#), and in accelerating the development of new therapies.

The research is part of a partnership between the National Stem Cell Foundation (NSCF) and the European commercial Axiom Space (Ax-3) astronaut mission, which carried the brain organoids to the station. . .

Deep brain stimulation surgery allows guitarist to play once again

Surgical treatment, and its adjustments, given at Toronto Western Hospital
by [Mary Chapman](#) | January 25, 2024



Before [deep brain stimulation \(DBS\)](#), a surgical treatment for [Parkinson's disease](#), made it possible for guitarist Fabio Dwyer to again play and return to his livelihood in Canada, all had seemed lost.

Be it performing, composing, or teaching, Dwyer's world was ensconced in music. He had helped to establish a band in Toronto and, as a proficient guitarist in a number of musical genres, had played with a variety of groups throughout Ontario.

Then he began having difficulty moving his right hand, and trouble with walking, talking, and swallowing. Fighting fatigue and a growing depression, Dwyer, then 40, went through a series of medical tests. Given his age, he was shocked by the [disease diagnosis](#) that arrived: early onset Parkinson's. In about 10% to 20% of Parkinson's cases, the disease begins before an individual turns 50.

Dwyer felt his world — which he and his partner, Laura, had built around music — starting to crumble. Co-owner of the Mill House School of Music in Toronto, he was concerned about how his family, which included two young children, would manage.

By 2019, the [disease tremors](#) that accompany a lack of dopamine signaling began to affect his fingers. “For a musician, that’s like a death sentence,” Dwyer said in a news article from the UHN Foundation, part of University Health Network of Toronto.

But he soon learned that he was a candidate for a DBS procedure . . .

Six months after his DBS surgery, which included 11 adjustment sessions, Dwyer again was able to manage his tremor and other symptoms. “Every day, I just continue to improve,” he said. The foundation reports that Dwyer now has regained 95% of his guitar-playing abilities.

Framework for Parkinson's stages, based on disease biology, proposed

Fox Foundation-led effort to move beyond symptoms in research, clinical trials

by [Lindsey Shapiro, PhD](#) | January 29, 2024



Led by the [Michael J. Fox Foundation for Parkinson's Research](#) (MJFF), an international group of patients, researchers, and industry leaders has proposed a framework for defining and staging [Parkinson's disease](#) based on its underlying biology rather than by hallmark [disease symptoms](#).

Called the neuronal alpha-synuclein disease integrated staging system (NSD-ISS), the proposed framework also would be relevant for other diseases marked by abnormal accumulation of the alpha-synuclein protein, such as Lewy body dementia.

“We propose that, given biomarker advances enabling accurate detection of pathological [alpha]-synuclein (ie, misfolded and aggregated) ... it is time to redefine Parkinson's disease and dementia with Lewy bodies as neuronal [alpha]-synuclein disease rather than as clinical syndromes,” the scientists wrote.

Although still being refined, scientists believe that by offering a standardized, shared tool for use by researchers and industry, the NSD-ISS ultimately could speed therapy development and facilitate clinical trials for disease prevention. . .

As this is an initial version, the NSD-ISS framework “is intended for research use only,” not routine clinical care, the scientists wrote. . . They urged the research community to work together in providing data that would enable it being fully tested. . .

WEBINARS/Resources

Parkinson Foundation Webinars

Watch each past one-hour Briefing at www.parkinson.org/webinar, click on Expert Briefing and then again on Expert Briefing in the paragraph that comes up. **NEW! These webinars now have closed captioning.** For *Mindfulness Mondays*, *Wellness Wednesdays*, and *Fitness Fridays* go to: www.parkinson.org/pdhealth. Not online? Have a question? Call: **Helpline at 1-800-4PD-INFO.**



Michael J. Fox Foundation -Third Thursdays Webinars:

“Finding Your Way: Working through Emotions in Early Years with Parkinson’s” Thursday, September 21 (archived)

In this replay of a popular webinar, our expert panelists will discuss ways to manage emotions and navigate the early years of a Parkinson’s diagnosis. We’ll feature reflections from a person recently diagnosed in addition to people who have been living with the disease for years. We’ll also cover the valuable role people recently diagnosed can play in research.

Watch previous Third Thursday Webinars at www.michaeljfox.org/webinars

Davis Phinney Foundation – Live Well Today Webinar Series

Interested in topics like: Depression, Memory, Mood and Parkinson’s; Exercise, Freezing and Gait; Emerging Therapies; Women and Parkinson’s; or non-Motro Symptoms Medications? Try going to the David Phinney Foundation website for a list of recorded and upcoming hour long webinars on these topics and many more.

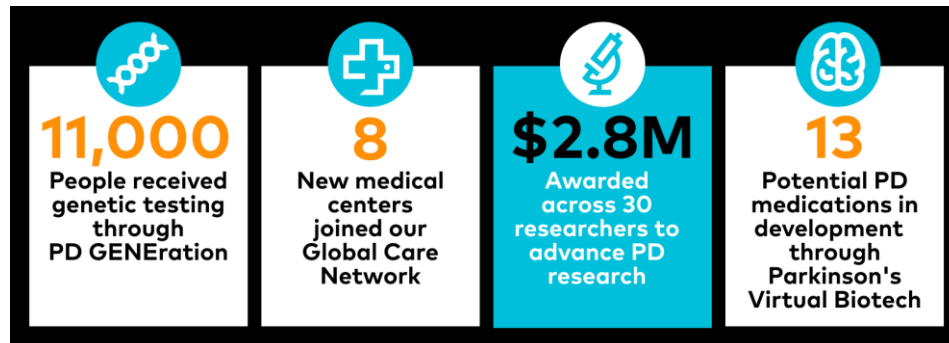
For more videos, books, articles, and blogs on Parkinson’s see:

- **American Parkinson Disease Assoc. at www.apdaparkinson.org**
- **Davis Phinney Foundation at www.dpf.org**
- **Michael J Fox Foundation at www.michaeljfox.org**
- **Parkinson’s Foundation at www.parkinson.org or call their Helpline at 1-800- 473-4636.**

MEMBER NEWS

DID YOU KNOW?

