



**\* Next Meeting \***

**“Discussion/Sharing”**

**(Your opportunity to join in listening and sharing)**

**Friday, March 22, 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](http://www.whud.com) and [www.wspkfm.com](http://www.wspkfm.com) storm closings/announced on **WHUD 100.7 FM** and **WSPK 104.7 FM** radio.

# Monthly Meeting - Friday, March 22, 2024

## “Discussion/Sharing”

As usual, we will separate into two groups following announcements: those with Parkinson’s will be in one room with a discussion leader, while care partners and family members will be in an adjacent room with a different discussion leader. This is your opportunity to share your latest insight or current challenge(s) and hear the same from others. Come! Share! Listen! Learn!



## Mark Your 2024 Calendar – Monthly Meetings

**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:

**April 7, 2024** – PASTA FOR PARKINSON’S 1:00 pm – 5:00 pm (See next page for details.)

**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 this event was emailed to members or you can contact Nancy Nealon at [nnealon@parkinson.org](mailto:nnealon@parkinson.org) or (585)743-1266*

**May 8, 2024** – 18<sup>th</sup> 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, but RESERVATIONS are required. Details to follow.

**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)



**SUNDAY APRIL 7, 2024**

**THIRD ANNUAL**

# **PASTA FOR PARKINSON'S**

**Bring your family to Sunday Pasta!**

Join our family as we enjoy Sunday Pasta Dinner and help support The Parkinson's Disease Support Group of the Mid-Hudson Valley.

This local, non-profit organization provides education, advocacy, and support to people with Parkinson's Disease and their families (like ours), caregivers and the medical professionals that treat them.

Bring Your Family – Make New Friends  
Support a Local Charity



**Proudly Hosted by Members of the Cox and Alongi Families  
With the Generous Support of Student Volunteers from  
Marist College Doctor of Physical Therapy (DPT) Program**

1:00 pm – 5:00 pm

Ziti – Meatballs  
Salad – Dessert

Come Enjoy Some  
Great Food and Help  
Support a Wonderful  
Cause

\$14 – Adults  
\$12 – Veterans and  
First Responders  
\$8 – Under 10

**THE AMERICAN LEGION**  
ARLINGTON POST 1302

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Poughkeepsie, NY 12603

Questions? Please Contact:

John Cox  
845-325-8320

Or

John Alongi  
845-473-9212

or email us at:  
[pasta4parkinsons@gmail.com](mailto:pasta4parkinsons@gmail.com)

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**(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.

### Dual-targeted adaptive DBS surgery may work better in Parkinson's

New protocol led to enhanced motor symptom control for 6 patients in study  
by Lindsey Shapiro, PhD | February 5, 2024



A new dual-target, adaptive deep brain stimulation (DBS) protocol may offer more clinical benefits for patients than does traditional DBS for Parkinson's disease, according to newly published data from a small clinical trial.

DBS surgery — in which a small device is implanted in the brain to deliver electrical stimulation — typically targets one brain region. Simultaneously targeting two brain regions implicated in Parkinson's, rather than just one, led to enhanced motor symptom control in the six patients in the study.

Further, implementing an adaptive approach that automatically adjusts the DBS stimulation to meet the patient's changing needs for motor control helped to maintain the treatment's effectiveness — and overall, required less electrical stimulation than do standard continuous delivery approaches. . . The study, "At home adaptive dual target deep brain stimulation in Parkinson disease with proportional control," was published in *Brain*. . .

The team now plans to further optimize their adaptive DBS protocol to advance the technology in clinical trials, according to Grill and colleagues. "This tool has great potential down the road for making DBS a more tailored and elegant therapy," Grill said. The work was supported by funding from the National Institute of Neurological Disorders and Stroke.

### Advocacy group highlights barriers to care for Parkinson's patients

Call to action sounded in new Movement Disorders Policy Coalition paper  
by Marisa Wexler, MS | February 13, 2024



In a new policy paper, the Movement Disorders Policy Coalition — an advocacy group for people living with movement disorders — highlights barriers to care that prevent Parkinson's disease patients from receiving optimal treatment. . .

The policy paper, titled "Parkinson's Disease — Improving Treatment While Working Toward a Cure," can be found on the coalition's website. . .

One major barrier to getting optimal care is a lack of access to specialists. According to the paper, Parkinson's patients who are treated by neurologists or movement disorder specialists tend to live longer and have better clinical outcomes. However, only about half of patients receive care from a specialist.

Other types of specialty care also are frequently not available to patients, according to the researchers, who report that 20% of people with Parkinson's receive physical therapy, and fewer than 10% receive speech or occupational therapy. . .

Another major barrier to optimal patient care is health plan restrictions, the paper reports. As an example, the researchers point to [Nuplazid](#) (pimavanserin), an oral therapy approved in 2016 to treat hallucinations and delusions associated with Parkinson's.

