



*** Next Meeting ***

Parkinson's Disease Support Group of the Mid-Hudson Valley

"Discussion/Sharing"

(Two separate groups: people with Parkinson's and care partners/family members)

Friday, May 26, 2023 10:00 am - noon

(In Person Only - Unitarian Fellowship, 67 So. Randolph, Poughkeepsie)



Come! Share! Listen! Learn!

Here's what one Discussion Group participant said about the benefits of attending our quarterly "Discussion/Sharing" sessions:

"I have found the Discussion/Sharing quarterly meetings an invaluable resource to me as a person living with Parkinson's. Everyone is so supportive of each other in our confidential meetings, and I always learn several helpful suggestions and useful nuggets of information. Being reluctant to attend these types of meetings for so long, I now realize how these sessions - with my "Parkinson's peers" - have greatly assisted me, and I highly recommend coming to join us!" **May 26th at 10:00 am.**

CALLING ALL BAKERS

Our group is expanding. We're looking for volunteers to take turns adding to our refreshment table and/or helping serve. Our meetings seem to be increasing everyone's appetite! THANKS!



Mark Your 2023 Calendar

May 26, 2023 (In Person) – “Discussion/Sharing”

June 23, 2023 (In Person) - Rachel Flannigan Frost “Planning for Peace of Mind”

July 28, 2023 (In Person) – Dr. Vishad Sukul – “Know Your Treatment Options”

August 25, 2023 (In Person) – “Discussion/Sharing”

September 22, 2023 (In Person) – Robin Barclay, PT “What’s New and Trending in PD Exercise”

Special Events:

September 24, 2023 – “11th Annual “Walk Over Water” on the Walkway Over the Hudson Demonstrations * Kid’s Booth * PD Information * Music * Ice Cream Truck

“Pasta for Parkinson’s” Presents Check to PDSGMHV



As the culmination to their *Pasta for Parkinson’s* event in April, John and Annie Cox recently presented a check for **\$3,500** to the PDSGMHV! The huge size of the check in the photo reflects the size of their family’s hard work, compassion, and big hearts.

Once again, our thanks to all who attended and special thanks to the Cox/Alongi family!

thank you



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*)

Women with Parkinson’s less likely to be referred for DBS than men

40% of patients are women, but that doesn't fully explain access disparity

by Andrea Lobo | April 14, 2023

Women with Parkinson’s disease are less likely to be referred for deep brain stimulation (DBS) evaluation than men, a study has found. Moreover, women with essential tremor, a disease that shares symptoms with Parkinson’s and can also be treated with DBS, were more likely to

decline surgery, once approved. Although further studies are needed to better understand these gender differences in accessing DBS, “women often have less support than men and less access to caregivers, so additional interventions, such as setting up home health after surgery, may be helpful,” the researchers wrote in “[Gender Disparities in Deep Brain Stimulation Surgery for Parkinson Disease and Essential Tremor](#),” which was published in [Deep Brain Stimulation](#).

AlphaSyn-SAA test accurately detects Parkinson’s, study finds

Discovery lauded as 'revolutionizing every aspect of research and care'
by [Marisa Wexler, MS](#) | April 13, 2023



A test called the alpha-synuclein seed amplification assay, or alphaSyn-SAA, can detect Parkinson’s disease with high accuracy, a new study reveals.

The research was conducted as part of the Parkinson’s Progression Markers Initiative (PPMI), an [international study](#) led by the [The Michael J. Fox Foundation for Parkinson’s Research](#) (MJFF).

“It would be difficult to overstate the implications of this discovery,” Deborah Brooks, CEO of the MJFF, said in a [press release](#). “With development and scaling, [alpha]Syn-SAA can usher in the era of objectively and biologically defining Parkinson’s disease — revolutionizing every aspect of research and care.”

Parkinson’s subtypes may be ID’d by analyzing nerves in the eyeball

Average length, density of corneal nerves were larger with TD than PIGD subtype
by [Marisa Wexler, MS](#) | April 20, 2023



Measuring the length and density of nerves in the cornea — the clear outer layer of the eyeball — can help distinguish between motor subtypes of [Parkinson’s disease](#), a new study suggests.

The [study](#), “[The severity of corneal nerve loss differentiates motor subtypes in patients with Parkinson’s disease](#)” was published in *Therapeutic Advances in Neurological Disorders*.

