



*** Next Meeting ***

“What’s Behind Hallucinations, Delusions and Acting Out in Sleep?”

Dr. Katherine Amodeo; Neurologist, Movement Disorders Specialist

Friday, April 26, 2024 10:00 am - noon

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.



Mark Your 2024 Calendar – Monthly Meetings

April 26, 2024 – “*What’s Behind Hallucination, Delusions, and Acting Out in Sleep?*” Dr. Katherine Amodeo, Neurologist, Movement Disorders Specialist

May 24, 2024 – “*Nutrition and Parkinson’s*” – Rachel Reynolds, MS, RDN, LDN;

Assistant Director, Senior Nutritionist, Boston University Sargent Choice Nutrition Center

June 28, 2024 – *Discussion/Sharing*

Special Events:

May 8, 2024 – 18th Annual Caregivers Conference; “Salute to Caregivers” 8:30 – 2:00 at a NEW VENUE - the Wallace Center on the grounds of the Franklin D. Roosevelt National Historic Site in Hyde Park. Free continental breakfast and lunch will again be available, along with a FREE optional tour of the grounds and museum. However, RESERVATIONS are required. Call the Alzheimer’s Association at **800-272-3900** to reserve your spot. There will also be lots of local health care agencies present to answer questions and give out information during breakfast, lunch and breaks in the program. This is a popular annual conference, so get your reservations in early.

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 Arlington High School on your left and 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.

Running for my life: How I exercise to feel better with Parkinson's

A memorable trek around the world offers motivation for today
by *Christine Scheer* | March 15, 2024



Have you ever had to run for your life? I have — a couple of times.

I attend a [spin class](#) every Thursday morning at our local Y. Although the class isn't explicitly designed for people with Parkinson's disease, I find it remarkable how good I feel for hours after the class.

I didn't start attending spin classes until a few years after my Parkinson's disease diagnosis in 2015. In fact, I hadn't really gotten on a bike in years, which is interesting considering my husband, John, and I spent the first year of our marriage cycling around the world.

When John and I embarked on our trip, we received lots of advice. One of the most memorable pieces of wisdom was to avoid dogs and monkeys. Dogs and monkeys were the animals most likely to bite us, and then we'd have to deal with rabies, which we were told meant needles in the stomach, which terrified me. . .


This morning, we did hill training and sprints as usual in spin class, and I felt it. I wanted to slow down and not push so hard. Then I remembered running from monkeys and dogs in those naive days before Parkinson's had hopped on my back, and thought, "I've done this before, and I can do it now."

I'm not suggesting that I can outrun the disease, but I am hoping it will take a while to catch me.

Produodopa available to treat advanced Parkinson's in Scotland

24-hour levodopa infusion therapy added to country's public health system

by *Andrea Lobo* | March 18, 2024

 Produodopa (foslevodopa/foscarbidopa; also known as ABBV-951), a continuous infusion formulation of levodopa/carbidopa, will be available to advanced [Parkinson's disease](#) patients in Scotland whose severe motor fluctuations and involuntary movements are no longer controlled by those standard therapies. . .

"Given the individual nature of Parkinson's disease and associated symptoms, some treatments may not be suitable for certain patients. As such, providing a choice around therapies for those with advanced or complex stages of the condition is important," said Esther Sammler, MD, PhD, a consultant neurologist at the University of Dundee.

Produodopa, supported by data from two Phase 3 clinical trials showing its use reduced motor fluctuations, has been approved in the European Union, the U.K., Canada (under the brand name Vyalev), and Japan. **The U.S. Food and Drug Administration (FDA) has requested more information on the specialized pump used to administer the medication before considering it for approval. . .**

Produodopa is a soluble formulation of prodrug versions of levodopa/carbidopa, which are converted to the active medication once inside the body, given as a continuous infusion using a pump. It is designed to provide more stable levodopa levels, thereby minimizing off episodes.