While Nuplazid has proven effective when used for this indication, the paper suggests that health insurance providers may use cumbersome requirements — such as prior authorization and specialty medication tiers — to steer Parkinson's patients away from the drug, which as a newer therapy is more expensive. Instead, patients are given older, cheaper antipsychotic medicines — even though these older drugs lack proven efficacy and some carry notable safety risks.

The third barrier highlighted in the policy paper is coverage delays... (and) new rules have led to delays expected to last longer than a year for some infusion-based therapies for Parkinson's. . .

The coalition is calling for new or at least updated policies to address these barriers. Among them are steps to expand access to specialist care, restricting insurers' ability to prevent patients from accessing effective treatments, and speeding up the time from approval of new drugs to access for patients. . .

## High-intensity exercise can boost dopamine signaling in the brain

Exercise's neuroprotective effects seen in 10 participants in 6-month program

by [Marisa Wexler, MS](#) | March 1, 2024



Participating in high-intensity exercise can help protect the brain from progressive damage in [Parkinson's disease](#), a proof-of-concept imaging study suggests.

“This is the first time imaging has been used to confirm that the biology of the brain in those suffering with Parkinson's disease is changed by intense exercise,” Evan Morris, PhD, a professor at Yale School of Medicine and co-principal investigator of the study, said in a university news story.

The study, “[Intense exercise increases dopamine transporter and neuromelanin concentrations in the substantia nigra in Parkinson's disease](#),” was published in *npj Parkinson's Disease*. . .

“Our observations could also have far-reaching implications for neuroprotective effects of exercise in [Parkinson's], but further work is needed to validate them and elucidate the underlying mechanisms,” they concluded.

## WEBINARS/Resources

### Parkinson Foundation Webinars

#### **“Understanding Pain in Parkinson’s” (archived)**

If you live with Parkinson’s disease (PD) and experience pain, you are not alone. Pain is a common **non-movement symptom** of Parkinson’s that is often under-recognized. Learn about the types of pain in Parkinson’s, its impact on the individual and the many ways to manage pain in PD.



Watch each past one-hour Briefing at [www.parkinson.org/webinar](http://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](http://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](http://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](http://www.apdaparkinson.org)**
- **Davis Phinney Foundation at [www.dpf.org](http://www.dpf.org)**
- **Michael J Fox Foundation at [www.michaeljfox.org](http://www.michaeljfox.org)**
- **Parkinson’s Foundation at [www.parkinson.org](http://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 link below:

**March 30<sup>th</sup>** (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](mailto: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](mailto:passasalex@gmail.com).

### **DID YOU KNOW?**

**Office for the Aging says gardening great all-around exercise.**

According to the Dutchess County Office for the Aging, gardening is not only good exercise, but has also shown strong signs of lowering your risk of dementia. They say that "a study that followed elderly Australians from 1988 to 2006 found a 36% lower incidence of dementia among those who were regular gardeners." Who knew!



Regardless, gardening gets you out in the sunshine, which boosts your vitamin D levels, which are key to healthy bones and a strong immune system. The alternating standing, sitting, kneeling, stretching, pulling, pushing – all help maintain and promote flexibility and balance. If you remember to bend at the knees rather than the waist, use appropriate tools, take regular breaks, and use sunscreen, sunglasses and wide-brimmed hats, you can mitigate muscle fatigue and over exposure to ultra violet rays. You may get dirty, but, again, the OFA points out that multiple studies have linked gardening to exposure to beneficial soil bacteria as well as to improvement in mood and reduced anxiety.

Best of all, the mere act of planting is an activity of hope, hope in the future. As in all of life, we will reap what we sow. Spring is here! Whether it's fruits and vegetables or ornamental flowers, pots on your patio or one or more dedicated places in your yard, it may be time to consider - or resume - gardening.

## Obituaries

We were sad to learn of the death of PDSGMHV member William John Young, 72, in Stuart, FL. A graduate of Franklin Delano Roosevelt High School in 1971, Bill liked building computers and working on electronics. This led him to a career at Dutchess Community College in the Instructional Media Department from 1974 until he retired in June 2015.

With a private pilot's license, he spent much of his spare time flying and working on planes.

His sister, Carol Schmitt, suggests donations in lieu of flowers be sent to PDSGMHV at P.O. Box 304 Lagrangeville, NY 1250 or Dutchess Community College Aviation Department, 53 Pendell Rd. Poughkeepsie, NY 12601. We extend our sympathy to his entire extended family and friends.

## Need some Equipment?

To donate or borrow, you can call Nancy Redkey at **914-475-2793** or email [nredkey@aol.com](mailto: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](http://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](mailto:nredkey@aol.com), or PDSGMHV | P.O. Box 304 | Lagrangeville, NY | 12540.*