



*** Next Two Meetings ***

Friday, October 25, 2024 10:00 am – noon (In Person ONLY)

“Discussions Caregivers Need to Have” – Shannon White
and

Friday, November 8, 2024 - 10:00 am – noon (In Person ONLY)

“Discussion/Sharing”

Your chance to share your latest victory or challenge and hear from others about theirs. Those with Parkinson's will be in one room with a discussion leader and care partners/family members will be another room. (Light refreshments)

Come ~ Listen ~ Share ~ Learn

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



(No November newsletter; only postcard reminder)

“Discussions Caregivers Need to Have”

All too often, conversations we need to have about the future with our spouse, partner, children, or parents stay in our head. Our expectations, hopes and fears go unaddressed. This program will address helpful tools to assist you in starting meaningful conversations on challenging topics concerning health, finances, and quality of life issues.



Mark Your 2024 Calendar – Monthly Meetings

October 25 – “*Conversations Caregivers Need to Have*” - Shannon White
November 8 – *Discussion/Sharing*
December 13 – *Holiday Festivities*

We are now meeting at our easily accessible new venue, the ***Freedom Plains United Presbyterian Church (FPUPC), 1168 Rt. 55 Lagrange***. Coming into Lagrange from Poughkeepsie on Rt. 55, go past the Arlington High School entrance 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.



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.

Trial data advance understanding of adaptive DBS in Parkinson's

Brain signals in most patients strong enough to trigger deep brain stimulation

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



Nearly all people with Parkinson's disease taking part in Medtronic's ADAPT-PD trial had symptom-related brain signals strong enough to trigger adaptive deep brain stimulation (DBS), known for short as aDBS, according to early data.

Among the findings: that results were similar regardless of disease severity or the location of DBS electrodes in the brain.

“This clinical trial and associated methodology ... represents a significant advancement in our understanding of aDBS therapy for Parkinson's disease,” Scott Stanslaski, the study's lead author and senior distinguished engineer at Medtronic Brain Modulation, said in a press release.

The study detailing those results, titled “Sensing data and methodology from the Adaptive DBS Algorithm for Personalized Therapy in Parkinson's Disease (ADAPT-PD) clinical trial,” was published in the journal *npj Parkinson's Disease*.

DBS is a well-established [surgical treatment](#) for Parkinson's that uses a small pacemaker-like device placed under the skin of the chest or abdomen to deliver electrical stimulation to specific parts of the brain. It's typically used to treat Parkinson's [motor symptoms](#) when pharmacological [treatments](#) are no longer effective.

In 2021, Medtronic [launched](#) a clinical trial called [ADAPT-PD \(NCT04547712\)](#) to investigate the efficacy and safety of adaptive deep brain stimulation, or aDBS, compared with conventional DBS, called cDBS. **Unlike cDBS, which delivers constant stimulation but is unresponsive to fluctuations in symptom severity, aDBS automatically adjusts signals based on individual responses. . .**

Medtronic stated that it has filed for regulatory approval of adaptive DBS in the U.S. According to the company, the findings of the ADAPT-PD trial are expected to support further regulatory submissions worldwide. . . "This first-of-its-kind trial is a significant step forward in our journey to bring sensing-enabled DBS enhancements to patients."

New method may identify younger people at risk for Parkinson's

Identifying toxic protein clumps in skin may enable early diagnosis, treatment

by *Katherine Poinsatte, PhD* | September 20, 2024



A new method for detecting toxic protein clumps of alpha-synuclein in skin cells may help diagnose Parkinson's disease up to two decades before motor symptoms appear, according to a recent study.

The novel technology combines super-resolution microscopy and advanced computational analysis to precisely map the protein clumps' molecules and structures in skin samples.

"In this study we began to develop a research tool to enable diagnosis of Parkinson's at a much earlier stage, when it is still treatable, and deterioration can be prevented," Uri Ashery, PhD, a professor at Tel Aviv University and lead researcher on the study, said in a press release.

Their study, "A novel super-resolution microscopy platform for cutaneous alpha-synuclein detection in Parkinson's disease," was published in *Frontiers in Molecular Neuroscience*. . .

Increasing the number of samples and developing machine learning algorithms in future studies will allow researchers to identify young individuals at risk for the disease.

