

January 2025

Parkinson's Disease and Movement Disorder Center Monthly News and Updates



Happy New Year from all of us at Northwestern's Parkinson's disease and Movement Disorders Center! We are looking forward to 2025 as a year of hope for the larger movement disorders/Parkinson's community!

Dancing with Parkinson's will have three virtual classes in January and February!

If you hate the cold but still want to dance, sign up for these virtual classes.

Virtual Dancing with Parkinson's

*Northwestern Medicine, in partnership with Joffrey Ballet, is happy to
bring you Dancing with Parkinson's.*

Dates: January 23, January 30, and February 6

Location: Virtual

Cost: Free

Join us for a wonderful bonding opportunity for People with Parkinson's & their Care Partners. Dancing with Parkinson's is a research-backed program that facilitates movement and increases physical, mental, and emotional wellbeing. Dances can be performed either standing or seated.



Register by scanning this code.

Questions? Email Katie at
movementdisorders@nm.org
or Ivy at ianderson@joffrey.org

**Register for Dancing with Parkinson's
here!**

**Updates on Advanced Therapies for
Parkinson's Disease at Central
Dupage Hospital (hybrid program)**

Updates on Advanced Therapies for Parkinson's Disease



The Northwestern Medicine Parkinson's Disease and Movement Disorders Center invites you, your family members and care partners to a learning event on treatment options for Parkinson's disease.

The presentation will focus on deep brain stimulation for Parkinson's disease, focused ultrasound for tremor, as well as pump and infusion therapies.

This event is designed to give you valuable insights, answer your questions and help you understand if these therapies might be right for you.

During the event, you'll have the opportunity to:

Learn from leading experts about the benefits of these advanced therapies.

Hear personal stories from people who have experienced the positive effects of these therapies.

Gain a deeper understanding how these mechanisms work and how they can be used as treatments.

Participate in an interactive session where you can ask questions of medical professionals and people who have experienced these treatments.

This event will be on February 11, 2025, from 4 to 6 pm.

We encourage you to attend in person.

The in-person event will be at:
Northwestern Medicine Central DuPage Hospital
25 North Winfield Road
Inpatient Pavilion, Conference Rooms 1, 2 and 3
Winfield

If you register to attend virtually, you will get an email on the day of the event with a link to join.

There is no cost to attend, but you must register for each individual person attending. Valet parking will be available.

You can call 630.933.4234 to register to attend virtually or in person.

Or, you can go online at nm.org/pd-symposium:

- Register to [attend in person](#).
- Register to [attend virtually](#).

For more information, contact Debi Crystal, LCSW, at debra.crystal@nm.org

Register for Updates on Advanced Therapies in Parkinson's Disease

Vyalev: What People Living with Parkinson's Need to Know About This New Treatment

By: Juan R Deliz, MD

Vyalev is a recently FDA-approved treatment (October 2024) for adults with advanced Parkinson's disease. As Parkinson's disease progresses, many individuals experience periods where symptoms return between doses of carbidopa-levodopa – also known as “OFF” periods – requiring more frequent dosing of medication. Vyalev is specifically designed to minimize these fluctuations when medication control of symptoms is interrupted, delayed or inconsistent. Vyalev works through a continuous subcutaneous (under-the-skin) infusion of foscarnidopa and foslevodopa, which are precursors to carbidopa and levodopa, proven treatments for the motor symptoms of Parkinson's disease.

The initial clinical trial for Vyalev reported patients treated with subcutaneous Vyalev experienced an average reduction of 2.75 hours per day in “OFF” time compared to those receiving oral carbidopa/levodopa. These effects were observed as early as the first week of treatment [1]. In a separate study, Vyalev demonstrated an average increase of 3.8 hours of ON time without dyskinesia and a reduction of 3.5 hours in OFF time over a 52-week period. Additionally, the percentage of patients experiencing inability to initiate movement in the early morning dropped significantly, from about 78% to 28% [2].

What makes Vyalev unique is its delivery system: a small, wearable pump that provides a steady supply of medication throughout the day. This consistent infusion helps reduce “OFF” periods caused by fluctuating drug levels. The device is portable, and users can temporarily pause the infusion for daily activities like showering. This approach can offer more stable symptom control compared to traditional oral medications.