PDSGMHV, once again raised over \$30,000 for the (national) Parkinson's Foundation through our 2023 "Walk Over Water." In thanking us, the Foundation shared a summary of the 2023 accomplishments that we helped them achieve. **WELL DONE!**



STRETCHING CLINIC - Special Opportunity

The new FREE stretching clinic at **Marist College**, just for people with Parkinson's, has announced the next open dates. Your personal appointment can be made through the links below:

February 24th (11:00-3:00) <https://calendly.com/juliefineman/parkinson-stretch-clinic-2-24-24>

March 7th (1:00=5:00)

<https://calendly.com/julliefineman/pd-stretch-clinic-clinic-thursday-march-7th>

March 30th (10:30-3:00) <https://calendly.com/juliefineman/pd-stretch-clinic-3-30-24>

You can also contact Dr. Kristin Mende at Kristin.Mende@marist.edu for more information and how to join. This is run out of the Doctoral Program for physical therapists at Marist.

Don't like to exercise alone?

Anne Olin is offering classes on **Tuesday mornings from 10-11:30 am** at the Town of Ulster Senior Center, #1 Town Hall Drive, Lake Katrine NY 12249. Classes are geared for all levels and spouses and partners are welcome. Sitting, standing, balance and gait exercises are included, all done to musical accompaniment. The Senior Center is a lovely, bright new building with an entrance ramp and lots of parking. Contact **Anne at (845) 679-6250**

Wish You Could Go to Florida for a Break?

Not in your travel plans right now? How about a Certified *Dance for PD* Program in Florida that you can join for FREE from Florida online? Many of you have heard of David Leventhal and the worldwide *Dance for PD* program. Now the *Boca (FL) Ballet Theater Community Program* is offering *Dance for PD* classes on Tuesdays and Thursdays ONLINE. To REGISTER for FREE, call (561)995-0709 or email bocaballet.org.

The Connection Between Parkinson's and Exercise

The Parkinson's Foundation website notes six facts about Parkinson's and exercise:

1. Reported benefits of exercise include improvements in gait and balance, posture, endurance, memory, decision making, quality of sleep, depression and anxiety.
2. When you learn a new exercise skill (such as Tai Chi, boxing or yoga) it helps how you move and think.
3. There is not one best exercise – try to combine aerobic, strength and skill-based exercises to maximize benefits.
4. Doing a variety of exercises, as well as pushing yourself to get better at the exercises you do, helps your brain cells grow new connections.
5. You have access to PD-tailored exercise videos right now! Visit **Parkinson.org/PDHealth**.
6. It is better to start exercising soon after a PD diagnosis, but it is never too late.

You can download a free copy of *Fitness Counts* at Parkinson.org/Library.

Attention PDSGMHV Care Partners!

Did you know that we have an online care partners Support Group that meets the first Thursday of every month at 5:30pm? This group is facilitated by PDSGMHV member and peer councilor Alex Passas. If you'd like to be on the list for monthly invitations, you can contact Alex directly at passasalex@gmail.com.

NEW!! Mentoring/Buddy Option

Did you ever wish you had the phone number or email address of someone in the group that you could contact about a question, issue, or discovery you'd like to share? Did you ever just want to talk to someone else in our Parkinson's group? For privacy reasons, we don't share our membership list, but for those who would like a list of others who don't mind being contacted, you can join our new "buddy" list and have the contact information of others on the list. Contact John Cox at medicjcox@gmail.com to be added to the list. You will get periodic updates as others join.

Let's stay connected all month long!

Obituaries

We are sad to announce the death of PDSGMHV member David Brands, 78. A lifetime resident of the Hudson Valley area, he graduated from Roosevelt High School in Hyde Park in 1963 before attending Albany College of Pharmacy, where he earned his Bachelor of Science in Pharmacy. His career as pharmacist took him from Cortland Memorial Hospital, to Bob Drug, Green Haven, Harlem Valley Psychiatric Center and, finally, Hudson River Psychiatric Center from which he retired in 2007.

The birth of twin boys in 1981 led to many happy years of town baseball and soccer games, followed by Arlington track and marching band. Aside from his delight in socializing with family and friends, David was also a member of the First Presbyterian Church of Pleasant Valley where he served as elder, deacon and trustee. He was also a member of the Pleasant Valley Grange, Dutchess County Pomona Grange, New York State Grange and National Grange. In addition to family dinners, picnics, and card parties, he played pinochle with a men's group that played continuously since the 1940s, through three generations! The outdoors also called, where he loved camping trips to explore nature and history.

Even as his Parkinson's progressed, he maintained his cheerful disposition and sense of humor, finding special joy in his children and grandchildren. In lieu of flowers, memorial donations can be made to the First Presbyterian Church, Pleasant Valley. Our condolences go out to his wife Marilyn and their entire extended family.

Need some Equipment?

To donate or borrow, you can call Nancy Redkey at **914-475-2793** or email nredkey@aol.com. We currently have a variety of commodes, walkers, wheelchairs, and other adaptive accessories.



Parkinson's Disease Support Group of the Mid-Hudson Valley is a non-profit, tax-exempt organization.

www.midhudsonparkinsons.org

914-475-2793

NOTE: *If you no longer wish to receive this newsletter, please call or write Nancy Redkey at 914-475-2793, nredkey@aol.com, or PDSGMHV | P.O. Box 304 | Lagrangeville, NY | 12540.*