



*** Next Meeting ***

“Hot Tips on Communicating with PD”

Dr. Phil Schneider, EdD, CCC-SLP (person with Parkinson's, family care partner)

Friday, January 26, 2024 10:00 am

VIA ZOOM ONLY



New Year Kick-Off Meeting

“Hot Tips for Communicating with PD”

January 26, 2024

Are you constantly asking someone with Parkinson's to speak up or not mumble? Or, if you have Parkinson's, are you always telling people they need a hearing aid because you feel you are practically shouting, yet they say they can't hear you? Regardless, we all know that Parkinson's can present some unique challenges to good communication for everyone.

This month's speaker, **Dr. Phil Schneider**, founder of **Schneider Speech**, says the aim of his team for the last half century is to “provide...opportunities for people to become the best communicators they can be... (They) focus on people, not problems.”

ZOOM registration information went out via email. Email nredkey@aol.com if you didn't receive the email or if you have questions. We highly recommend Dr. Schneider's professional, but caring and thoughtful approach to improving communication. As his website says “Let your voice be heard.”

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

January 26, 2024 – “*Hot Tips for Better Communication with PD*” – Dr. Phil Schneider (**via Zoom only**) **10:00 am** (registration required)

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

This month’s meeting is via Zoom only, but the remainder of our 2024 meetings will be in person. We will continue to meet at our easily accessible new venue, the ***Freedom Plains United Presbyterian Church (FPUPC)***, unless otherwise noted. Coming into Lagrangeville from Poughkeepsie on Rt. 55, go past the church to the East 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)



**PAR KINSON'S
NEWS TODAY**

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.

Swallowing problems may be due to poorer sensation in the airways

Small study finds no major problems in issue of importance due to dysphagia

by [Lindsey Shapiro, PhD](#) | November 8, 2023



Major problems with sensation in the airways — essential in preventing the dysphagia or swallowing difficulties that can lead to complications like aspiration pneumonia — were not observed between Parkinson's disease patients and healthy adults in a small recent study.

But given the proposed relationship between airway sensory impairments and dysphagia, a common Parkinson's symptom, its researchers consider it important to evaluate airway sensory status in Parkinson's, possibly with a more sensitive technique than that used in this work. They also favored larger studies in this area.

“A routine clinical examination of the sensory input of PD [Parkinson's disease] participants is a must since dysphagia is one of the main symptoms of the disease,” the researchers wrote.

“Protective reflexes are paramount to airway protection. ... [and] recent studies have demonstrated that airway protection mechanisms are negatively affected in PD.”

The study, “Assessment of the Sensitivity of the Vocal Tract in Parkinson Disease by Nasal Video Endoscopy,” was published in the *International Archives of Otorhinolaryngology*. . .

Phase 3 trials of oral tavapadon in easing motor symptoms nearing end

Results of TEMPO program in early and late-stage Parkinson's due in 2024

by [Patricia Inácio, PhD](#) | November 7, 2023



An ongoing and global Phase 3 clinical trial program for oral tavapadon, a selective dopamine receptor agonist aiming to improve motor function in people with Parkinson's disease, expects to release study findings next year.

Three separate, 27-week trials are evaluating tavapadon's efficacy, safety, and tolerability against a placebo in recently diagnosed adults to those with advanced disease. . .

Tavapadon is designed to bind selectively to dopamine D1 and D5 receptors on the surface of nerve cells, aiming to “maximize motor benefit while reducing the prolonged receptor overexcitation and desensitization caused by full agonists, which can lead to dyskinesias,” Cerevel reports.

Report: Addressing swallowing issues requires carer-clinician effort

Writer calls for protocols to guide care for Parkinson's patients with dysphagia
by Marisa Wexler, MS | November 7, 2023



Swallowing problems can cause deadly complications for people with Parkinson's disease, if not handled appropriately, making it critical that hospital clinicians partner with caregivers to help address the needs of patients.

That's the argument made by Annie Brooks, director of strategic initiatives at the [Parkinson's Foundation](#), in "[Dysphagia and aspiration during a Parkinson's hospitalization: a care partner's perspective and recommendations for improving standards of care](#)," which was published in *Frontiers in Aging Neuroscience*.

"Care partners are essential as advocates during hospitalization and should be acknowledged as an important member of the care team. Without staff respect for care partner input, however, the success of advocacy is limited," Brooks said. "It is important for hospitals to adopt standard protocols that honor the care partner role and create opportunities for their input on the care being provided."

A problem swallowing, or dysphagia, is a [common complication in Parkinson's disease](#) that can set the stage for life-threatening concerns like choking and pneumonia. For clinicians, especially those without much expertise in Parkinson's, working with patient caregivers may prevent dysphagia-related problems.

"Bringing a care partner to the hospital who can advocate for one's needs is critical for people with [Parkinson's] because staff may not fully understand [Parkinson's] or know how to properly manage a patient's [Parkinson's] symptoms, including those related to swallowing," writes Brooks, who described the case of the husband of a Parkinson's Foundation volunteer to illustrate her point.