Like all treatments, Vyalev may cause side effects. Those familiar with levodopa therapies may recognize potential issues like involuntary movements (dyskinesias), drowsiness, hallucinations, lightheadedness, or compulsive behaviors. However, Vyalev introduces a new consideration: infusion site reactions. These may include redness, swelling, pain, or itching at the injection site. Because of these potential issues, use of this medication requires regular skin care to reduce the risk of irritation or infection. Patients should work closely with their healthcare provider to monitor side effects and ensure Vyalev is the right choice.

Vyalev represents a step toward personalized medicine in Parkinson's care, especially for individuals struggling with consistent symptom control on traditional therapies. However, it requires training and commitment to use the infusion pump effectively. In addition to monitoring for skin reaction, patients are advised to keep a supply of oral Parkinson's medication as a backup. This ensures that if the infusion is interrupted for any reason—such as technical issues with the pump or problems at the infusion site—individuals can still maintain symptom control. This added layer of preparedness can provide peace of mind as individuals transition to this new treatment.

As of December 2024, Vyalev is currently available only to patients with private insurance, as its approval for Medicare coverage is still pending. However, specialists anticipate that Vyalev will become more widely accessible in the coming years, offering new hope to a broader group of patients with advanced Parkinson's disease. To make the treatment more affordable, the manufacturer plans to offer financial assistance

programs for eligible patients. Additionally, they aim to provide educational nursing support to help patients and caregivers feel confident in managing the infusion system. If you're considering Vyalev, talk to your healthcare provider to see if this treatment is a good fit for your individual needs and circumstances.

References:

[1] Soileau MJ, Aldred J, Budur K, et al. Safety and efficacy of continuous subcutaneous foslevodopa-foscarbidopa in patients with advanced Parkinson's disease: a randomised, double-blind, active-controlled, phase 3 trial. *Lancet Neurol.* 2022;21(12):1099-1109.

[2] Aldred J, Freire-Alvarez E, Amelin AV, et al. Continuous Subcutaneous Foslevodopa/Foscarbidopa in Parkinson's Disease: Safety and Efficacy Results From a 12-Month, Single-Arm, Open-Label, Phase 3 Study. *Neurol Ther.* 2023;12(6):1937-1958.

**PD Care Partner Support Group is
meeting in-person!**

PD Care Partner Support Group

Please join us for our support group for care partners of those with Parkinson's disease. We hope the support group provides you with a place to connect with other care partners, share stories, gain new perspectives, and share coping strategies with others going through similar experiences.

Virtual Meeting

Date: 2nd Wednesday of the month

Time: 2:00-3:00 PM (CT)

Location: Via Zoom

Cost: Free

In-person Meeting

Date: 4th Wednesday of the month

Time: 1:00- 2:00PM (CT)

Location: Conference Room on the 19th floor of Lavin (near the neurology clinic)

Cost: Free

2025 Schedule:

Virtual dates: January 8, February 12, March 12, April 9, May 14, June 11, July 9, August 13, September 10, October 8, November 12, and December 10

In-person dates: January 22, February 26, March 26, April 23, May 28, June 25, July 23, August 27, September 24, October 22, November 26, December date TBA

Contact Katie to register via e-mail at movementdisorders@nm.org

Parkinson's Players: Ping Pong is back!

Parkinson's Players: Ping Pong

Date: Weekly on Saturdays
Beginning on December 7th
Time: 11:15AM- 12:45PM (CT)
Location: Edgewater Fitness Center
1106 W. Bryn Mawr
Chicago, IL 60660
Cost: Free for Participants

Please join us for an instructional ping pong clinic and open play at the Edgewater Fitness Center (following Rock Steady Boxing).

The Parkinson's Players Program is designed to promote play-based activities and foster friendship with those facing similar challenges.

No ping pong experience is necessary.

Space for the group is limited. RVSP Required.
Please contact Katie at
movementdisorders@nm.org, if you are
interested in joining.