It “offers an additional treatment option that can be self-administered, or administered with the assistance of a caregiver, when currently available combinations of treatments have failed to provide satisfactory results,” Sammler said. . .

Trial data showed that people treated with Produodopa had significantly higher control of motor symptoms without troublesome dyskinesia and reductions in off time, compared with those given oral levodopa/carbidopa.

Similarly, data from the open-label M15-741 study showed that Produodopa’s continuous use eased motor fluctuations. After one year of treatment, patients experienced an average of 3.58 more daily hours of on time — periods with adequately controlled motor symptoms — and an average of 3.39 fewer daily hours of off time.

ND0612 allows for better on time than oral levodopa: Phase 3 trial

Update on study in advanced Parkinson's patients finds longer symptom control

by *Steve Bryson, PhD* | March 20, 2024



ND0612, a liquid formation of levodopa/carbidopa given without interruption via an under-the-skin pump, continues to outperform standard oral levodopa/carbidopa at controlling motor symptoms in people with advanced Parkinson’s disease, without causing troublesome side effects.

That’s according to newly published data from the Phase 3 BouNDless (NCT04006210) trial, sponsored by the therapy’s developer NeuroDerm, a subsidiary of Mitsubishi Tanabe Pharma Corp. (MTPC). . .

BouNDless trial details were published in *Lancet Neurology* in the study, [“Safety and efficacy of continuous subcutaneous levodopa–carbidopa infusion \(ND0612\) for Parkinson’s disease with motor fluctuations \(BouNDless\): a phase 3, randomised, double-blind, double-dummy, multicentre trial.”](#)

The loss of brain cells that make the signaling molecule dopamine, and the subsequent reduction in dopamine levels, leads to the onset of Parkinson’s symptoms. Oral levodopa plus carbidopa is a standard treatment, whereby levodopa is converted into dopamine in the brain, while carbidopa helps to prevent levodopa from being broken down in the gastrointestinal tract, so more of it can access the brain.

Although effective, the oral combination therapy often loses its ability to manage Parkinson’s motor symptoms over time, and patients experience so-called off times, periods when symptoms aren’t controlled between doses. Moreover, long-term levodopa/carbidopa use is associated with a side effect known as dyskinesia, marked by uncontrolled movement. . .

ND0612 is a liquid formulation of levodopa/carbidopa delivered continuously under the skin, or subcutaneously, using a small pump. It aims to improve levodopa/carbidopa’s pharmacokinetics

(a drug's movement into, through, and out of the body) by avoiding the digestive system while maintaining 24-hour exposure to the therapy. . .

Participants who completed BouNDless had the option to enter the BeyoND (NCT02726386) trial, an ongoing long-term safety study, with some patients in their eighth year of follow-up. Data to date show that ND0612 is generally well-tolerated across more than four years of treatment. This study is due to finish in early 2027. . .

Presence hallucinations can affect patient's social perception: Study

Virtual reality with robotics used to test overcounting of people in a room

by *Patricia Inácio, PhD* | March 20, 2024



When asked to quickly assess the number of people in a room, the average person tends to overcount them.

In Parkinson's disease patients with presence hallucinations — the strong sensation of a presence when no one is there — this overestimation is much more heightened when compared with patients without these hallucinations, a study has found. . .

“The fact that patients of Parkinson's disease have a much higher over-estimation in counting people is mind-blowing because Parkinson's disease is classically viewed as a movement disorder,” Olaf Blanke, MD, PhD, at the Swiss Federal Institute of Technology (EPFL), in Switzerland, and the study's lead author, said in a press release. “We show that Parkinson's may also be a perceptual disorder, especially of social stimuli, and that invisible presences in Parkinson's disease may impair even more the counting social brain!”

The study, “Numerosity estimation of virtual humans as a digital-robotic marker for hallucinations in Parkinson's disease,” was published in the journal *Nature Communications*.

