



*** Next Meeting ***

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

“Moving Better for Living Better”

Anne Olin, M.Ed, Board-Certified Dance Movement Therapist

Friday, April 28, 2023 10:00 am - noon

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



Can Exercise Be Fun? Yes!

If you'd like to lift your mood, address balance, flexibility and coordination, as well as breathing and voice projection, this month's meeting with Anne Olin, our Dance/Movement Therapist, is for you! Here's what Dr. Fabio Danisi, neurologist and Movement Disorders Specialist, says about her, "Most communities are not fortunate to have someone like Anne provide such a wonderful venue for people with Parkinson's and other movement disorders. Her classes are expertly geared to (their) specific needs." Give your mind, mood and body a treat. Join us **April 28th at 10:00 am**, try it out and learn why it works.

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

April 28, 2023 (In Person) - Anne Olin “*Moving Better for Living Better*”

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 ((n Person) – Robin Barclay, PT “*What’s New and Trending in PD Exercise*”

September 24, 2023 – “11th Annual “**Walk Over Water**” on the Walkway Over the Hudson

Special Events:

May 10, 2023 – 17th Annual Dutchess Caregivers Conference, “*Caregivers: Our Unsung Heroes*” at **The Grandview**, 176 Rinaldi Blvd. Poughkeepsie; **8:30 am – 2 :00 pm**; breakfast/lunch included. This is a free event, but registration is required. Call the Alzheimer’s number **800-272-3900**.

“Pasta for Parkinson’s” Kicks off Parkinson’s Awareness Month!



April 2, 2023, **Parkinson’s Awareness Month**, arrived in style in the Hudson Valley! There was a steady stream of hungry customers filling the American Legion Hall in Poughkeepsie, looking for an empty table. Overseen by John and Annie Cox, center photo, each diner was served by cheerful student volunteers from the Marist College Doctoral Program for Physical Therapists. The Cox’ son Zach, left photo, served up generous portions of ziti and Annie’s special meatballs. To top off the meal, each got to select from a tray of enticing desserts, shown on the right.

The entire Cox/Alongi family was again involved in this second annual event, marked this year by balloon centerpieces and the addition of a 50/50 raffle and gorgeous raffle baskets donated by individuals and businesses who wanted to support the family’s event. In addition to a fun-filled afternoon of good food and good company, the event raised needed funds for our Mid-Hudson Parkinson’s support group. Stay tuned for the final total! Meantime, our thanks to all who attended and special thanks to the Cox/Alongi family for their hard work, fabulous results and generous hearts!

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*)

Parkinson's Foundation wins nearly \$800K for research, genetic testing by *Lindsey Shapiro, PhD* | March 8, 2023



The Parkinson's Foundation was awarded nearly \$800,000 to support research efforts that aim to improve the lives of the estimated 18,000 people living with Parkinson's disease in Arizona... "We know that genetic testing is a critical tool for understanding the puzzle of Parkinson's disease," said Mark Grayson, president of the Pat Simone Charitable Foundation. "We are thrilled to support the Parkinson's Foundation and hope that many people with Parkinson's will benefit from this research..."

The award also will bolster efforts to increase local participation in PD GENERation: Mapping the Future of Parkinson's Disease — the Parkinson Foundation's national initiative to provide no-cost genetic testing for patients at participating Centers of Excellence or at home...

The PD GENERation study (NCT04057794) is open to Parkinson's patients in all 50 U.S. states, Puerto Rico, and the Dominican Republic, as well as in Canada; the estimated enrollment is 15,000 people. It aims to combat the high costs associated with Parkinson's genetic tests, which can pose a barrier for patients.

To that end, it offers no-cost genetic testing for people who have been diagnosed with the neurodegenerative disease. Through a simple cheek swab, a person's DNA will be screened for mutations in seven different genes that have been linked to the neurodegenerative disease. These are *GBA*, *LRRK2*, *PRKN*, *SNCA*, *PINK1*, *PARK7*, and *VPS35*.

Once the testing is complete, participants receive genetic counseling in English or Spanish about what the results mean for them and their families...

Student-led startup working on way to help Parkinson's patients write by *Marisa Wexler, MS* | March 8, 2023



SteadyScrib, a startup company led by undergraduate students at Northwestern University, is working on a pen-and-clipboard system that can make writing easier for people with [Parkinson's disease](#).