**Register for Parkinson's Players
Ping Pong here!**

PDMDC in the News



WGN Story about Improv for PD

In November, WGN news attended the performance by our improv-ers. This eight week class, held at The Second City, is a wonderful experience for participants where they play improv games. 2024 saw the inaugural performances on a stage at The Second City. Our improv-ers illustrated that Parkinson's doesn't dampen a person's sense of humor or their ability to have fun.

Click the photo above to watch the video/ read the story.

For more information about this program, email Katie at movementdisorders@nm.org.

2025 session dates will be announced soon.

Parkinson's Revolution will be February 22nd!



2.22.2025

The Movement Begins With You

STUDIO ///

Studio Three | Lincoln Park
Rides at 1 p.m. and 2 p.m.

Parkinson's Revolution is an indoor cycling experience that combines passion, determination and community to generate awareness and advance our mission toward a cure— **because every 6 minutes someone is diagnosed with Parkinson's disease.**

PDRevolutionChicago.org



**Shirley Ryan Ability Lab's Narratives
of Parkinson's: A Journey on Screen**

The Shirley Ryan AbilityLab PDMD Program and Tellin' Tales Theatre presents...

Narratives of Parkinson's: A Journey on Screen

Sunday, January 12, 2025

FREE | Join us in-person at our Flagship location
(355 E. Erie Street, 10th floor) or via Zoom.

Doors open at 1:30pm, screening begins at 2pm



Join us for a **screening event**
showcasing **six** inspiring stories that
bring the journey of living with
Parkinson's to life.

Shirley Ryan
Abilitylab



Register Here:

Scan the QR Code or [click HERE](#) to register:



For any questions,
contact **Eric Espinoza**,
eespinoz02@srailab.org

**Click here to email for more
information or register!**

Research Corner

If you have been suffering from symptoms of Parkinson's Disease, speak to your Doctor about a new clinical study involving Spinal Cord Stimulation.

What is Spinal Cord Stimulation?

Spinal Cord Stimulation (SCS) is a safe and effective treatment for chronic back and leg pain. The eCAP-PD Study will evaluate SCS to treat Parkinson's Disease symptoms including freezing of gait and tremor. This study aims to assess whether a novel spinal cord stimulator can alleviate these symptoms and improve the quality of life for individuals affected by Parkinson's Disease.

The Evoke® Closed-Loop SCS System is currently being evaluated in the U.S. as investigational to treat Parkinson's Disease symptoms. Unlike conventional SCS systems, the Evoke® SCS System is designed to measure your body's response to stimulation and make automatic, real-time adjustments intended to maintain a consistent level of therapy.

✓ In SCS, a small device called an implantable pulse generator (IPG) is implanted under your skin and connected to thin leads placed near your spinal cord that conduct electrical impulses in order to manage your symptoms.



The Evoke® System is an investigational device for the treatment of Parkinson's Disease symptoms that has risks that must be weighed against the potential benefits.

These risks and any additional risks associated with the study procedures are fully outlined in the Informed Consent Form. Prior to joining the study, your doctor will discuss the risks and potential benefits with you to help you decide whether this study may be right for you.

As a participant in the eCAP-PD study, you will play a crucial role in advancing medical knowledge and potentially benefiting from the latest breakthroughs in SCS technology.

Throughout the study, you will be closely monitored by experienced medical professionals to assess effectiveness of the therapy to manage your Parkinson's Disease symptoms.

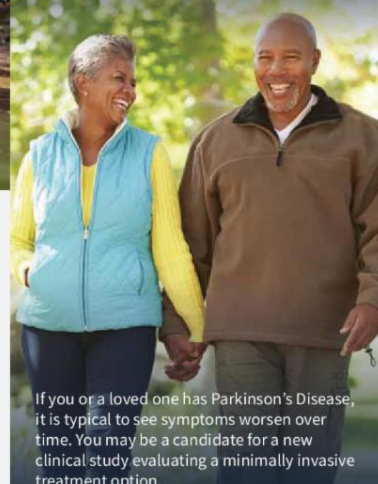


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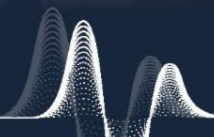
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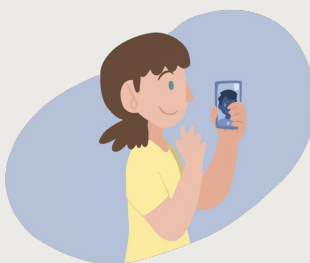
Has a physician diagnosed you or a loved one with Parkinson's Disease?