Parkinson’s can cause a range of [motor symptoms](#). Depending on which symptoms are most apparent, the disease may be divided into tremor-dominant (TD) or postural instability and gait disturbance (PIGD) subtypes. The former is marked by more tremors, the latter by greater problems with walking and balance. Generally, patients with the TD subtype have a better response to treatment and fewer cognitive issues.

Finding his community was key for patient living with Parkinson’s

by [BioNews Staff](#) | April 19, 2023 (This is Mark Milow’s story)

With a [Parkinson’s disease diagnosis](#), there are a lot of things to consider. And that’s further complicated with a diagnosis of [early-onset](#) or young-onset Parkinson’s disease (YOPD) — having symptoms before age 50.

When you're in that age range, you're usually still working or raising kids, or helping a child through college. Adding a diagnosis of a degenerative neurological condition into the life of someone working full time, with an active lifestyle, can really complicate things.

Many people know Parkinson's comes with tremors, along with stiffness, and balance issues. But many don't realize the general fatigue, exhaustion, and seemingly myriad other nonmovement symptoms that accompany the disease. Things like panic attacks, depression, sleep issues, constipation, pain, memory issues, and even sweat control!

That's exactly where I was in February 2021 — living a busy life and smacked square in the face with a YOPD diagnosis.

Upon receiving a life-changing diagnosis like this, I had a choice: How would I respond? Former football coach Lou Holtz once said, "Life is 10% what happens to you and 90% how you respond to it."

So how did I respond? It wasn't very inspirational. I asked a lot of questions like "Why me?" or "Am I the only one other than Michael J. Fox who has Parkinson's before age 50?" I felt alone, scared and lost. And alongside all those emotions, I began to feel sorry for myself.

Mark with his dog, Bandit.



But a funny thing happened around the time self pity was setting in. I began seeing examples of bravery in the face of adversity all around me. I also began realizing it was OK to find humor in the situation. Finding something to laugh about can certainly help fend off self pity.

I think the biggest thing that's helped me keep perspective, though, is people. Having people around me who understand and care. To find those who truly understand, we really need to search among those impacted directly by Parkinson's.

Shortly after being diagnosed, I created accounts on Instagram and TikTok, specifically to talk about what I was going through. I didn't know if anyone would see what I was posting, and I didn't care. This was therapy for me to talk through the situation. But as I went along, people began to comment. I got questions from viewers. People responded with resources that could help or anecdotes from their own story. Very soon, friendships were made and bonds were formed. People I'd never met in person became some of my best friends. And that network of people I still count on today for understanding, for ideas, for accountability, for encouragement.

People make all the difference.

The shortage of dopamine caused by Parkinson's does a number on our thoughts and emotions. Surrounding ourselves with people who understand the struggles and can encourage us in the midst of hard times is a key to fighting self pity. We were not meant to fight this battle alone. We need community.

AAN 2023: Apomorphine infusion pump SPN-830 reduces 'off' time

Participants in Phase 3 INFUS-ON trial also reported health gains

by Marisa Wexler, MS | April 26, 2023



Most people with Parkinson's disease treated with SPN-830, an apomorphine infusion pump, report improvement in their health status. SPN-830 also reduced "off" time, when symptoms are not being adequately controlled, by an average of about three hours a day.

That's according to new results from an open-label clinical trial. Stuart Isaacson, MD, a neurologist at the Parkinson's Disease and Movement Disorder Center of Boca Raton in Florida, discussed the findings at this year's American Academy of Neurology (AAN) annual meeting in a presentation titled, "Continuous, Subcutaneous Apomorphine Infusion for Persistent Motor Fluctuations in Parkinson's Disease: Full results of the AP2-3000 open-label study."

Parkinson's is caused by the death and dysfunction of cells in the brain responsible for making the signaling molecule dopamine. Standard treatment includes levodopa and its derivatives, which give these cells more material to make dopamine.

While levodopa can manage symptoms, many patients have off episodes with long-term treatment where symptoms are not adequately controlled between doses. Dyskinesia, or uncontrolled movements, can also occur over time.

Apomorphine (sold as Apokyn, among others) mimics dopamine's activity in the brain. It's approved in the U.S. for managing off episodes and the approved version of it is administered subcutaneously (under the skin).

SPN-830 delivers the therapy in a continuous infusion, making it more convenient and with fewer injection sites. It's approved in much of Europe, Asia, and Australia.