The company hopes to launch its pen sets by this year's end, and it offers a [waitlist](#) for people who want to stay informed about their availability. Currently, the system can be used in physical and occupational therapy sessions at three Northwestern Medicine locations.

Izzy Mokotoff, a junior studying journalism at Northwestern and SteadyScrib's CEO, was inspired to start the project by her grandfather, Neal Charles Andelman, better known as "Pops." Growing up, Mokotoff and her grandfather regularly exchanged handwritten letters, but as his Parkinson's progressed, writing these letters became more difficult and, eventually, impossible.

... "When my pops called me over a year ago and told me there were no existing technologies to enable people with Parkinson's to physically write, I just thought my grandparents weren't googling a solution properly. But it turns out, there truly isn't anything out there," Mokotoff said in a university news story...

The SteadyScrib system uses a galvanized steel clipboard and a pen with a weighted, magnetic core and wide, pliable grip. Its overarching aim is to make the pen easier to hold and keep steady on the clipboard, where paper is held in place, even while patients are experiencing symptoms like tremors.

...After Pops died late last year, the team continued to work and refine its product's design. The startup recently won a \$20,000 support grant from the Venture E-Team Program. "SteadyScrib is a beautiful reminder of the love between a grandchild and her grandfather, and the impact that Pops' legacy can have on the lives of many," Mokotoff said.

Prebiotic bar, eaten daily, helps to ease inflammation in patients' gut

by *Patricia Inácio, PhD* | March 14, 2023



Eating a tailored prebiotic fiber bar — meant to help nourish good bacteria in the gut — for 10 days boosted the abundance of anti-inflammatory bacteria in the microbiome of people with Parkinson's disease, a proof-of-concept clinical trial reported.

These effects were associated with better intestinal health and protection against inflammation, supporting the "the scientific rationale for placebo-controlled trials using prebiotic fibers in PD [Parkinson's disease] patients," the researchers wrote...

An exploratory analysis also linked the prebiotic intervention to a reduction in disease severity, as assessed with the Unified Parkinson's Disease Rating Scale...

Overall, "this proof-of-concept study demonstrates that a SCFA-promoting prebiotic fiber mixture can be used to modulate the intestinal microbiota in PD patients (i.e., the approach is feasible) and that the prebiotic mixture is well-accepted, tolerated, and safe for use in PD patients," the researchers wrote. "Moreover, the prebiotic fiber mixture may have a clinical impact leading to reduced severity of motor and non-motor PD symptoms and improved gastrointestinal function," they added.

Ban sought for TCE, common chemical likely linked to Parkinson's

Chemical is banned in EU; in US, Minnesota and New York disallow its use

by *Marisa Wexler, MS* | March 17, 2023



Scientists are calling for a ban on trichloroethylene (TCE), a common and widely used chemical that's increasingly linked to multiple health problems, including cancer and [Parkinson's disease](#).

"Through a literature review and seven illustrative cases, we

postulate that this ubiquitous chemical is contributing to the global rise of PD [Parkinson's disease] and that TCE is one of its invisible and highly preventable causes," the researchers wrote.

TCE is banned in the European Union except for authorized industrial uses and it's been banned by Minnesota and New York in the U.S., but not by the federal government...

The international team, comprised mainly of U.S. researchers, also called for more studies into TCE's potential health risks, for the cleanup of contaminated sites, and for more information to be made available about the dangers of contamination.

The team posed their argument in the study "Trichloroethylene: An Invisible Cause of Parkinson's Disease?," which was published in the *Journal of Parkinson's Disease*.

Parkinson's is believed to be caused by a combination of genetic and environmental factors. Mounting evidence shows that exposure to environmental pollutants, such as pesticides and certain chemicals, may put people at increased risk of developing it.

TCE was developed in the lab in the 1860s and began to be commercialized in the 1920s. The chemical is a powerful solvent — a liquid that can dissolve other substances — and it's been widely used in cleaning applications, from making refrigerants to removing grease on military equipment and dry cleaning clothing. It's also been used to decaffeinate coffee and in consumer products, including adhesives and various cleaning supplies...