"Our main target population are relatives of Parkinson's patients who carry mutations that increase the risk for the disease," Ashery said. "Specifically, we place emphasis on two mutations known to be widespread among Ashkenazi Jews."

The researchers hope this "new molecular toolbox" could be used to quantitatively track disease progression, measure the efficacy of disease-modifying treatments, and serve as a measurable marker of disease that can be used to set objective thresholds for Parkinson's patients recruited for clinical trials. . .

"Our method can be used to identify early signs and enable preventive treatment in young people at risk for developing Parkinson's later on in their lives," the researchers said in the press release.

Living with my hallucinations from Parkinson's

A patient perspective by [Dr. C](#), Sept. 23, 2024

Oliver Sacks in his book “Awakenings” describes Parkinson’s patients as commonly getting “revved up” and unable to stop physical movements or being frozen and unable to move. I call this “Go – No Go” and relate it to the problem of dysregulation caused by dopamine depletion.

Dysregulation also affects sensory input that underlies the occurrence of hallucinations. I deal with sensory exaggeration in some form every day, which I will refer to here as “hallucinations.”

Hallucinations are perceptions of something that I know are not real when I experience them. These are different from delusions — which is when someone honestly believes something that does not exist. . . The exaggerated sensory input is perceived as “real” — a hallucination. But I can stand back and see the exaggerated input for what it is, evaluate it properly, then change my response. In this way, it becomes another symptom of the disease.

Exaggerated sensory perceptions that occur with [Parkinson's](#) can manifest in different body sensations. I quite often experience olfactory sensations, which are strong smells that are not connected to the environment. . .

My sensory exaggeration experiences can also be visual. I see things in the shadows and in the visual periphery, but I can’t describe them other than as a fleeting nebulous event. I also hear things that are not there. And sometimes I have skin sensations like spiders crawling, not connected to reality, though quite often I will check — just to be sure! To be clear, not everyone with Parkinson’s is going to experience exaggerated sensory input and need to try evaluation and reaction management. . .

When I write about managing Parkinson’s, I often state how important it is to practice mindfulness. Mindfulness starts simply with the practice of focusing attention on the body. When getting up out of a chair, focus on getting up — nothing else. Then focus on taking that first step, feeling the ground under your foot. Now focus on the next step. I like to think of it as doing a performance and everyone is watching.

My practice of mindful attention to walking has stopped all occurrences of falling (although I still wobble when first getting up). The practice of mindful self-awareness and sustained focused attention can be applied to the problems (perceptions) of hallucinations from our exaggerated sensory input.

When practicing mindful awareness while walking, your focus is on your body. But when practicing awareness of hallucinations, your focus is on your mind and trying to evaluate what is happening before you react. . . My practice of mindful attention to thoughts and perceptions has been strengthened through daily meditation. What happened over time, as I became skilled at self-awareness, was that the effects of dysregulation became less problematic. The exaggerated sensations haven’t stopped, but I can recognize them for what they are so they stop being true hallucinations. . .

The dysregulation and the exaggerated sensory input experiences (my perception of hallucinations) are always worse during the bad days and the off periods. It means I must be especially mindful of these cycles and change the demands I place upon myself. In other words, to deal more effectively with my hallucinations, I need more rest, more patience, and more meditation.

Regular exercise, even if moderate, helps ease motor symptoms: Study

Gains also seen in fatigue across 10 weeks of intense or moderate activity

by [Margarida Maia, PhD](#) | September 23, 2024



Ten consecutive weeks of either high-intensity interval training or continuous training, which is moderate in intensity, effectively eased disease [motor symptoms](#) by about 25% and reduced fatigue in adults with [Parkinson's disease](#) taking part in a small study. These findings further emphasize the significance of exercise as a valuable supportive treatment for Parkinson's.

A 25% change in symptoms “is a very significant amount that can make a meaningful change to someone’s life,” Philip Millar, PhD, who led the study and is an associate professor of cardiovascular physiology at the University of Guelph in Canada, said in a [university news story](#). “Across any disease, when we think of taking medication, we should equally think of exercise as well.”

In the long run, Millar said, the goal is “to help contribute to greater knowledge of the benefits of exercise for those with Parkinson’s so that clinicians, rehabilitation specialists, community supports, partners and family can help advocate for patients to exercise as much as they should.” The study, “High-intensity interval versus moderate-intensity continuous cycling training in Parkinson’s disease: a randomized trial,” was published in the *Journal of Applied Physiology*.