Supernus Pharmaceuticals is seeking SPN-830's approval with the U.S. Food and Drug Administration (FDA)

Exercise, especially mind-body, eases motor symptoms

Analysis of physiotherapy trials to spot forms that might most help patients

by Lindsey Shapiro, PhD | April 25, 2023



Physiotherapy, and mind-body exercise particularly, can meaningfully ease motor symptoms of Parkinson's disease, a recent meta-analysis of clinical trial data involving more than 2,500 people reported.

Mind-body exercise refers to practices that focus on the connection between the body, breath, and the mind, such as yoga, tai chi, or dance. This type of exercise therapy led to significant gains across most measures of Parkinson's motor symptoms, with beneficial changes in areas that also included patients' gait, balance, and mobility.

Clinical improvements also were seen in trials of physical exercise like strength training and aerobic exercise, as well as in those using noninvasive brain stimulation. . .

“The results showed that mind-body exercise had a good improvement in all four aspects of motor symptom severity, balance, gait, and functional mobility, and was the best of the six exercise interventions” evaluated, the researchers in China wrote. But further study to validate these findings and to compare various approaches are needed, they added. . .”

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 the **Helpline** at **1-800-4PD-INFO**.



“A Balancing Act: Freezing and Fall Prevention in Parkinson’s”

Date: April 12, 2023 at 1 pm (archived)

People living with Parkinson’s have twice the risk of falling as their peers without PD. Falls often result in injuries ranging from minor cuts to serious fractures, impacting mobility and quality of life. Learn how freezing and other movement and non-movement symptoms can contribute to falls and how to lessen the risk.

“Parkinson’s & Medications: What’s New” (archived)

Tanya Simuni, MD, discusses the advances in Parkinson’s treatments for movement and non-movement symptoms and where we are on the path to personalized medicine.

Michael J. Fox Foundation -Third Thursdays Webinars:

“Trouble Sleeping? What to Know About Acting Out Dreams and Other Sleep Issues”

Thursday, March 16, 2023; 12-1:00 pm (archived)

This month we will replay a popular webinar on sleep issues. Our expert panelists discuss the many sleep issues that can come with aging and Parkinson’s, including acting out dreams while asleep. We share tips for managing sleep problems and cover research into the latest treatments.

“Major Research Breakthrough: A New Biomarker for Parkinson’s”

Thursday, April 20, 2023; 12 – 1:00 pm (archived)

This groundbreaking research, led by MJFF and its Parkinson’s Progression Markers Initiative (PPMI), is paving the way for a future where every person living with Parkinson’s can expect improved care and treatments.

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

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, cushions, and other adaptive accessories.

NOTE: Time for 2023 DUES (\$15/INDIVIDUAL; \$20/COUPLE)

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

Obituaries

We are sad to announce the death of **Richard Siegmund**, 83, in Gilbert, AZ, where he and his wife, Martha, had moved to be near their children. Born in Slovenia, Richard and his family moved to Ridgewood Queens, NY in 1955. He began his professional career as a Tool & Die maker (Swingline and IBM) until earning a degree in Finance from Marist College which led him to serve in various positions in finance and finance management at IBM and, later, Netscape.

In addition to family and friends, Richard's passions included hiking, camping, fishing, and skiing, as well as landscaping his yard and tending his gardens. His homegrown vegetables were always a treat! Dedicated to health and fitness, he continued water and snow skiing into his 70s. In retirement, he took up watercolor painting - winning awards at the Dutchess County Fair. He and Martha both enjoyed polka dancing at Germania and attending Gottscheer festivals with close

family and friends. Of Martha's amazing cooking, he quipped that his favorite meal of hers was "breakfast, lunch, and dinner!"

The two recently celebrated 58 years together, happily raising three children in the Hudson Valley. His notable humor, determination, work ethic, assorted collections and his love of friends and family will long be remembered. We hear that neighborhood dogs also considered him a friend for the treats he carried on his daily walks.

The family suggests, for those who wish, that contributions in Richard's memory be made to Parkinson Voice Project, the Parkinson's Foundation or a charity of your choice. We offer our condolences to Martha, his entire family and all those who knew him.

A Celebration of Life

The family of late PDSGMHV member **Shirley Bernard** has announced a Celebration of Life for her on Saturday, June 17th at the Rosendale Community Center on Route 32 in Rosendale, NY at 2:00 pm. Contact her daughter, Elizabeth Fleming, at **845-399-1005** or her sister, Linda Hacksteiner, at **845-452-1025** for details and to register



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.*