PARKINSON'S DISEASE AND MOVEMENT DISORDERS CENTER

July 2025 **Parkinson's Disease and Movement Disorder Center Monthly News and Updates**

Dancing with Parkinson's will be grooving at Shirley Ryan Ability Lab's Adaptive Fitness Center this summer!





Dancing with Parkinson's

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

Date: Thursdays

July 24th and August 21st

Time: 12:00pm- 1:00pm PM (CT)

Location: Shirley Ryan Ability Lab

Adaptive Fitness Center

541 N. Fairbanks Ct., Mezzanine Level

Chicago, IL 60611

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

Register here!

Join us for Parkinson's 201: Managing the Middle Stages of Parkinson's Disease on July 16th!

Parkinson's 201: Managing the Middle Stages of Parkinson's Disease

PD 201 provides a deeper understanding of the medications, treatments and advanced therapies available in the management of Parkinson's disease.

After a presentation, you will have the chance to ask your questions!

People with Parkinson's, family members, care partners, and community members are welcome to attend.

Class Dates in 2025: July 16th and October 15th Time: 4:00-5:30PM (CT) Where: Zoom

E-mail movementdisorders@nm.org to register.





Register here

Calling Care Partners! Join us for In-Person Care Partner Bootcamp in Oak Brook, Illinois on August 1st!



Midwest Chapter Care Partner Bootcamp

Date: Friday, August 1, 2025
Time: *12:00 – 4:00 p.m. CT
*Check-in, lunch, & vendor fair
starts at 12:00 p.m., program
starts at 12:45 p.m.

Location:

Christ Church Oak Brook 501 Oak Brook Road Oak Brook, IL 60523 This informative program is designed specifically for care partners of individuals living with Parkinson's disease. Connect with others who share similar experiences and gain valuable tools to support your caregiving journey. Take the first step toward a more informed and supported caregiving experience!

Attendance is free, but registration is required to account for seating and refreshments. Learn more and register at www.Parkinson.org/MidwestBootcamp or call Jessica at (312)762-5706 or Katie at (312)503-0160





Parkinson's Players: Golf and Tennis is RETURNING this summer- starting on June 10th!



Parkinson's Players: Golf & Tennis

Date: Weekly on Tuesdays Beginning June 10th

Cardio Tennis: 4:00pm- 4:50pm Instructional Golf: 5:00pm- 5:50pm

Location: Diversey Driving Range & Tennis Courts

141 W. Diversey PKWY Cost: Free for Participants

The Parkinson's Players Program is designed to promote play-based activities

Tennis: A fun filled session for players of all abilities. Cardio tennis emphasizes drills and tennis instruction. Bring your own racket or rackets will be available at the tennis center.

Golf: Whether an avid golfer or a novice, receive instruction on the fundamentals of golf, geared towards each player's skills level. Bring your own clubs or clubs will be available through the driving range.

Participants must be able to stand unassisted for 1 hour.

and foster friendship with those facing similar challenges.

The program is at no cost for participants. Paid parking is available.

Space for the group is limited. RVSP Required.

Please contact Katie at movementdisorders@nm.org, if you are interested in joining.

Email to Register

New virtual support group coming this fall!



Grief and Loss Support Group

Northwestern University offers support groups patients and families who are being treated for movement disorders.

Grief and Loss Virtual Support Group Starting September 2025 First Tuesday of every month at 1 PM, CST

For registration and meeting link please email:

movementdisorders@NM.org

New Research Opportunity for people with Parkinson's Disease! We are looking for participants!

There is a new research study with Vyalev, the recently approved subcutaneous levodopa infusion system for Parkinson's disease (PD). While approved, and clinically available for those with private insurance (Medicare hopefully to follow

soon!!), there are still factors that require longerterm follow-up and this is why this phase 4, 'realworld' study is important.