If you or a loved one has Parkinson's Disease, it is typical to see symptoms worsen over time. You may be a candidate for a new clinical study evaluating a minimally invasive treatment option.



Click here to learn more about ongoing research at Northwestern.



Virtual Support Group and Class Schedule

We use Zoom for all our support groups!
Some classes meet in person.

Register for any of the groups and classes [here!](#)

General PD Support Group
1st Wednesday of the month
2:00 pm – 3:00 pm

Women and PD Support Group
2nd Wednesday of the month
11:00 am – 12:00 pm

PD Care Partner Support Group
Virtual: 2nd Wednesday of the month, 2:00 pm – 3:00 pm

In-person: 4th Wednesday of the month, 1:00 pm- 2:00 pm

Therapy Tuesdays Exercise Class
1st Tuesday of the month
11:00 am – 12:00 pm

Chair Yoga for PD
2nd, 3rd, 4th (and 5th)
Wednesday of the month
10:00am – 11:00am

Art Therapy for PD
3rd Monday of the month
10:00 am – 11:00 am

Improv for PD

Young Onset PD Support Group
4th Wednesday of the month
6:00 pm – 7:00 pm

PD 101
May 21st and November 19th
4:00 pm - 5:30 pm

Dancing w/ Parkinson's
Thursdays 11:30am- 12:30pm
February 27th- May 26th

2025 dates TBA

PD 201
April 16th and September 17th
4:00 pm- 5:30 pm

Parkinson's Players Ping Pong
Saturdays beginning 12/14/24
11:15am - 12:45pm

Music Therapy for PD
Tuesdays 1:00pm- 2:00pm
January 14th- April 1st

For a complete list of our groups and classes, including those offered at Central DuPage and Lake Forest Hospitals, click [HERE!](#)



UPCOMING NATIONAL EDUCATIONAL PROGRAMS

PD HEALTH @ HOME (National Virtual Programming)
Don't forget our weekly (M, W, F) virtual programming that focuses on Mindfulness, Wellness and Fitness! Our PD Health @ Home offers so much! To learn more visit this link: Parkinson.org/PDHealth

[Mindfulness Mondays- Embracing Beginner's Mind - January 6th](#)

Approach the new year with a fresh perspective. This session explores the concept of “beginner’s mind,” encouraging curiosity, openness, and a sense of wonder.

Whether this is your first mindfulness Monday, or you are a returning participant, these sessions are created with the intention of including everyone. There will be time for questions following the practice.

[Register Virtual](#)

[Social Engagement: Using our Voices- January 8th](#)

Whether it's improving communication, fostering

creativity, or simply having fun, this program focuses on embracing the unique experiences of using your voice. Together, we'll engage in activities that build confidence, connection, and joy while supporting vocal health and self-expression.

Join us to celebrate the many ways our voices can inspire, connect, and empower! [Register Virtual](#)

[Empowerment Through Movement- January 15th](#)

Exercise is a powerful tool for managing Parkinson's symptoms and enhancing overall well-being. Join us for an empowering session focused on practical, evidence-based strategies to integrate movement into your daily life. This webinar will explore the ways that exercise can improve mobility, balance, and mood, and why it's essential for symptom management.

Whether you're just beginning or looking to elevate your routine, discover how movement can make a meaningful difference in living well with Parkinson's.

[Register Virtual](#)

As a reminder, the Foundation has a variety of resources available to support you and the PD community, including:

[HELPLINE:](#) 1-800-4PD-INFO (473-4636)

or helpline@parkinson.org

[PD Conversations](#) an online PD community, to connect with others living with PD and be part of a network of support.

[Newly Diagnosed Kit](#)

[Medical Alert Card](#)

[Fact sheet: Staying Safe in the Hospital with Parkinson's Disease](#)

[Tips for How to Prepare for a Telemedicine Appointment](#)

[Aware in Care Kit](#)

[Podcasts](#)

PARKINSON'S DISEASE AND MOVEMENT DISORDERS CENTER

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