Minor hallucinations, like presence hallucinations, can be experienced early in people with Parkinson's disease, sometimes prior to their diagnosis. They are linked to early cognitive decline, supporting their potential as an early marker for dementia. . .

Nuplazid Parkinson's medication also found to improve quality of life

Drug approved in US for treating disease-related psychosis in patients

by *Steve Bryson, PhD* | March 19, 2024



Four months of daily Nuplazid (pimavanserin), an approved oral therapy for psychosis associated with Parkinson's disease, was also found to significantly improve cognitive abilities, daily living activities, and health-related quality of life for patients in a Phase 4 study.

“These findings suggest that treatment with [Nuplazid] can result in both an improvement in psychosis and corresponding improvements in various health outcomes and health-related quality of life metrics,” the researchers wrote.

The study focused on Nuplazid's impact on several measures of physical and psychological functions, as assessed by clinicians, patients, and caregivers. The results showed gains across all areas, but specifically in activities of daily living, or “typical ADLs required for day-to-day activities such as eating, dressing, and bathing,” according to the team.

“These findings demonstrate a parallel improvement in psychosis symptom scores with an improvement in functional outcome scores,” the researchers wrote.

Titled “The effects of treatment with pimavanserin on activities of daily living in patients with Parkinson’s disease psychosis: a 16-week, single-arm, open-label study,” the work was published in the journal *Therapeutic Advances in Neurological Disorders*.

Skin test can detect alpha-synuclein clumps, aiding Parkinson’s diagnosis

Results of Syn-One Test were positive in 92.7% of patients

by Patricia Inácio, PhD | March 27, 2024



CLINICAL TRIALS



A test that uses skin biopsies was able to detect the form of alpha-synuclein protein that causes toxic clumps in the brain of people with Parkinson’s disease and similar conditions in more than 90% of the patients enrolled in a National Institutes of Health (NIH)-sponsored clinical trial.

“We believe this is a crucial decade of innovation for the neurodegeneration field, one that will result in major progress in precision diagnostics, new treatments, and more promising futures for patients and families,” said Roy Freeman, MD, senior scientific advisor and co-founder of CND Life Sciences, the developer of the Syn-One Test, in a company press release.

WEBINARS/Resources

Parkinson Foundation Webinars

“**Trouble with Zzz’s: Sleep Challenges with Parkinson’s**” May 8, 2024

For people with Parkinson’s, sleep is critical — as the brain and body need more time to restore. Explore the common sleep issues associated with Parkinson’s, how it affects sleep quality, and ways to get a better night’s sleep with PD.



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 upcoing 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



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:

Monday, May 13th <https://calendly.com/juliefineman/pd-stretch-clinic-monday-may-13th>

Saturday, May 25th <https://calendly.com/juliefineman/pd-stretch-clinic-3-25-24>

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**

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**.

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.

Love Freihofer's Products?

Turn your love into a contribution to the Parkinson's Foundation. If you shop at Price Chopper and buy any Freihofer's product, Price Chopper will donate ten cents to the Foundation with each purchase of specially marked Freihofer's items.



Obituaries

We are sad to announce the death of Joan Alongi, 88, mother-in-law of PDSGMHV Vice Chair John Cox and mother of his wife, Annie Alongi Cox. Although she did not have Parkinson's, Joan was matriarch of the Alongi family, half of the Cox/Alongi family team that conceived of, organized, and did all the cooking for the annual festive fundraiser "*Pasta for Parkinson's*."

One of eight children, Joan had four children of her own, the lights of her life. Living most of her life in Poughkeepsie, she earned an RN from St Francis Hospital and went on to work at The Hudson River State Hospital, Carillon and Eden Park Nursing Homes. In addition to being an exceptional caregiver, she so enjoyed getting out with friends and family that she was affectionally know as the "Gypsy from Poughkeepsie."

The family requests any memorial donation be sent to Hudson Valley Hospice, www.hvhospice.org. Our condolences go out the John, Annie, and their entire family.



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.