Therefore, if you and your doctor think that your regular oral medications do not control your motor fluctuations (OFF periods during which you experience a return of stiffness, slowness, tremor, or gait difficulties) and IF your doctor thinks continuously administered subcutaneous levodopa is an option for you, then please ask to be enrolled in this study. Almost anyone who is a good candidate for this in the judgement of your doctor, will qualify for the study. There are 9 study visits over the entire 3 year study period. During the visits we will ask questions, do a few rating scales and have you fill out questionnaires. We will also examine infusion sites for possible skin reactions that are an inherent part of this therapy, but are usually not bothersome. That's it! There are no costs/bills (and free parking!) for research visits, and you can still see your regular PD doctor throughout this period. Please talk to your PD specialist about how you can participate!

For questions you may reach out to the Research Study Coordinator- Grace Jones. Her email address is gracejones@northwestern.edu.

Shirley Ryan Ability Lab's Summer Programs include Boxing and Nordic Poles Agility!



Boxing for Individuals with Parkinson's Disease

Empower Your Body & Mind Through Boxing

Join us for our 11-week boxing class tailored for individuals with Parkinson's Disease. The session will be led by champion instructor Aisling Holt, a four-time Chicago Golden Glove champion in boxing and Tai Chi coach. The class focus will be on basics, enhancing cognitive fitness and overall brain health. Challenge your mind with hand-eye coordination, memory drills and reaction training. No equipment is needed.

\$110 for 11-week session or \$15 drop in fee \$45 New member registration fee

Every Thursday, 2-2:45 pm

Adaptive Sports & Fitness Center 541 North Fairbanks Court Mezzanine Floor Chicago, IL 60611

Requirements

Participants must complete intake form and sign a waiver.



Now Offering 1:1 Sessions

Individuals of all abilities can take

- Building strength and power
- Improving reaction time coordination and cognitive engagement
- Enhancing balance, agility, and trunk control

Exercises can be performed seated, standing or in combination

\$60 per session or \$550 per 10-pack

For more information, please contact Aleks Gebska at 312.238.5001 or agebska@sralab.org.

Nordic Poles Agility Workshop

Join our 7-week session to learn how to use Nordic walking poles safely and effectively, with a strong focus on gait training, balance and strength exercises.

Nordic walking is a research-based intervention for individuals with neurological conditions including Parkinson's disease, stroke, spinal cord injury, multiple sclerosis, as well as for aging adults, looking to improve mobility, posture, balance and endurance.

Aug 13–Sept 24, 2025 Wednesdays 9:45–10:30 am \$70 for 7-week session or \$15 drop in fee \$45 new member registration fee which includes fitness assessment Nordic poles will be provided; space

Lake Shore Park 808 N Lake Shore Dr Chicago, IL 60611

is limited



Workshop requirements:

- Intake form and waiver required
- Participants must be ambulatory and able to walk unassisted, caregivers are encouraged to attend if additional support is needed.

To register, please contact the fitness center at 312.238.5001



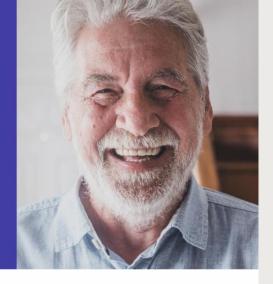
Click here to read Shirley Ryan Ability Lab's Summer Program Summary

Research Corner

xx Sano

Your guide to participating in Parkinson's Disease research

You are invited to support research aiming to identify people with Parkinson's disease who have a specific set of genetic changes in their DNA.



In this document you'll find information about

- → Why this study is happening and what it aims to achieve
- What participation involves
- How your health information will be used and kept private, safe and secure

Where can I direct questions?

We're here to help in any way we can. Call us, email us, or start a live chat via the Sano Genetics website

XX Sano

Why is this study happening?

- about how specific changes in a genetic pathway may be linked to the development of Parkinson's Disease (PD).
- About 30% of people with Parkinson's have overactivity in this specific gene
- By learning more about the biological mechanisms behind Parkinson's, researchers aim to provide a startingpoint for developing new treatments.

