

LIVING WELL WITH PARKINSON'S DISEASE

Winter 2024

CUIMC'S New Embedded Supportive Care Clinic



Are you or your loved one experiencing difficulty with the invisible effects of Parkinson's disease, such as: weight loss, memory or thinking changes, pain, urinary symptoms, or dizziness? Do you run out of time during your appointments with your Movement Disorders Specialist or just need more time to discuss and develop strategies to address your concerns? Have you sat down to discuss future planning? Is your care partner overwhelmed with the day-to-day tasks of caregiving?

Parkinson's disease can present challenges for both individuals and their families. It is important to address the physical, social, emotional, and spiritual impacts of the disease. We have launched the Supportive Care Clinic to address these concerns and aim to provide individuals and families an additional layer of support, resources, and tools to maximize quality of life at all stages.

A referral to the Parkinson's Disease Supportive Care Clinic is not about giving up; it is about focusing on what matters most to you and determining the best next steps. Supportive care, also known as palliative care, focuses on improving quality of life, reducing suffering, and managing bothersome symptoms. In other words, trying to manage the "total pain" of living with a chronic condition. Supportive and palliative care are NOT THE SAME as end-of-life care or hospice. Supportive care can (and should) be provided to people at any age and any stage of a serious illness.

All supportive care clinic visits are conducted either in-person or via telehealth. During your visit, you will meet with our Nurse Practitioner, Janice Smolowitz, DNP, EdD, ANP-BC, DCC, who is pictured above. If necessary, our Social Worker and Chaplain may be involved in your visit as well, or they might follow-up with you after you are seen. These providers will work closely with your primary movement disorders specialist and other members of your care team to enhance your overall care plan.

Referrals to the supportive care clinic may be recommended for several reasons, including:

- Extra time to discuss your condition and treatment options.
- Help with understanding and navigating your illness and managing symptoms.
- Help with advance care planning. This may include discussing personal values and health care preferences, integrating your preferences into medical care plans and documenting your advance directives and Durable Power of Attorney for health care.
- Caregiver support

The overall goal of the clinic is to improve quality of life while living with and/or caring for someone with Parkinson's. For a referral to the Parkinson's Disease Supportive Care Clinic, please contact our office at 212-305-1303. Currently, we can only accept referrals for existing patients that reside in New York that have Medicare, Medicare Advantage Plans, HMO plans, and PPO plans, but we encourage anyone living with PD to contact their neurologist and discuss if palliative care may be right for you.

PD Patient Support Group
Meets the third Tuesday of every month from 2:00PM-3:30PM.

Caregivers Support Group
Meets the first Wednesday of every month from 2:00PM-3:30PM.

Deep Brain Stimulation (DBS) Information Sessions
Meets the first Friday of every month from 3:00PM-4:00PM.

To register for our support groups, and/or our DBS information sessions, please contact Erika Adelman, LCSW, SIFI at 929-695-0282.

Music and Movement Virtual Concert Series
Meets the first and third Wednesday of every month from 5:00PM-5:45PM. To register, please contact Hannah Lee at 212-305-9718.

Speech for PD
Meets every Tuesday and Thursday from 11:15AM-12:30PM. For more information and to register please contact Gemma Moya-Gale, Ph.D., CCC-SLP at gm2446@tc.columbia.edu.

Adjustment Disorders Group
Meets for 8 consecutive sessions starting in January. For more information and to register please contact Micah Savin, PhD at ms6870@cumc.columbia.edu.

On behalf of the entire Movement Disorders Division at CUIMC, the Parkinson's Foundation, and CurePSP, we would like to wish all of you and your loved ones a joyous holiday season, and a happy and healthy new year!!





Laboratory for the Study of Upper Airway Dysfunction

TEACHERS COLLEGE, COLUMBIA UNIVERSITY

Just like Parkinson's Disease (PD) can make it hard to move your arms and legs, it can also make it hard to control your face, throat, and breathing muscles. This can lead to trouble speaking (dysarthria) and/or swallowing (dysphagia).

When someone has dysphagia, food or liquid can 'go down the wrong pipe' into the airway, and may not be cleared with a strong cough. Some people with PD may not even realize when this happens. If food or liquid gets into the lungs, it can cause a condition called aspiration pneumonia, which can be very dangerous. Dysphagia can also make it tough to socialize and enjoy eating/drinking with friends and family.

But there is great news! We recently completed a clinical trial funded by the Michael J Fox Foundation comparing the effectiveness of two therapies: Expiratory Muscle Strength Training (EMST) and Cough Skill Training (CST). These treatments use handheld devices which strengthen the breathing, cough, and swallowing muscles.

We are happy to share that both treatments were effective for helping people with PD improve how they cough and swallow. This is very exciting because these treatments are now being used by Speech Language Pathologists across the country to improve cough and swallowing function in people with Parkinson's Disease.