New imaging technology may help diagnose neurological conditions

Researchers in Canada refine targeted ocular spectroscopy for the eyes
by *Andrea Lobo* | December 22, 2023



Targeted ocular spectroscopy, a technology that allows real-time imaging of the back of the eye (or eye fundus) while observing how light interacts with specific structures in the retina, can help diagnose several eye and neurological conditions, including [Parkinson's disease](#), according to a recent study.

The retina is the light-sensitive layer at the back of the eye. It plays a crucial role in converting incoming light into electrical signals, which then are transmitted through the optic nerve to the brain.

The study "Targeted spectroscopy in the eye fundus," was published in *the Journal of Biomedical Optics*.

The assessment of biomarkers in the eye can be used to help screen, diagnose, and monitor diseases affecting the eyes, as well as neurological conditions, including Parkinson's

and Alzheimer's disease. These conditions were shown recently to cause observable changes in the nerves and blood flow of the retina. . .

Overall, the new technology “provides structural, compositional, and functional information of specific regions of the eye fundus from a non-invasive approach to ocular biomarker detection,” the researchers wrote.

Study finds pain to be common in early-onset Parkinson's

More severe pain linked to older age, nonmotor symptoms such as depression
by [Lindsey Shapiro, PhD](#) | December 27, 2023



More than three-quarters of people with early-onset [Parkinson's disease](#) (EOPD) experience pain, according to a recent study conducted in Vietnam, with more severe pain reported by older patients and those with nonmotor symptoms such as depression, sexual dysfunction, and hallucinations.

Additional studies with well-validated tools are needed to further understand pain in this patient population and its interplay with other [Parkinson's symptoms](#), according to scientists.

Wearable device prevents freezing of gait in Parkinson's patient

Man, 73, with 'incapacitating' episodes able to walk indoors using soft exosuit
by [Mary Chapman](#) | January 10, 2024



Researchers at Harvard and Boston universities have adapted a soft, robotic wearable device to help mitigate the effects of gait freezing, a potentially disabling [Parkinson's disease](#) symptom marked by patients feeling like their feet are stuck to the floor, and they're unable to take another step.

The device or exosuit, which they initially designed to help adults with walking difficulties due to a stroke or other conditions, “instantaneously eliminated” freezing of gait while walking indoors for a 73-year-old Parkinson's patient in tests done across six months, the scientists reported. The man was reported to have daily and “incapacitating” episodes of gait freezing, a fairly common [disease motor symptom](#).

Use of this “soft robotic apparel that augments hip flexion” also permitted the patient to walk faster and for a greater distance, the researchers wrote.

An article describing the device and its use, “[Soft robotic apparel to avert freezing of gait in Parkinson's disease](#),” was published in the journal *Nature Medicine*. . .

“We see that restoring almost-normal biomechanics alters the peripheral dynamics of gait and may influence the central processing of gait control,” Ellis said.

The work was supported by grants from the National Science Foundation, the National Institutes of Health, and the Massachusetts Technology Collaborative.

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



STRETCHING CLINIC - Special Opportunity

Want to be more flexible? Want to feel better? Want to do it under professional guidance? The new **FREE** stretching clinic at **Marist College**, just for people with Parkinson's, may be your answer.

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.

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!

Need some Equipment?

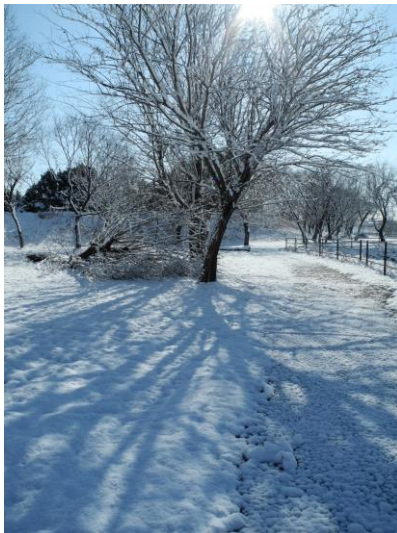
To donate or borrow, you can call **Nancy Redkey at 914-475-2793** or email nredkey@aol.com. We currently have a variety of commodes, walkers, wheelchairs, and other adaptive accessories.

Obituaries

We are sad to announce the death of PDSGMHV member Neil Victor Salzman, 83, on November 14, 2023, of complications due to Parkinson's. After a boyhood in Brooklyn, Neil went on to earn both his Master's and Doctorate Degrees in history and political science at City College of New York, before becoming history and political science professor at Fairleigh Dickinson University. In addition to his formal academic training, he was also a scholar of secular Jewish and Yiddish culture and language and a lifelong student of nature, especially birds.

He is survived by his wife, Dr Robin Flam, three sons and their wives, four grandchildren, and a brother and sister-in-law.

His lively intellect, kindness to others, curiosity, joy of life, and his ever-present smile will be missed by all who knew him. The family suggest that memorial contributions be made to our PDSGMHV group at P.O. Box 304, Lagrangeville, NY 12540, *Hudson Valley Hospice*, or the *Ralph T. Waterman Bird Club*, P.O. Box 487, 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.*