This research aims to identify people with PD who have a specific genetic profile by



By gathering genetic data from people affected by PD, researchers hope to better understand the biological mechanisms behind genetic changes in the condition - with the hope this will provide a foundation for developing new treatment options in the

The only way to find out if you have these genetic changes is to take a test which analyzes your DNA (a simple and completely painless process which involves collecting a saliva sample and sending it to a lab by post).





Participating in Parkinson's Disease research

If you join this study and are eligible to take part, we will send a free, easy-to-use investigational genetic test to your home. Nour saliva sample will be used to test if your nome. Your saliva sample will be used to test if your PD is linked to changes in the genetic profile researchers are investigating. The outcome of the test could contribute to helping researchers better understand PD and support future research for new treatment options. Depending on the outcome of the test, you may be eligible to support future clinical trials.



Why was I invited?

You have been invited to participate in this study because you have a confirmed diagnosis of Parkinson's Disease.

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What's involved? Participate entirely from home Receive a free, easy-to-use genetic test and return it by post Answer a brief online survey including questions about your medical history and ongoing symptoms Step by step process O1 Answer a brief survey and enroil O2 At-home genetic test O3 Genetic counseling (optional)

about other opportuni
to support research

Taking part

If you agree to take part you will be asked to provide your name, date of birth, sex at birth, ethnicity, contact information and shipping address so that we can send you your genetic test kit.

You'll also be asked to answer some questions about your medical history and ongoing symptoms.

Risks and Benefits

Potential Benefits:

Taking part gives you access to a free genetic test and online genetic counseling services

The results from this test may mea you are eligible to participate in future research studies

Potential Risks

While we prioritize safeguarding your data, sharing personal information online carries inherent risks

Our partner labs validate genetic sequencing methods rigorously, but there is a small risk of receiving inaccurate results

Genetic testing

- If you're eligible to take part, we'll provide you with further information about this study and you'll be asked to order a free, at-home genetic testing kit. The kit will include easy-to-follow instructions on how to collect your sality sample and send it to the lab
- Once your sample reaches the lab, DNA extraction and sequencing will begin.
- We'll keep you updated via email throughout the process.
- Once your results are ready, you'll have the opportunity to speak to a genetic counselor, a healthcare specialist who will explain your results and help plan your next steps.
- Your results will be available to download via your secure Sano Account. Within your account you'll be able to stay up to date as the study progresses, read, listen and lear more about the genetic elements of Parkinson's, and gain access to further opportunities to contribute to research.







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 1:45pm- 3:00pm

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 – 3:30 pm

In-person: 4th Wednesday of the month, 1:00 pm- 2:30 pm

Young Onset PD Support Group

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 11:00am – 12:00pm

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

Improv for PD

Thursdays 2:00pm- 3:30pm September 18-November 20 4th Wednesday of the month 6:00 pm – 7:00 pm

PD 101

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

<u>Dancing w/ Parkinson's</u> Thursdays 12:00pm- 1:00pm July 24th and August 21st PD 201

July 16th and October 15th 4:00 pm- 5:30 pm

Parkinson's Players Golf & Tennis Tuesdays beginning 6/10/25

Tennis: 4:00pm-4:50pm Golf: 5:00pm- 5:50pm

Music Therapy for PD
Tuesdays 1:00pm- 2:00pm
September 2 - November 18

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**

Social Engagement- Everyday Safety at Home Moment- July 2nd

This session offers practical tips to help you move with confidence and ease at home, especially if you live alone or manage most of your care. Register Virtual

Mindfulness Mondays: Awareness of Emotions- July 7th

In this session, we will look at how to use mindfulness to tend our emotions and find the wisdom that lives in every feeling. <u>Register Virtual</u>

Beyond Movement: Understanding Non-motor Symptoms- July 9th

When most people think of Parkinson's disease, they often

picture tremors or stiffness—but there's much more to the experience than meets the eye. <u>Register Virtual</u>

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

<u>PD Conversations</u> 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

<u>Fact sheet: Staying Safe in the Hospital with Parkinson's</u>

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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