We are now continuing this work thanks to funding from the National Institutes of Health – but we need you!

Please contact us if you have PD and are interested in a free evaluation of your swallowing and speech OR are interested in learning more about our research which includes treatment for swallowing disorders in-person or via telehealth.



Laboratory for the Study of Upper Airway Dysfunction – uadlab@tc.columbia.edu – (212) 678-3072
Michelle S. Troche, PhD, CCC-SLP – mst2139@tc.columbia.edu – (212) 678 – 3953



**Division of
Movement Disorders**
Columbia University Irving
Medical Center
710 West 168th Street
New York, NY 10032
212-305-1303
[www.columbianeurology.org/
patient-care/specialties/
movement-disorders](http://www.columbianeurology.org/patient-care/specialties/movement-disorders)

**Parkinson's Foundation
National Hotline:**
1-800-473-4636

**CurePSP's
National Hotline:**
1-800-457-4777

**Make a Gift--Make a
Difference**
Wish to Donate?...

Should you be interested in discussing how you can help support our clinical, research, and patient care activities, please contact Matthew Reals, Senior Director of Development, at **212-304-7203** or mr3134@columbia.edu.

FDA Approves New Infusion-based Treatment for Parkinson's

excerpted from: www.michaeljfox.org

The U.S. Food and Drug Administration has approved AbbVie's Vyalev, an infusion-based Parkinson's treatment that is shown to increase "on" time (when symptoms are well controlled) by providing a continuous source of levodopa/carbidopa.

The innovation here lies in how the medication is delivered: through a continuous pump, much like the one used by people who receive insulin therapy for diabetes. The steady infusion of levodopa/carbidopa has been shown to reduce fluctuations in an individual's symptoms (motor fluctuations) and give more "on" time compared to oral levodopa/carbidopa.

In a Phase 3 study, the treatment provided roughly three additional hours of "on" time for people with advanced Parkinson's. The study admitted people who were taking a minimum of 400 milligrams/day (mg/day) of levodopa equivalents but still experiencing inadequately controlled motor symptoms, such as tremor or issues walking. Participants had at least 2.5 hours of "off" time (when symptoms are not well-controlled) each day. "More treatment options, especially those that can help as the disease progresses, have the potential to make a big difference in the lives of so many people and families with Parkinson's," says MJFF's principal medical advisor Rachel Dolhun, MD, DipABLM.

Vyalev for Parkinson's Disease Symptom Relief

Parkinson's disease disrupts dopamine production in the brain, leading to the symptoms most associated with PD. Levodopa helps temporarily replace some of the lost dopamine; carbidopa helps improve uptake of levodopa. Vyalev delivers these medications continuously. Vyalev is intended to treat people with progressing Parkinson's who benefit from oral levodopa/carbidopa but do not have satisfactory control of symptoms and experience significant motor fluctuations, including "off" time and/or bothersome dyskinesia. As with all medication decisions, it is best to discuss with your care provider to see if Vyalev meets your individual needs.

The FDA approval is based on a Phase 3, 12-week study that evaluated continuous, under-the-skin infusion of Vyalev in patients with advanced PD. The study compared the infusion to immediate release oral carbidopa/levodopa and found that Vyalev provided close to three hours more "on" time and less "off" time, while oral medication in the trial only added one hour of "on" time. The most common side effects for people on Vyalev included problems with the infusion site (redness, swelling, etc), hallucinations and dyskinesia.

It's worth noting that while the treatment has FDA approval, there are still additional government and regulatory processes to complete before it will be widely available and covered by insurance, including Medicare. This could take several months or more. AbbVie expects Medicare coverage by the second half of 2025.

The approval comes from the bustling pipeline of PD drugs, with three additional therapies engaged in the regulatory process in 2024. The FDA approved a treatment from Amneal Biosciences, while it issued response letters for treatments from Supernus and MT Pharma. Supernus has already resubmitted its treatment (an apomorphine infusion device), with a target date of February 1, 2025 for a decision on approval. These are just the options to come before the FDA in 2024; overall, The Michael J. Fox Foundation (MJFF) is monitoring 151 treatments in clinical testing for Parkinson's disease.

If you have a question regarding Parkinson's and there's a treatment that you would like featured in the next newsletter, please email your questions and/or inquiries to Erika Adelman, LCSW, SIFI at era2142@cumc.columbia.edu.

The information published in this newsletter is not intended to replace, and should not be interpreted or relied upon, as professional advice, whether medical or otherwise. Please refer to your own professional for all advice concerning legal, medical, or other matters published in connection with this article.

"Don't count the days, make the days count."

-Muhammad Ali, diagnosed with PD in 1984