"TCE pollutes outdoor air, taints groundwater, and contaminates indoor air," the researchers wrote, adding that the chemical "evaporates from underlying soil and groundwater and enters

...The researchers emphasized that more research into these connections is needed and that clinicians should talk to their patients about potential exposure...

"In many ways, the long-established health risks of TCE dwarf its relationship with PD. TCE causes cancer, increases the risk of miscarriages, contributes to birth defects, and is associated with diseases in nearly every organ system," the researchers wrote...

Older adults sought for Smell Test Challenge

by [Marisa Wexler, MS](#) | March 16, 2023

Now Recruiting

The Michael J. Fox Foundation for Parkinson's Research (MJFF) is calling on adults 60 and older in the U.S. and Canada who do not have Parkinson's disease to participate in the Smell Test Challenge, which aims to better understand the connection between loss of smell and neurological disease.

To participate, adults need to go to the Smell Test Challenge website, and answer three yes/no questions to confirm their age, residence, and Parkinson's status. They then can enter their address to be sent a free scratch-and-sniff test in the mail.

After taking the test, participants can enter their results online, which will be analyzed by MJFF scientific experts. Depending on their results, certain participants may be eligible to join an important brain health study. To ensure participant privacy, only de-identified data will be shared with the global research community...

The challenge is part of the Parkinson's Progression Markers Initiative (PPMI), a large MJFF-sponsored international study following patients and healthy people over time to better understand the biological causes of Parkinson's.

FDA needs additional information before approval of ABBV-951

The formulation is the first to offer a nonstop supply of levodopa/carbidopa
by *Margarida Maia, PhD* | March 23, 2023



The U.S. Food and Drug Administration (FDA) has requested more information about the specialized pump used to administer ABBV-951 ([foslevodopa/foscarbidopa](#)), an under-the-skin formulation of levodopa/carbidopa, before it will consider approving the therapy for motor fluctuations in people with advanced Parkinson's disease.

The agency's complete response letter comes 10 months after AbbVie, the therapy's developer, filed the regulatory application based... Data showed ABBV-951 did better than oral tablets of levodopa/carbidopa at keeping motor fluctuations under control over three months. No additional safety and effectiveness clinical trials of ABBV-951 were required in the response... The company said it plans to resubmit the application with the required pump-related information "as soon as possible."

If approved, ABBV-951 will become the first formulation of its kind to ensure a round-the-clock, nonstop supply of levodopa/carbidopa prodrugs. A prodrug is an inactive compound that's converted into an active medicine once it's in the body...

With oral tablets, the amount of levodopa that reaches the brain can differ from one time to the next. This happens because the digestive system can absorb the medicine differently each time.

Because ABBV-951 is continuously delivered under the skin through a specialized pump, typically placed in the abdomen, it can be absorbed directly into the bloodstream. This means it can deliver more consistent amounts of levodopa to the brain, start working faster, and reduce off times...

Results from the long-term trial of 244 Parkinson's patients having motor fluctuations on standard oral levodopa/carbidopa showed ABBV-951 was generally safe and well tolerated over a year of treatment. Participants saw a drop in daily off time by about three hours on average and a comparable increase in daily on time.

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

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.

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.

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

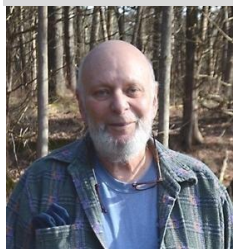
Need some Equipment?

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 were sad to learn that Hugh “Neil” Zimmerman died on February 28th, at his home in Accord. His “day job” from 1974 to 2017 was as chief librarian at the Population Council in New York City, where one of his many accomplishments was the development and implementation of a global program to provide academic books to libraries in developing countries. An avid hiker, he was president of the NY/NJ Trail Conference (1987-1999) where he was instrumental in developing their excellent hiking maps. He also served as the Chair of the American Hiking Society, a Governor of the Adirondack Mountain Club, and as a member of the DEC’s Forest Preserve Advisory Committee, along with other local boards. Neil hiked the world over, from Nepal to Peru, including the demanding Annapurna circuit and the Tour de Mont Blanc, and rafted the Colorado River – twice! Family and friends will especially miss his remarkable talent for making friends and bringing people together. He will be greatly missed.

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.