Exercise training is recommended for people with Parkinson’s to help them stay active and maintain effective movement and coordination.

Extended-release Parkinson’s therapy Crexont available in US

Levodopa-carbidopa formulation designed to extend on-time periods

by [Andrea Lobo](#) | September 24, 2024



[Crexont](#), an extended-release formulation of levodopa and carbidopa, is now available in pharmacies across the U.S. for people with [Parkinson's disease](#). The Parkinson’s therapy, marketed by [Amneal Pharmaceuticals](#) is designed to maintain steady levels of levodopa and carbidopa in the body, extending periods of optimal symptom management, known as good on time, with fewer daily doses. . . It contains both immediate-release and extended-release components, ensuring an initial quick release of carbidopa and levodopa, followed by a sustained release over time. . . showing the treatment increased good on time by 1.5 hours per dose.

New site to manufacture stem cell therapy for Parkinson's clinical trial

Aspen's certified facility to speed cell lines for patients in ongoing ASPIRO study
by [Esteban Dominguez Cerezo](#) | October 7, 2024



Aspen Neuroscience has opened a manufacturing facility for ANPD001, its investigational stem cell therapy for [Parkinson's disease](#) being used in an ongoing Phase 1/2a clinical trial. . .

“This new site will help accelerate the manufacture of patient-specific cell lines for our ASPIRO trial patients in California and across the U.S.,” Damien McDevitt, PhD, president and CEO of Aspen Neuroscience, said in a company press release.

Watch app StrivePD helps patients between doctor visits in pilot

App reduces ER, specialist visits for patients in pilot program

by [Margarida Maia, PhD](#) | October 7, 2024



App-based consumer technology like Rune Labs' StrivePD may help people with Parkinson's disease feel more confident in managing their symptoms, bridging the gap in specialty care by providing continuous monitoring, according to the results of a pilot program done in collaboration with Kaiser Permanente.

Patients in the program used the app on an Apple Watch to record their daily activities, allowing for better tracking of their [symptoms](#). They saw a 42% reduction in emergency room visits and an 18% reduction in movement disorder specialists' visit rates.

With better tracking, doctors may identify red flags early, reducing the need for emergency care. For patients, engaging in the pilot program also meant more time spent exercising and better adherence to their medication schedules.

“By taking a tailored approach informed by ongoing patient-specific data, we have seen substantial improvements in symptom management,” Ro'ee Gilron, PhD, lead neuroscientist at Rune Labs, said in a [company press release](#).

WEBINARS/Resources

Parkinson Foundation Webinars

“Addressing the Challenge of Apathy in Parkinson's”

Sept 11, 2024 (archived)

Apathy can significantly impact quality of life for people with Parkinson's disease (PD). This invisible symptom can make it difficult to maintain interest in daily activities and manage PD symptoms. Apathy can be frustrating for people with PD and loved ones, but understanding it and finding ways to cope can help you live better 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 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



STRETCHING CLINIC - Special Opportunity

The new FREE stretching clinic at **Marist College**, just for people with Parkinson’s, has announced the next open dates. Each session is one-on-one, tailored to you. Your personal appointment can be made through the links below:

Saturday, November 9th

<https://calendly.com/juliefineman/pd-stretch-clinic-saturday-november-9-2024>

Saturday, November 23rd

<https://calendly.com/juliefineman/pd-stretch-clinic-saturday-november-23-2024>

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 College.

Have You Checked Out Our New Website?

Have you explored the new face of our *Parkinson’s Disease Support Group of the Mid-Hudson Valley*? Go to www.midhudsonparkinsons.org to see expanded information on Parkinson’s, our history, meetings, resources, Walk Over Water, Board members and much more. Share! Enjoy!

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 participate, you can contact Alex directly at **passasalex@gmail.com**.

Need some Equipment?

JUST IN: A U-Step Walker! Like new. 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.

\$\$\$ SAVING MONEY \$\$\$

As postage fees continue to rise, we continue to look for cheaper ways to share our newsletter. If you would be willing to read the newsletter online, please let Nancy know and we will deliver it to your computer instead of your mailbox.

NOTE: Have you paid your 2024 DUES? (\$15/INDIVIDUAL; \$20/COUPLE)

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



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.